EMPIRICAL MANUSCRIPT

Cochlear Implantation Among Deaf Children With Additional Disabilities: Parental Perceptions of Benefits, Challenges, and Service Provision

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Abstract

Although increasing numbers of children with additional disabilities are receiving cochlear implants (CIs), little is known about family perspectives of the benefits and the challenges of cochlear implantation in this pediatric population. This study examines perceptions among parents of deaf children with additional disabilities regarding satisfaction with service provision, benefits, and challenges of the CI process. This was a mixed-methods study, which included a survey and interviews. Twenty-three families of deaf children with additional disabilities participated in this study, and 17 of these parents participated in in-depth interviews regarding their child’s experience with the CI, including benefits and challenges. Interviews were analyzed through inductive thematic analysis. Parent-perceived benefits of cochlear implantation included children’s improved sound awareness, communication skills, and greater well-being compared to preimplantation status. However, the majority of families felt that they and their children were not receiving enough services. Major challenges included managing funding; coping with limited availability of specialized services, particularly in rural areas; and continuing concerns about the child’s communication, social skills, and academic performance. Results suggest that children with additional disabilities benefit from CIs, but they and their families also face unique challenges that professionals should consider when working with these families.

Over the years, candidacy for recommending cochlear implantation has expanded and an increasing number of deaf children with additional disabilities are receiving cochlear implants (CIs) (Edwards, Frost, & Witham, 2006; Wiley, Meinzen-Derr, Grether, Choo, & Hughes, 2012). This group of children pose unique and heterogeneous challenges in assessment, treatment, and determination of suitable mode of communication, both pre- and postimplantation. However, in spite of this, relatively little research has examined the benefits and challenges of cochlear implantation for this population of children. The majority of the scant research that has been conducted on this group has focused on speech perception and speech intelligibility outcomes, indicating wide variation in outcomes but improvement overall (Dettman et al., 2004; Pietola et al., 2012; Steven et al., 2011). Children with cognitive or developmental delay, in particular, tend to perform below their typically developing peers (Holt & Kirk, 2005; Oghalai et al., 2012). Little research has investigated the impact of cochlear implantation on children’s and family’s lives beyond outcome measures related to spoken language.

Parents play a critical role in initial decision making to proceed with cochlear implantation and commitment to ongoing habilitation. This is even truer among deaf children with additional disabilities. One theoretical perspective that underscores...
The critical value of families in the development of young children with disabilities is the family-centered approach to service provision, which is a philosophy and set of practices that characterize service delivery (Bailey, Raspa, & Fox, 2012). The family-centered approach contains two major components, namely relational and participatory (Dunat & Trivette, 1996). Relational components include professional skills such as active listening and empathy. Participatory components include practices that are personalized, flexible, and responsive to each family’s needs, priorities, and values. This allows families opportunities to be actively involved in their child’s intervention while collaborating with professionals (Bruder & Dunst, 2008; Epps & Jackson, 2000; Murray, Salomon, & Mathers, 2000; Sass-Lehrer, 2002). Some of the core principles of the family-centered approach include “focusing on family strengths, respecting family diversity and values, encouraging family decision making and empowerment, communicating with families in an open and collaborative fashion, adopting a flexible approach to service provision, and recognizing the value of informal support systems” (Bailey et al., 2012, p. 217). Bailey et al. have suggested that the assessment of the delivery of a family-centered approach should include aspects such as families understanding their child’s strengths, abilities, and special needs; knowing their rights and being able to advocate effectively for their child; helping their child develop and learn; having received the services to which they are entitled and being satisfied with the services they are receiving; having support systems; and accessing desired services, programs, and activities (Bailey et al., 2006; 2012).

Accordingly, it is crucial to understand parent perceptions of the benefits and challenges of implantation and service delivery. Without an understanding of the impact of cochlear implantation on the lives of deaf children with additional disabilities and their families, it is difficult, if not impossible, to satisfy the participatory components of family-centered care. In other words, service providers need to understand the needs, priorities, and values of these families. This valuable information could help tailor support and interventions for families whose children are deaf with additional disabilities. There is a small but growing body of research examining parental perceptions of cochlear implantation outcomes—both benefits and challenges—for their typically developing deaf children. Many parents have reported that they were largely satisfied with the CI outcomes (Archbold, Sach, O’Neill, Lutman, & Gregory, 2008; Hyde, Punch, & Komesaroff, 2010). In addition, the majority of parents indicated that their children made gains in spoken language development and communication within the family, and the children became more confident and independent (Archbold et al., 2008). However, even parents of deaf children without additional disabilities often experience stresses and challenges associated with the cochlear implantation process. For example, Zaidman-Zait (2008) reported that parents continue to have concerns with their child’s language development and behavior after their child received a CI and experienced challenges with managing CI equipment, therapies, and associated financial costs. Taken together, these parental reports of both positive outcomes and challenges are important for two main reasons. First, parents are the decision makers on proceeding with cochlear implant surgery (if their child is a candidate), so understanding their perceptions of the benefits, stresses, and challenges is essential for shedding light on the decision making process. Second, parents are critical partners in the habilitation process, so it is vital that their postimplant challenges be understood and addressed, with the aim of facilitating and improving the efficacy of habilitation.

Very little research has examined parental perceptions of cochlear implantation for deaf children with additional disabilities, and the respondents in these few studies identified both benefits and challenges in terms of outcomes and access to services. With regard to benefits, Filipo, Bosco, Mancini, and Ballantyne (2004) reported on cochlear implantation outcomes for a group of children and adults in Italy, some of whom had additional disabilities. Based on caregiver reports (parents, caregivers, professionals), most of the recipients showed benefits from cochlear implantation in terms of self-sufficiency, that is, self-help skills, independence, and initiative. Similarly, Berrettini et al. (2008) asked parents of children with additional disabilities to complete a questionnaire on the perceived benefits of cochlear implantation. One hundred percent of their 23 respondents reported improved awareness to sound, and 96% reported an increase in communication and peer interaction. Additionally, Wiley, Jahnke, Meinzen-Derr, and Choo (2005) conducted interviews with parents of deaf children with multiple disabilities, all of whom reported some gain in their children’s communication skills following cochlear implantation.

A small body of literature has also reported some challenges faced by families of implanted deaf children with additional disabilities. Huttunen et al. (2009) compared quality of life indicators among families of deaf children with additional disabilities to those among families of typically developing children. The mean scores on quality of life measures for the first group were lower; however, the difference was significant only for the subscale measuring satisfaction with the child’s educational placement, reflecting a lack of adequate educational services. This is consistent with previous findings that the demands on parents of deaf children with additional disabilities (not specifically focused on children who had received CIs) often increase in comparison to those of typically developing deaf children. These increased demands require parents to deal with multiple therapies and multiple professionals, often with little coordination between services (Myyk-Wayne, Robinson, & Henson, 2011). Furthermore, parents may be less satisfied with the actual outcomes after CI surgery. For example, Hyde et al. (2010) surveyed 250 parents, 25.3% of whom reported that their child had an additional need or disability. Their qualitative findings indicated that the parents of these children were often disappointed in CI outcomes, particularly when implantation occurred before the additional disability was known.

In order to effectively enhance family-centered service provision, researchers and professionals need to understand the experience of families of children with additional disabilities who choose cochlear implantation for their child. In particular, it is imperative to examine the many challenges experienced by these parents that may be unique from those reported by parents of children without additional special needs. For example, in terms of similarities, researchers have highlighted some parallel benefits among the two groups of implanted children, such as improved communication skills and independence (Archbold et al., 2008; Berrettini et al., 2008). By contrast, other researchers also underscore some unique perceived challenges for parents of deaf children with additional disabilities in terms of educational services and access to necessary educational and medical services (Myyk-Wayne et al., 2011). However, there has been insufficient research on this population of children and parents to determine if these perceptions are widespread or limited to the participants involved in the reported studies.

Taken together, the small collective body of studies examining parental responses to cochlear implantation in their deaf child provide some limited understanding of parent perceptions and also suggest reasonable next steps for further inquiry. In particular, the existing body of research would benefit from an
investigation that provides both expanded breadth and depth, namely an open-ended interview approach with parents. This would allow for a more extensive investigation of previously highlighted issues, such as satisfaction with child outcomes and service provision. Existing questionnaires combined with this open-ended interview approach would provide a more quantified assessment of service provision and everyday challenges, as experienced by the children and their families, than has been documented. The goal of the current study was to broaden our understanding of parental perceptions of the cochlear implantation process for deaf children with additional disabilities, so as to systematically understand the benefits and challenges of this population, as well as the nature of those unique challenges. Specifically, the purposes of this preliminary investigation were twofold, both emanating from a family-centered perspective: (a) to examine the daily benefits and challenges of cochlear implantation from the perspective of parents of children with CI and additional disabilities and (b) to examine parents’ satisfaction and perceptions regarding service provision for their child and family. Specifically, do families perceive that they are receiving adequate levels of services for themselves and their children? What are the helpful and unhelpful aspects of service provision?

Method

Procedure

This mixed-methods study was part of a larger research project examining parental experiences following pediatric cochlear implantation among deaf children with additional disabilities. The study was reviewed and approved by the university research ethics board and the hospital ethics committee. Parents were recruited from the cochlear implant program at a Children’s Hospital in a western Canadian province. The CI team and program coordinator conducted a comprehensive file review to identify all children in their program who had received a CI and had been diagnosed with additional disabilities. Inclusion criteria were (a) children under 18 years of age, (b) CI had been activated for at least 9 months, and (c) documented diagnosis of at least one disability in addition to deafness. Table 1 presents the frequencies of the additional disabilities of the final sample of the study. Among the families who declined to participate, there were no disabilities that were not represented in the participant sample. It should be noted that the diagnostic labels of learning disability, language disorder, and cognitive delay reflect the diagnoses as they were indicated in the psychoeducational reports in the hospital files.

The CI team identified 45 children who met the inclusion criteria, and the survey was mailed to all 45 families. Twenty-three families participated in this study, and informed consent was obtained from all of them. Language interpretation services were offered to any families who spoke a language other than English or used sign language; however, no parents requested these services. The package mailed out to each family contained three questionnaires. Parents were asked to complete the forms and return them to the hospital in a self-addressed, stamped envelope. The hospital removed any identifying information from the envelope so that families’ individual identities remained anonymous to the researchers.

Participants

Twenty-three parents completed the survey, representing 51.1% (N = 23) of the total group of parents initially contacted. This proportion is somewhat higher than that usually reported in similar studies (e.g., Hintermair, 2006; Nunes, Pretzlak, & Ilicak, 2005; Zaidman-Zait, 2008). Participants were comprised of 21 mothers and 2 fathers, each a parent of 1 deaf child. Regarding parents’ education level, 52.1% of the children had mothers and 43.4% of the children had fathers with at least 1 year of university or college education. Twenty-eight percent (28.6%) of the participants had an annual average household income lower than $49,999; 38.1% had a yearly income between $50,000 and $79,999; and 33.3% had a yearly income higher than $80,000. Thus, approximately two thirds of the families could be described as middle class. The majority of parents resided in either urban (42.9%) or suburban (42.9%) areas. The most common language used at home was English (91.3%). The children (63.3% male) ranged in age from 3 to 16 years (M = 8.60 years; SD = 4.34 years). Hearing loss had been diagnosed at an average age of 12.06 months (SD = 8.8 months). Mean age of implantation was 40.34 months (SD = 33.42 months). The additional disability or disabilities had been identified prior to the children’s cochlear implantation surgery for 10 of the 23 children (43.5%). Children’s additional disabilities are described in Table 1.

The majority of parents reported that their current approach to communicating with their deaf child at home was spoken language with some sign language support (59.1%); 31.8% of the parents reported using only spoken language, and the remaining parents (9.1%) reported using other communication methods such as augmentative/alternative communication (AAC).

Measures

As previously mentioned, the package that was mailed out to the parents contained three questionnaires:

Child and family background questionnaire

This questionnaire tapped information on family demographics, including parents’ education level, number of children in the family, place of residence (e.g., urban vs. rural), and siblings’ and parents’ hearing status. In addition, information was gathered on the implanted child: age, gender, etiology of deafness, communication approach, educational setting, age at implantation, intervention setting, and any additional known disabling conditions.

Table 1. Children’s additional disabilities

<table>
<thead>
<tr>
<th>Additional disability</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability</td>
<td>5</td>
</tr>
<tr>
<td>Language disorder</td>
<td>2</td>
</tr>
<tr>
<td>Cognitive delay</td>
<td>1</td>
</tr>
<tr>
<td>Vision</td>
<td>2</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>1</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>4</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Fetal alcohol syndrome</td>
<td>1</td>
</tr>
<tr>
<td>&gt;1 additional disability*</td>
<td>6</td>
</tr>
<tr>
<td>Additional diagnosis known prior to surgery</td>
<td>10</td>
</tr>
</tbody>
</table>

*Note. Children with >1 additional disability included: seizure disorder and severe intellectual disability; severe retinitis, ventilicuropertoneal shunt, and significant motor delay; extracerebral membrane oxygenation, congenital diaphragmatic hernia, scoliosis, musculoskeletal and pulmonary problems; cerebral palsy and bronchopulmonary dysplasia; Kasabach-Merritt syndrome and hemangiopericytoma; cerebral palsy and cognitive delay; and seizure disorder, language disorder, and learning disability.
Services inventory
The Services Inventory was designed to assess families' perceptions of services that they believed were needed, and whether they considered they were receiving adequate amounts of those services (Summers et al., 2007). This inventory was originally designed to investigate the service provision for children with a wide range of special needs, including various child and family service needs, and was judged to be appropriate for the purpose of the current study. Services for children covered on the inventory included provision of special equipment, therapies, and specialized services and service coordination. Services for families included provision of care, resources, and self-help groups, as well as information related to specific disabilities, services, and legal rights.

Everyday problems, challenges, and associated stress
The Everyday Problems, Challenges, and Associated Stress Questionnaire was chosen, as it was originally developed and used in the context of parenting children with CIs (Zaidman-Zait, 2008). An additional benefit of using this questionnaire in the current study was that it provided an opportunity for parents to reflect openly on various everyday problems they may encounter within the specific context of having a child with CI and an additional disability. Open-ended questionnaires have been found to be efficient in capturing the problems most salient to parents of deaf children with CIs (Zaidman-Zait, 2008) or adults in general (e.g., Strough, Patrick, Swenson, Cheng, & Barnes, 2003). In the Everyday Problems Questionnaire, parents were asked two open-ended questions: first, to describe in detail the types of everyday problems they encountered within the specific context of parenting a child with an implant and second, to describe in detail the types of everyday problems their child encountered. In addition, parents were asked to rate on a 7-point scale, from (1) minor annoyance to (7) an extremely stressful event, how stressful they perceived each problem.

Interviews
Of the 23 participating parents, 73.9% (N = 17) agreed to participate in an individual semi-structured, follow-up interview. The interviews were conducted by the first two authors, both of whom have training and extensive experience interviewing parents of children with disabilities. The background of the first author is counseling and the second author (who was a doctoral student in Special Education) worked for many years with families of children with hearing loss. Each interview lasted from 60 to 90 min. Parents were asked open-ended questions about their experiences, starting from the time of the decision to undergo cochlear implantation to the present day. They were also asked to report on daily benefits and challenges of their child having a CI. In addition, parents were asked about their experience of accessing services for their family and child. All interviews took place at a location convenient to the parents, and were audio taped, and then transcribed verbatim. The first and second authors jointly analyzed the transcribed interviews using inductive thematic analysis (Hsieh & Shannon, 2005; Pope, Ziebland, & Mays, 2000). Thematic analysis is a flexible research tool due to its independence from theory (Braun & Clarke, 2012). Coding was done with the assistance of NVivo 8.0 software to facilitate management and retrieval of the vast data. Following transcription, the first two authors read the transcripts individually several times. They began with a systematic analysis of the data through the creation of initial codes. The codes identified and provided labels for features of the data that were relevant to the research questions. Topics, patterns, and themes were identified, and these were later shared among all the authors. The authors then analyzed the joint codes into themes that summarized and systemized the repeated patterns of meaning of the data. A theme “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). At the final stage, the two authors went through a recursive process where they reviewed the developing themes in relation to the coded data and entire data set, to ensure the quality of the coding process.

Results

Perceived Daily Benefits and Challenges
The first research question pertained to parental perceptions of the daily benefits and challenges of cochlear implantation for their children with additional disabilities.

Perceived benefits
From the surveys, it was indicative that the most commonly cited benefit of the CI was the child’s enjoyment of music and awareness of environmental sounds (43%). Another frequently reported benefit was increased communication ability (35%). Parents also indicated that increased safety was a benefit of cochlear implantation, as their children were able to respond to a warning shout or safety-related environmental sounds, such as alarms or sirens (22%). Finally, some parents indicated that the CI contributed to their child’s well-being (17%).

Benefits raised in the interviews
Based on the qualitative analysis of the interviews, parents expressed satisfaction with their child’s CI and spoke of the transformation of their children as they gained auditory skills. “He’s like a different person when he can hear,” and “It’s like going from a deaf child to a hearing child.” Moreover, positively perceived benefits were reflected in advice to other parents who were considering cochlear implantation for their child. The majority of the participants recommended the procedure, with comments such as, “Go for it!” or, “Do it ASAP.” Other participants emphasized that it was the parents’ decision and wrote “Do what you feel is right.” There were also references to the low risk of the procedure, as well as an adjustment period, for example, “It’s safe!” and “Don’t give up.”

Parents described benefits regarding changes in their child’s communication skills. However, it should be noted that there was variability among parental perceptions of the way their child responded with the CI and communicated with family members during daily routines and at school. Overall, the perceptions seemed to range from positive to neutral. For children with low or nonverbal communication skills, parents attributed responses to sounds, such as quieting down, turning or changing facial expression to improved auditory awareness:

“He stills, he’ll stop kicking; he does tilt his head towards the side of the magnet. And if it’s something that’s really uncomfortable, if he’s in preschool and another child yells or screams ...you can see the grimace on his face, like, really bothered by it.”

Parents also saw child actions, such as hand-pulling, vocalizations, and reaching as communicative. “He’ll actually take [his sister] by the hand, and he’ll take her upstairs, and be like, ‘OK, let’s go play in your room.’” With regard to communication method, some parents used sign language to support their
spoken language communication with their child. A parent of a preschool child with developmental delays explained,

At bedtime, I always sign ‘bed.’ When it’s time to brush her teeth, she just points at her mouth. Like, that’s her sign. And I’ll be like, yes, it’s time to brush your teeth. So, you know, the things that we do every day, the signs that you would use every day, I sign with her.

A number of parents described how their child was developing both signed and spoken language. “He’s signing quite regularly as well, but speech is still his first expression. But in his reception, it’s still very much mixed between the two. If I really want to get a point across, I’ll sign it and say it.” Parents of children who were primarily verbal communicators also described using sign language as a “back-up system” for occasions when the CI was not on, or when the children were in noisy environments.

“Usually we just sign when he doesn’t have his equipment on, which is, you know, sometimes in the morning he doesn’t put it on right away… or I’ll just clarify if we’re at a restaurant or something like that. If it’s noisy and he can’t hear as well then I might sign a bit.”

**Perceived challenges**

Parent-perceived daily challenges were identified through two means: first, a content analysis of responses to the Everyday Problems, Challenges, and Associated Stress Questionnaire (Zaidman-Zait, 2008) and second, the qualitative inductive content analysis of the interviews. In terms of the former, the first two authors, both with expertise in early intervention and school-based programs with children who are deaf or hard of hearing, conducted a content analysis of the everyday problems reported by the parents. Each rater separately read the problems and then categorized each problem into an appropriate domain derived from the content. For example, a problem related to difficulty in conversing about complicated topics with the child was categorized as a communication difficulty. Final categorization of the problems into domains was determined by consensus between the two researchers. Parents reported an average of 3.04 domains of problems (SD = 1.82), with an associated mean problem-related stress level of 4.93 (SD = 1.40) on a scale of 1–7. The content analysis procedure yielded problems across nine domains. Table 2 describes the nine domains and, in descending order of frequency, indicates the percentage of parents who identified at least one problem in each respective domain. As shown in Table 2, the most frequently reported domain for everyday problems was communication difficulties (60.9%), followed by implant drawbacks (47.8%), child’s behavior and character (39.1%), and child’s use of the CI (34.8%).

**Challenges identified in the interviews**

The interviews provided the opportunity for parents to elaborate on the daily challenges they faced with their child, as identified in the responses to the Everyday Problems, Challenges, and Associated Stress Questionnaire (Zaidman-Zait, 2008). Based on the qualitative inductive thematic analysis of the interviews, the daily challenges that were commonly cited were concerns about the equipment, challenges in school, and social-emotional well-being. Although there was a difference in the precise names of the identified domains from the Everyday Problems, Challenges, and Associated Stress Questionnaire and the predominant interview themes, there was considerable overlap in the challenges described by the parents.

Although parents expressed satisfaction with their child’s CI and improved communication, many parents spoke of the challenges of managing the device and equipment. A number of parents were concerned about the child chewing on the equipment, throwing it or losing it. Some parents also expressed frustration with the CI falling off or malfunctioning. Parents also spoke of an adjustment period in which their children resisted the CI at first, but then came to use it more regularly. “At the beginning, it was a fight. She doesn’t [sic] want it on. It scared her. And now she can wear it all day at school.”

A number of parents mentioned the challenges that their children faced in school, such as difficulties in classroom learning:

> Sometimes she doesn’t catch everything in class. The teacher will be saying it fast, or you know, they’ll skip to the next subject right

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
<th>% of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication difficulties</td>
<td>Communication breakdowns in child-parent interactions, children’s speech perception and production competence, language level, home language considerations</td>
<td>60.9</td>
</tr>
<tr>
<td>Implant drawbacks</td>
<td>Equipment breakdowns and failures, maintenance of parts, troubleshooting, device limitations</td>
<td>47.8</td>
</tr>
<tr>
<td>Child’s behavior and character</td>
<td>Children’s interactive behaviors and temperament</td>
<td>39.1</td>
</tr>
<tr>
<td>Child’s use of the CI</td>
<td>Mishandling the equipment, not wearing the CI</td>
<td>34.8</td>
</tr>
<tr>
<td>Rehabilitation demands and parenting role</td>
<td>Demands and responsibilities placed on parents due to rehabilitation needs and parents’ uncertainty regarding fulfillment of their role in rehabilitation</td>
<td>21.7</td>
</tr>
<tr>
<td>Relationships with siblings</td>
<td>Challenges in siblings’ interaction</td>
<td>21.7</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>Costs associated with the CI device, travelling for rehabilitation or appointments, need to change residence</td>
<td>17.4</td>
</tr>
<tr>
<td>Educating others/advocacy</td>
<td>Need to explain child’s hearing loss and communication needs to others and to advocate for services and/or accommodations</td>
<td>17.4</td>
</tr>
<tr>
<td>Academic concerns</td>
<td>Concerns about child’s academic performance</td>
<td>17.4</td>
</tr>
<tr>
<td>Other problems</td>
<td>Examples include: decision making, accessibility of services, child care options, child’s social competence and peer relationships, safety concerns</td>
<td>4.3–13</td>
</tr>
</tbody>
</table>
away, and she doesn’t have a chance to write it all down.” Another parent described her son’s challenges in social listening situations at school. “Now that he’s getting older, like there’s a group of probably ten of them that hang out. And, it’s getting harder, because when they all talk at once, he can’t follow the conversation.”

Other parents expressed challenges that were related to their children’s social-emotional competencies, including children’s challenges in developing social skills:

“So he has exhibited some inconsiderate behaviour at school that they do have some issues with. You know, not playing nicely, going around and snatching toys off other children. If they’re playing a game, walking through the middle of it, not caring that he’s breaking their game, you know things like that.”

Other parents expressed concern with regard to their children’s poor self-advocacy skills in academic and social situations:

“It’s been a really hard struggle, because she’s not an aggressive student at all. If the question doesn’t get asked, she’ll just kind of leave it. And I always say, ‘No! Go up and ask them, go after school, go at lunch! They give you all the opportunities. Go!’

Perceptions Regarding Service Provision

The second research question involved parents’ satisfaction with and perceptions regarding service provision for their child and family. This was investigated through responses to the Services Inventory (Summers et al., 2007) and qualitative inductive content analysis of the interviews.

Responses to the Services Inventory

The responses to the Services Inventory (Summers et al., 2007) indicated that the median number of needed specialized child-oriented services, as identified by parents, was 6.5 (range = 1–12; SD = 2.2, median = 6.4). The six child-oriented services that most families reported needing were: speech-language therapy (90%), hearing or vision services (90%), Special Education services (79%), special equipment to help the child (79%), physical or occupational therapy (60%), and behavior support (55%). Respondents who indicated a need for a service were asked to report whether they were receiving “none at all,” “some but not enough,” or “enough.” For these six most-needed services, on average 13.3% were receiving “none at all,” “some but not enough,” or “enough.” For these six most-needed services, 34.5% of the participants on average (range = 0–87.5%) reported not receiving them at all. Overall, the majority of parents reported that they were either not receiving enough family-oriented services or were receiving none at all. The service that families indicated they needed most often was “information about where to get services for the child”; however, none of the families who indicated that they needed this information stated that they were getting enough. Overall, families reported a greater need for child-oriented services than family-oriented services.

Themes identified in the interviews

The qualitative inductive content analysis of the interviews allowed for a deeper exploration of parent perceptions of and satisfaction with services. Based on this analysis, the experience of the parents can be described under three overarching themes, including management and coordination of services, service availability and accessibility, and family–professional partnership.

Management and coordination of services

Several aspects of the service system structure were reported as challenging for parents. One challenge was the management of funding. Although medical supplies, home-based nursing, and home- or center-based therapy services were government-funded, parents were required to manage the funds and complete a significant amount of paperwork. Parents also described the stress of scheduling and managing multiple appointments.

### Table 3. Most-needed services reported by parents and parents’ adequacy ratings

<table>
<thead>
<tr>
<th>Services</th>
<th>Need for services indicated (N = 23)</th>
<th>Service adequacy ratings (percentage of only of those indicating a need)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (%)</td>
<td>None</td>
</tr>
<tr>
<td>Child-oriented services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech and/or language services</td>
<td>90</td>
<td>10</td>
</tr>
<tr>
<td>Hearing and/or vision services</td>
<td>90</td>
<td>0</td>
</tr>
<tr>
<td>Special Education services</td>
<td>79</td>
<td>12</td>
</tr>
<tr>
<td>Special equipment to help child</td>
<td>79</td>
<td>6</td>
</tr>
<tr>
<td>Physical and/or Occupational therapy</td>
<td>60</td>
<td>21</td>
</tr>
<tr>
<td>Behavior support</td>
<td>55</td>
<td>31</td>
</tr>
<tr>
<td>Family-oriented services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about where to get services</td>
<td>42</td>
<td>25</td>
</tr>
<tr>
<td>Respite care</td>
<td>39</td>
<td>37.5</td>
</tr>
<tr>
<td>Sibling support</td>
<td>33</td>
<td>87.5</td>
</tr>
<tr>
<td>Parent training</td>
<td>30</td>
<td>0</td>
</tr>
<tr>
<td>Support groups</td>
<td>30</td>
<td>0</td>
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or nursing care services. In addition, they discussed the challenges associated with following the recommendations of diverse professionals.

“I used to cry at some of these meetings. We’d be in a meeting with 20 people, [who] would be there to represent every aspect of his care. And they would all be telling us things to do. And it was a lot of pressure when he first got his cochlear implant because, you know, on top of that, we had all the speech things to do with him, and that was just another thing to add on to everything else that we have to do.”

Parents reported it to be helpful when therapists and health care providers communicated and worked together to coordinate or combine visits and therapies.

“We’ve sometimes felt it’s too much going on (laugh). But lately, I just find it’s the perfect amount, because at the family support meeting, we discussed who’s going to play the main roles in things. So, all the therapists kind of talked at that meeting to make sure that we’re not overbooking and stuff. So that’s why we started doubling up on appointments. They’ll call each other.”

Parents also appreciated the convenience and customization of home-based services.

“That just took such a big burden off of everything when they come into the home. That makes it easier. And it also makes it so that you can be really specific and talk about things, like, this is where he sits and eats his dinner, you know. How can you make this better for him, you know.”

Service and availability and accessibility
Parents discussed a number of issues regarding the availability and accessibility of services, which included contextual influences and CI technical support. They reported limited availability of specialized services, especially in remote or rural communities.

“It would have been great to have more services for him, for speech and language or whatever else is necessary. But, it’s just not available, so, I don’t dwell on things that can’t change at the moment. And we just make it up at home. We just do what we have to do here and just help him as best we can.”

In addition, many parents indicated that it was difficult to find extracurricular or after-school programs that accommodated children with complex needs.

“It’s really hard to get into the programs. First of all you have to find the programs, which aren’t easy. And then you have to weigh out the cost of the program, because some of them are quite expensive.”

Parents unequivocally agreed that services were easy to access and that the response was swift regarding technical support for CIs from the manufacturers or from the medical center.

“She’s only really out for a day. And if I find out first thing in the morning, we usually have it by that evening. Like, it’s incredible, the service we get. It’s awesome. You know, they don’t want her to be without hearing.”

Family–professional partnership
A third theme that emerged was family–professional partnership. Several parents commented on the support they received from early intervention professionals. Parents emphasized the positive contribution of both emotional support and resource provision.

“I think that she [the early interventionist] was more of an emotional support for me than anything. Like, it was really nice to have that. And one thing, I always looked forward her coming. If I had any questions, or where do I go next, or – [she] was always there.”

Parents commented on the importance of communication with school-based professionals with regard to their child’s skill development. They reported communicating with professionals by a variety of methods: face-to-face, texting, emails, phone calls, or communication books that were passed between home and school. However, a few parents felt uninformned of the daily events in their child’s school life.

“I think in the long term, I definitely have a say, because I get to help make that [IEP] plan. But then on a daily basis, and seeing it carried out – I’m very uninvolved. Or uninformed.”

Discussion
The current study examined parents’ perceptions of benefits and challenges for deaf children with CIs who have additional disabilities and their families, as well as parental perceptions and satisfaction regarding service provision.

Perceptions of CI Benefits and Challenges
The results of the current study extend the findings of previous studies on the challenges of cochlear implantation in children with additional disabilities (Wiley et al., 2005; Zaidman-Zait, 2008). Overall, the findings are consistent with previous findings regarding benefits, such as communication skills (even if at a very low level), musical and environmental sound awareness, and safety and quality of life (Steven et al., 2011; Wiley et al., 2005). Thoutenhoofd et al. (2005) asserted that parents’ perspectives were underrepresented in the literature, and affirmed their importance, as they may more closely reflect the functional outcomes of children in everyday situations than assessments made in clinical settings. Other researchers have suggested the necessity of including broader outcome measures, particularly parental report, in the assessment of the outcomes of implantation in children (Lin et al., 2008). The present study reveals that parent perceptions of benefits of the CI for their child with additional disabilities include more than the typical clinically based perceptions of medical professionals, such as speech perception or speech-language assessments. The most frequently cited benefit of cochlear implantation among our participants was the child’s response to environmental sounds and enjoyment of music, followed by improved communication skills and increased safety awareness. In children with cognitive delay, parents felt strongly that the CI offered their child improved quality of life. In previous studies on parental satisfaction with CIs for deaf children without additional disabilities, parents spoke of benefit more narrowly in terms of oral/aural communication and academic outcomes (Huttunen & Välimaa, 2012; Hyde et al., 2010).

Parents’ perceptions of benefits following cochlear implantation did not eliminate the everyday challenges they faced in raising their child. Approximately, half of the parents reported challenges in the communication domain in their everyday contexts. Among children with CIs and no additional disabilities, communication problems still occur in the everyday context, but less often (Zaidman-Zait, 2008). In addition, the parents in the present study reported challenges related to their child’s acceptance and use (or misuse) of the CI. This suggests that ongoing training and guidance is needed to enhance parent competence in encouraging the child to wear the CI and solving technical problems when possible.
Perceptions of and Satisfaction With Services

In regard to services, participants identified three main issues: (a) the ease or difficulty with which they were able to obtain adequate services for their child and family; (b) challenges associated with the management and coordination of services delivered; and (c) partnership with professionals. We consider each of these issues in turn. The services survey highlights the notion that this group of children have a high need for extensive family and child support services. In this study, the reported need for child- oriented services was relatively higher than that found in previous studies that examined early childhood service needs for young children with special needs in general (Summers et al., 2007). In the present study, parents, for the most part, believed they were not receiving enough child-oriented services, especially speech- language therapy and behavioral support. These findings were consistent with previous reports in which parents indicated insufficient provision of speech and language therapy services for their implanted child (Barker et al., 2009). Additionally, previous research points to elevated rates of behavioral problems both among children with hearing loss (Cruz, Vicaria, Wang, Niparko, & Quittner, 2012) and children with other disabilities (Sach & Whynes, 2005; Zaidman-Zait, 2008). Consistent with this, parents of deaf children have cited their children’s language and communication difficulties as a major stressor (Kluwin & Stewart, 2000; Zaidman-Zait, 2008), as well as their children’s behavior and social-emotional competence (Sach & Whynes, 2005; Wodehouse & McGill, 2009). Thus, the findings from the present study and previous research strongly suggest that more attention is needed in facilitating provision of these services, a recommendation that has implications for both child and family functioning and well-being (Friend, Summers, & Turnbull, 2009).

The challenges around accessing and locating services were reflected in parent interviews. The parents commented on how time-consuming it was to manage associated paperwork, find information about services, coordinate multiple professional visits, and follow numerous recommendations—sometimes contradictory—from different professionals. This suggests that effective case management services and a team-based approach in providing therapy and support services for these families are needed. Case management services have the potential to address many of the information and practical needs identified by parents (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009). Service-planning efforts should be directed at exploring ways of making case management services more readily available for families (Wiese & Parmenter, 2009). Moreover, it would be helpful to adopt a team-based approach when working with them. A team-based approach is recommended as an optimal system for serving children with special needs and their families (Bagnato & Neisworth, 1991). A central tenet of this approach is that all of the professionals involved understand one another and work together for the common interest of the child and the family (Mc Gonigel, Woodruff, & Rossmann-Millican, 1994). As the parents in the present study indicated, it was very helpful when therapists or health care providers communicated and worked together as a team to coordinate visits and therapies. In some situations, cotreatment sessions (e.g., vision therapist and aural habilitation specialist treating a child collaboratively, at the same time) should be considered so that service provision can be more integrated. Consistent with this, Opletree, Bull, Drew, and Lunnen (2001) recommended that a case coordinator should be assigned to serve as an active liaison between all team members (including the family) to facilitate coordinated care.

Consistent with previous findings, the number of families needing family-oriented services was less than the number needing child-oriented services (Ellis et al., 2002; Summers et al., 2007). Six parents in this study expressed a need for “information about where to get services for the child,” and 17 indicated that they were receiving adequate family-oriented services. At the same time, there was a definite gap between the number of families who expressed a need for family-related services and those who believed they were getting enough of those services. This recurring finding might, as suggested by Summers et al., reflect a lack of clarity in the definition of family-related services in intervention programs. On the other hand, it may also be indicative of more complex needs for information and family support on the part of some parents of implanted deaf children with additional disabilities, in comparison to families of typically developing deaf children with CIs.

Lastly, the findings strongly emphasize the significant contribution of partnership between professionals and families to ensure coherence, collaboration, and respect. The findings highlight the importance of the relational components of a family-centered approach, such as active listening, compassion, empathy, respect, and a set of beliefs about parenting capabilities and competencies (Dunst & Trivette, 1996). The findings also suggest that barriers to care may exist at the system level. Family-centered and “wrap-around” care, an approach that combines numerous coordinated services to meet the needs of patients, caregivers, and families, may help to streamline the process of obtaining resources for these families and alleviating their burdens. Professionals would be well advised to take the time to establish rapport and trust with families and to work closely and collaboratively with families to develop individually relevant family-driven plans. This family-professional partnership would thereby enhance the relational component of the family-centered service delivery. Given the importance of service provision in the lives of families raising a deaf child with additional disabilities, further examination of the design and delivery of multiple services is warranted.

In drawing conclusions, we are aware of certain limitations of the current study. Given the relatively low incidence of severe-to-profound hearing loss in young children, and the even lower incidence of implanted children with additional disabilities, our sample size was both relatively small and heterogeneous. The sample included a diverse group of children in terms of age, disability, and years implanted, which limits our ability to fully understand the specific experiences of parents who have children with a particular diagnosis or disability. In addition, we should be cautious when generalizing our findings. Nevertheless, our study is one of the few that has attempted to explore parent perceptions of cochlear implantation and services for deaf children with additional disabilities. Future research should investigate the perceptions of families of implanted children who share a similar additional disability. Research is also needed to investigate how professionals manage care and service delivery to families of deaf children with multiple needs.

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Conflicts of Interest

No conflicts of interest were reported.

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