

**PARENTING CHILDREN WITH COCHLEAR IMPLANTS: CHALLENGES, STRESS,  
COPING, AND PROCESSES**

**by**

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### **Abstract**

The central goal of the current dissertation was to expand the research on the experiences of parents of children with cochlear implants (CIs). To accomplish this goal, three studies were conducted:

The first study explored everyday problems associated with parenting children who undergo cochlear implantation; to investigate parents' interpersonal relationships as a resource for collaborative problem solving; and to examine links between parents' everyday problems, stress, and life satisfaction. Thirty-one parents of children with CIs responded to open-ended questions regarding the types of everyday problems they encountered in parenting their child, and also rated their stress and life satisfaction. Problems were categorized into nine domains: implant drawbacks, communication difficulties, child's behavior, child's social competence, rehabilitation demands and parenting role, financial difficulties, services, educating others/advocacy, and academic concerns. Professionals, spouses, and other parents of deaf children were frequently nominated partners for collaborative problem solving and coping. Significant correlations emerged among parents' everyday problems, stress, and life satisfaction.

The second study described and categorized the attributes that parents of young children with CIs consider as facilitating their parental coping experience. Fifteen hearing mothers and thirteen hearing fathers whose children had CIs were interviewed, using the critical incident technique. A total of 430 critical incidents were documented and sorted into 20 categories. Results indicated various sources of influence on parents' coping experience, associated with social contextual aspects, with the parent himself or herself, and with the child.

The third study examined the complexity of parenting children who have received CIs as well as parents' involvement in the CI rehabilitation process. Action theory and its related

qualitative action-project method were used in this study. Two cases were used to describe the individual and joint actions and projects, as related to the promotion of children's outcomes post-cochlear implantation that mothers engage in with their young children. Potentially illuminative implications were drawn for the 'current thinking' in relationship to parenting children with cochlear implants.

Finally, four overarching themes emerging from the findings of the three studies were identified and described. These themes were discussed in terms of implications for practice and future research.

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*To Idan Zait*

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### **Co-Authorship Statement**

The research and writing of this thesis was supervised by Professor Janet Jamison and Professor Bruno Zumbo. In chapters 2, 3, and 4 I was responsible for conceptualizing and designing the research program, performing the research, conducting all the statistical analysis and writing of the manuscripts. In chapter 4, Dr. Richard Young contributed to the conceptualization of the study and was involved in the manuscript preparations. Throughout the dissertation Professor Janet Jamieson and the supervisory committee provide helpful editorial comments and suggestions.

## **Chapter 1**

### **Introduction:**

## **Deafness and Cochlear Implantation**

## Deafness and Cochlear Implantation

From the time of earliest infancy – and, in fact, during gestation – hearing provides essential access to communication and language and, from this perspective, hearing is an initial building block of social interaction. Children who are born deaf or who become deaf during infancy typically experience significant delays in speech and language development, cognitive and psychosocial skills, and academic achievement (Davis, Elfenbein, Schum, & Bentler, 1986; Geers, 1989; Moeller, Osberger, & Eccarius, 1986).

### What is a Hearing Loss?

Hearing loss is the inability to hear sounds at normal level. Infants' hearing sense is present even before birth (approximately 5 months after conception). The ear consists of three parts that play a vital role in hearing -- the external ear, middle ear, and inner ear. The hearing process consists of two types of hearing processes, **conductive hearing** and **sensorineural hearing**. In **conductive hearing** the sound travels along the ear canal of the **external ear**, causing the ear drum to vibrate. Three small bones of the **middle ear** conduct this vibration from the ear drum to the cochlea (auditory chamber) of the **inner ear**. **Sensorineural hearing** occurs when the three small bones move and cause waves of fluid in the cochlea, which stimulate delicate hearing cells (hair cells). As these hair cells move, they generate an electrical current in the auditory nerve. The current travels through inter-connections to the brain area affiliated with hearing, which recognizes it as sound.

Hearing impairment can be a result of a disease or obstruction in the **external** or **middle ear**, an impairment in conductive hearing, or an **inner ear** problem that results in a sensorineural hearing loss or **nerve deafness**. In most cases of sensorineural hearing loss, the hair cells are

damaged and do not function. Although many auditory nerve fibers may be intact and can transmit electrical impulses to the brain, these nerve fibers are unresponsive because of hair cell damage.

A deaf child is one who cannot hear speech alone with or without the assistance of a hearing assistance device, such as a hearing aid. The prevalence of infant hearing loss is estimated to range from 1.5 to 5.7 per 1000 live births (Watkin, Baldwin, & McEnery, 1991; White & Behrens, 1993). The previously mentioned delays in speech and language development, cognitive and psychosocial skills, and academic achievement typically experienced by children with significant hearing losses are apparent for both children with mild and moderate hearing loss (Geers & Moog, 1989; Moeller, Osberger, & Eccarius, 1986; Webster, 1986,) as well as for those whose losses fall in the severe and profound ranges (Andrews & Mason, 1991; Geers & Moog, 1989; Moeller et al., 1986).

Advances in technology in the past two decades, however, have contributed to improved developmental outcomes of deaf children. One advance is newborn hearing screening, a technique that allows infants with hearing losses to be identified before the age of six months. In the absence of universal newborn hearing screening, the average age of identification of hearing loss in children ranges from 19 to 36 months of age (Mace, Wallace, Whan, & Stelmachowicz, 1991). Indeed, recent research findings demonstrated that early identification has been associated with improved developmental outcomes in deaf children (Yoshinaga-Itano, 1999; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). A second major technological advance has led to the development of an implanted assistive listening device, namely the cochlear implant (CI).

## **What is a Cochlear Implant?**

A CI is an implanted electronic device that provides direct electrical stimulation to the auditory nerve. In sensorineural hearing loss (severe to profound nerve deafness) where there is damage to the tiny hair cells in the cochlea, sound cannot reach the auditory nerve. A CI is very different from a hearing aid. Hearing aids amplify sounds so they may be detected by damaged ears. A CI bypasses damaged portions of the ear and directly stimulates the auditory nerve. The CI does not result in "restored" or "cured" hearing. It does, however, allow for the perception of sound "sensation" and help a person with deafness to understand speech. Hearing through a CI is different from normal hearing and takes time to learn or relearn.

The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin. An external view of an implanted CI is shown in Figure 1.1, while the functioning of a CI is provided in Figure 1.2 and a detailed rendering of the parts of a CI is shown in Figure 1.3. An implant has the following parts:

### **External Parts:**

- A microphone, which picks up sound from the environment (typically worn behind the ear).
- A speech processor, which is a computer that analyzes and digitizes the sound signals (picked by the microphone) and sends them to a transmitter. The speech processor may be housed, with the microphone, behind the ear or it may be a small "box" worn in a cloth holder.
- A transmitter, which receives signals from the speech processor and converts them into electric impulses. The transmitter is worn on the head just behind the ear.

**Internal parts:**

- A receiver/stimulator, which is surgically implanted under the skin behind the ear, and contains a magnet, which couples to the magnet in the transmitter worn externally. The receiver takes the coded electrical signals from the transmitter and delivers them to the array of electrodes that have been surgically inserted in the cochlea.
- An electrode array inserted into the cochlea to provide direct electrical stimulation to the fibers of the auditory nerve to send information to the brain. The brain interprets this information and perceives it as sound sensations.

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Figures 1.1, 1.2, and 1.3  
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Cochlear implantation is one common and increasingly selected rehabilitation option for children who are deaf. Cochlear implantation was first approved for children in the United States in 1990, and by 2002, the United States Food and Drug Administration (FDA) had lowered the minimum age for implantation to 12 months (Spencer & Marschark, 2003). Currently some deaf children younger than 12 months are receiving them as part of clinical trials. According to the Food and Drug Administration's (FDA's) 2005 data, nearly 100,000 people worldwide have received cochlear implants (CIs). In the United States, roughly 22,000 adults and nearly 15,000 children have received them (National Institute on Deafness and Other Communication Disorders, 2006).

Once the decision has been made by parents to pursue the possibility of a CI for their child, there is a need to determine whether the child is a candidate. Most implant centers utilize a team approach to providing a comprehensive assessment of a child's candidacy for cochlear implantation. The assessment process usually involves medical, audiological, speech and language, education, and other support service professionals. The general candidacy requirements for cochlear implantation among children are as follows:

- According to the FDA, a current minimum age requirement of 12 months of age. Minimum age requirements continue to be reduced due to limited surgical risks and improved outcomes for children implanted at the youngest ages. Currently, some CI centers are completing the procedure earlier based on expectations of improved outcomes for early implantation. In addition, specific circumstances may require earlier implantation (e.g., conditions that cause ossification (bone build-up) in the cochlea, making it increasingly difficult to surgically insert the electrode array as time passes). These requirements continue to change, especially in relation to minimum age of implantation.
- The presence of bilateral (both ears), profound sensorineural hearing losses. However, increasing numbers of children with hearing losses in the severe range are being considered for CIs.
- Little or no useful benefit from hearing aids.
- No medical contraindications to electrode insertion or receiver placement.
- No medical conditions that would make the surgery risky.



- Family willingness to follow post-surgical recommendations, namely enrolling in speech, language, and listening therapy; returning for follow-up appointments; being involved in intensive rehabilitation services; and holding realistic expectations for CI.
- Educational and home environments that are supportive of CIs.

For a young child receiving an implant, the surgery takes approximately 3 hours. In general, cochlear implantation is a safe procedure with a low rate of complications (Campisi, James, Hayward, Blaser, & Papsin, 2004; Haensel, Engelke, Ottenjann, & Westhofen, 2005). Approximately 4 weeks post-surgery, the child returns to the implant centre for the initial stimulation of the device. At this point the child is “hooked up” to the external component of the implant, the “speech processor.” Each speech processor must be adjusted or “mapped” specific to each individual. Continuing mapping appointments are usually required over the following months.

### **Cochlear Implants in the Context of British Columbia**

The current studies were all conducted in British Columbia (BC), Canada. Hence, I will provide some background information regarding the cochlear implant program in BC. All the information was provided by the coordinator of the cochlear implantation services at BC Children and Women’s Hospital, Dr. Kristine Juck (Kristine Juck, personal communication, June 2007). The purpose of the BC Children’s Hospital Cochlear Implant Program (BCCH Cochlear Implant Program) is to “maximize the auditory potential of children with hearing loss. The Cochlear Implant program is the responsibility of Children’s and Women’s Hospital, part of the Provincial Health Services Authority.” (BC Children’s Hospital cochlear implant information package, p. 1, 2003).

The BCCH Cochlear Implant Program was established in 198, and it is the only pediatric cochlear implant program that operates in British Columbia. One hundred and sixty-two children have been implanted up to May, 2007. In January of 2004, the BC Ministry of Health funding was increased from support for only 6 pediatric cochlear implantation surgeries annually to 30 surgeries per year. The current BCCH Cochlear Implant Program team includes: coordinator of CI services, CI audiologists, Auditory-Verbal therapist, otolaryngologist, psychologist, social worker, community habilitationists, and consultants from other professions (e.g. developmental pediatrics). Some of the relevant cumulative statistics of the program are presented in Table 1.1.

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Table 1.1

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### **Eligibility Criteria**

The following is the BC CI program eligibility criteria for pediatric cochlear implantation (Juck, 2007):

- 12 months to 16 years of age
- bilateral severe to profound sensorineural hearing loss (exception: 12 –18 month olds require bilateral profound sensorineural hearing loss)
- little or no benefit from hearing aids as determined through a trial period with consistent binaural amplification (3-6 months)
- inner ear capable of accommodating the internal device
- no medical contraindications, e.g., active middle ear infection, ossification, etc.
- family support in place

- realistic parental expectations
- enrolment in an educational/habilitation program with emphasis on auditory/oral development

\* No patient will be accepted as a CI candidate if he/she does not have a primary habilitationist.

No CI surgery takes place until this has been established, and surgery could be delayed in order to ensure that this critical piece has been addressed.

### **CI Services**

The services that the BCCH Cochlear Implant Program offers are (Juck, 2007):

- providing resource information regarding cochlear implants
- determining if a child is a candidate for a cochlear implant
- providing cochlear implant surgery for accepted candidates
- providing ongoing programming of the cochlear implant until the child is 18 years of age
- collaborating with the habilitation programs and community professionals working with these children

In addition, there are four early intervention programs for deaf and hard of hearing children and their families that operate in BC, and they are the community partners of the BCCH CI program.

These programs provide rehabilitation services for children with CIs and their families (BC Children's Hospital and Sunny Hill Health Centre for Children, 2007). The programs include:

1. **The BC Family Hearing Resource Centre:** a provincial program for deaf and hard of hearing children birth to five years of age. The program offers a continuum of communication options and assists parents to discover, over time, the best way to help their child learn to communicate successfully.

2. **The Deaf Children's Society of BC:** a family-centered approach to supporting deaf and hard of hearing children under the age of five and their families. The program emphasizes the importance of early language acquisition and literacy for successful communication in the hearing world. As part of the program, sign language instruction for parents is offered.
3. **The Vancouver Oral Centre for Deaf Children:** a program dedicated to the education of deaf and hard of hearing infants, children and youth. The program focus is listening, talking and language development, including literacy. The educational approach and philosophy are based on developing high levels of listening skill and spoken language.
4. **Queen Alexandra Center for Children's Health:** a family-oriented program on Vancouver Island that provides services to children with hearing loss and their parents. The philosophy of the centre is to support parents in using a communication mode with their child that is based on the current needs of the child and family

## **Paediatric Cochlear Implantation: Child Outcomes and Parental Roles and Experiences**

Cochlear implantation among children has been associated with very positive benefits for children's speech perception, speech production, language, and communication (Bat-Chava, Martin, & Kosciw, 2005; Blamey, Sarant et al., 2001; Connor, Hieber, Arts, & Zwolen, 2000; Geers, Nicholas, & Sedey, 2003; Kluwin & Stewart, 2000; Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000), children's social competence (Bat-Chava & Deignan, 2001; Bat-Chava & Martin, 2002; Bat-Chava et al., 2005; Christiansen & Leigh, 2002), and children's reading ability (Tomblin, Spencer, & Gantz, 2000). At the same time, great variability has been reported in

children's outcomes following cochlear implantation (Bat-Chava et al., 2005; Purdy, Chard, Moran, & Hodgson, 1995; Sach & Whynes, 2005; Spencer, 2004; Spencer & Marschak, 2003; Svirsky et al., 2000). In the last decade, research has been conducted concerning the effects of cochlear implantation on children's speech and language outcomes and the various factors that might be associated with the apparent variability in children's outcomes (e.g., child's age at implantation and pre-implant duration of deafness). Less research has been devoted to understanding the experience of the child's cochlear implantation from the parents' perspectives. This is surprising in light of the consistent emphasis on the significant role of parents in the cochlear implantation rehabilitation process. For example, realistic parental expectations and parental involvement, commitment and support are stated in the candidacy criteria lists of many CI medical centers.

Moreover, although cochlear implantation is, in general, a safe procedure and is associated with positive improvements in speech perception and production, language, and communication, these improvements do not eliminate stressors from the process of adjusting to the CI and raising a child with an implant (Weisel, Most, & Michael, 2007). The process of cochlear implantation among children involves potentially stressful decision making, assessment of details, surgery, a lifetime's ongoing technical support, and a very demanding rehabilitation process. These all entail a great deal of personal investment by the parents (Archbold, Sach, O'Neill, Lutman, & Gregory, 2006; Most & Zaidman-Zait, 2003). First, parents must undertake the process of deciding whether or not the CI should be the choice of sensory aid for their child. This decision is particularly challenging given children's variation in outcomes that are not yet fully understood (Thoutenhoofd, Archbold, Lutman, Nikolopoulos, & Sach, 2005). It should be noted that, nowadays, based on the large body of literature examining factors that impact

outcomes, (e.g., age at implantation and duration of CI use) clinicians and researchers can make some generalizations about outcomes. However, what remains beyond their ability is the prediction of the exact outcome for any one individual child (Zaidman-Zait & Most, 2005). Later, the parents must deal with considerable anxiety and fear prior to and during surgery (Perold, 2001). Finally, the parents must decide on their child's educational placement and mode of communication, as well as maintain involvement in the extensive rehabilitation process.

The literature to date in the area of parental experience concerning children's cochlear implantation has focused on limited evaluations of parents' experience of stress and anxiety, parents' adjustment to their child's CI, parents' expectations, parents' needs, and parents' perceptions of outcomes. Information remains limited on the various parental experiences, such as the problems and stressors that parents face, parents' coping and adjustment processes, and parents' involvement experience and role in the child's rehabilitation process.

The investigation of various parental experiences in raising a child with a CI is important for several reasons. First, the importance of the family context to childhood development has been acknowledged by early intervention researchers and professionals for many years (Bruder, 2000; Dunst, 1999; Guralnick, 1999). The experience of having a child with a disability often has a significant impact on the family (Bailey & Powell, 2005). These notions of reciprocity have led to family-centered models of intervention, which deliver services not only for the child but for the parents as well. The philosophy of family-centered intervention proposes that professionals' provision of information, guidance, and support will empower parents to build a collaborative partnership, in order to develop competence and involvement in their child's education and development (Dunst, Trivette, Boyd, & Brookfield, 1994; Meadow-Orlans & Sass-Lehrer, 1995; Minke & Scott, 1995; Winton & DiVenere, 1995). Family-oriented

intervention programs have become a common practice in the education and intervention of children with hearing impairments. Recent models of early intervention (Guralnick, 2001, 2005; McWilliam & Scott, 2001) are based on Bronfenbrenner's (1979) ecological theory, emphasizing the notion that the child and family exist within a series of complex contexts of interaction between the child's disability, the individual, and the systems internal and external to the family. Second, it has been suggested that the role of parents throughout the rehabilitation processes is one of the many factors found to enhance the benefits of CI use and eventually the child's progress (Allegratti, 2002; Geers & Brenner, 2003; Spencer, 2004). Lastly, parents are the chief decision makers concerning cochlear implantation for their child. Parents often feel it would help them to know more about the experiences of parents whose children were already implanted (Nunes et al., 2005); this position acknowledges parents' epistemological position as the most suitable "knowers" (Young & Tattersall, 2005) when making such an important decision. Hence, in order to provide insights for other parents considering the CI option for their child, it is important to provide information pertaining to parents' various experiences. In addition, parent-generated information is important to implant teams and professionals working in early intervention program for deaf children and their families in planning best quality practice. Parents can make valuable suggestions to implant teams and policy makers (Nunes, Pretzlik, & Ilicak, 2005).

### **The central goal of the dissertation**

The central goal of the current dissertation is to expand the research on parenting children with CIs, specifically, to explore various parental experiences (See Figure 1.4). To accomplish these goals, three studies were conducted. The objectives for each of these studies are as follows:

Study 1 objective: To explore the everyday problems associated with parenting children who undergo cochlear implantation. This study asked the following questions: What are the specific types of everyday problems associated with parenting in the CI context? ; What interpersonal relationships serve as a coping resource for parents in collaboratively solving their everyday problems? ; What are the associations between parents' everyday problems, parental stress, and child and family characteristics (including child's communication ability)? ; What are the associations between parents' everyday problems, parental stress, and parents' sense of satisfaction with their lives? [Chapter 2]

Study 2 objective: To qualitatively investigate the phenomenological experience of parenting a child who is deaf and has undergone cochlear implantation, and to develop a comprehensive categorical system that represents the facilitating resources that parents attributed to their parenting coping experience. This study asked the question: What attributes facilitated mothers' and fathers' coping with this parenting experience? [Chapter 1]

Study 3 objective: To demonstrate the way in which the action theory approach to social inquiry developed by Young, Valach, and colleagues (e.g., Young, Valach, & Collin, 1996; Valach, Young, & Lynam, 2002) is able to increase the understanding of the complexities of parenting a child with a CI, by providing a wider perspective of, first, parenting responses to having a child with a CI and, second, parents' influence on their child's progress over time. This study asked: what are the individual and joint action and projects that mothers engage in over time with their young children as a response to the changes and possibilities brought about by the CI? [Chapter 4]



The common thread throughout this program of research, of which the current dissertation is a part (see Most & Zaidman-Zait, 2003; Zaidman-Zait & Jamieson, 2004; Zaidman-Zait & Most, 2005) is the exploration of the various experiences of parents of children with CIs. Coming from a *pragmatism* philosophical paradigm of mixed methods research (Tashakkori & Teddlie, 2003), the three studies were carried out from different perspectives, using diverse approaches, while valuing both objective and subjective knowledge in trying to illuminate the same phenomena, i.e., parents' experience (see Figure 1.4). Overall, the purpose of the current studies fall into two categories, that is, theory-oriented research and practice-oriented research (Haverkamp & Young, 2007). In other words, the goals were to gain a wide understanding and to elaborate on elements of a theory in new domains, and at the same time, "to inform practice by providing rich, elaborated descriptions of specific processes or concerns within a specific context" (p. 274, Haverkamp & Young, 2007). In each study, the research questions necessitated different methodological approaches, calling for both qualitative and quantitative methods. As highlighted by Tashakkori & Teddlie (2003) the research question has the primary importance in determining the methodological choices. It should be noted that the studies were conducted in a parallel fashion in different stages and were not generated in a linear manner where one study leads to the next one. In addition, these methodologies and, in fact, these studies privilege parents' epistemological positions by enabling the parents to reflect on their own experiences. Parents were enabled to define and describe what information is relevant to their own stresses and coping processes and to reflect on their personal and social meanings and their thoughts and feelings, based on their own experience and life context. The centrality of parents' involvement in the current knowledge production lies in the acknowledgment that

parents, with first-hand experience, are the most suitable informants to provide data on the specified dimensions of interest.

Chapters 2, 3, and 4 will present the previously mentioned studies. The major themes representing the commonalities across the three studies' findings will be summarized and discussed in Chapter 5, along with implications for future research and practice.

Table 1.1 BCCH Cochlear Implant Program – Cumulative Statistics

	May 2002	October 2004	May 2007
Average age of implantation	5 years, 2 months	5 years, 8 months	18 months
Average wait time for surgery	3 years, 4 months	between 3 and 6 months	3 months
Youngest age of implantation	18 months	11 months	8 months

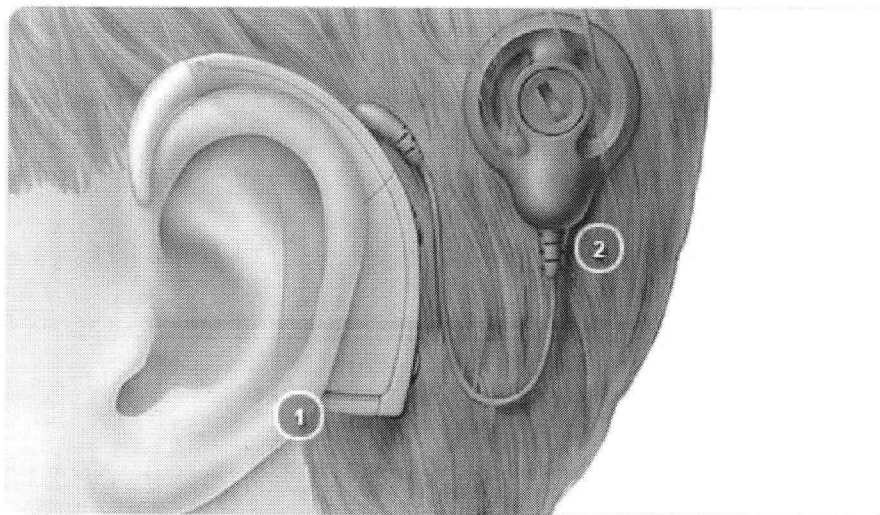


Figure 1.1 A Cochlear Implant: Nucleus Freedom Speech Processing

**Note.** The Nucleus Freedom implant with Contour Advance electrode is the internal part of the system. It includes an electrode array which, when inserted into the cochlea (inner ear), bypasses damaged hair cells and stimulates the hearing nerve directly.

1. Freedom BTE sound processor
2. Cable and Coil

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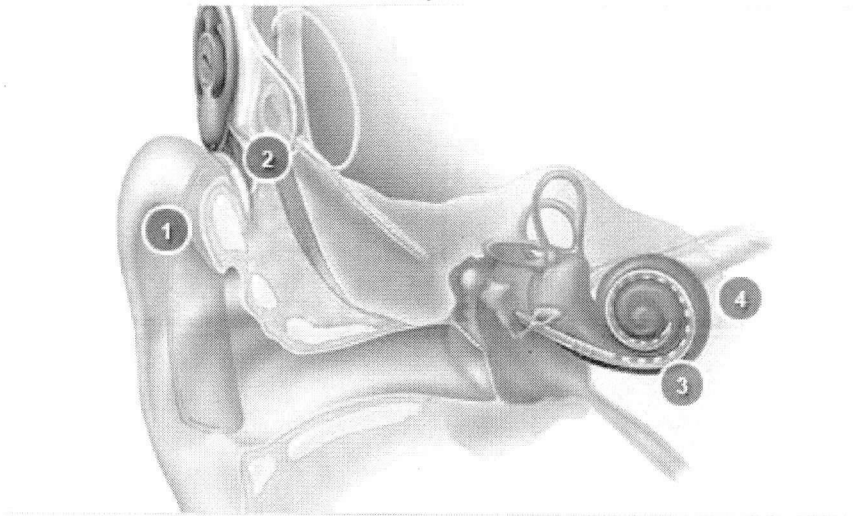


Figure 1.2 The functioning of a cochlear implant (the Nucleus Freedom™)

**Note. 1. Sound processor:** External sound processor captures sound and converts it into digital signals. **2. Digital signals:** Processor sends digital signals to internal implant. **3. Electrode array:** Internal implant converts signals into electrical energy, sending it to an electrode array inside the cochlea. **4. Hearing nerve:** Electrodes stimulate hearing nerve, bypassing damaged hair cells, and the brain perceives signals as sound

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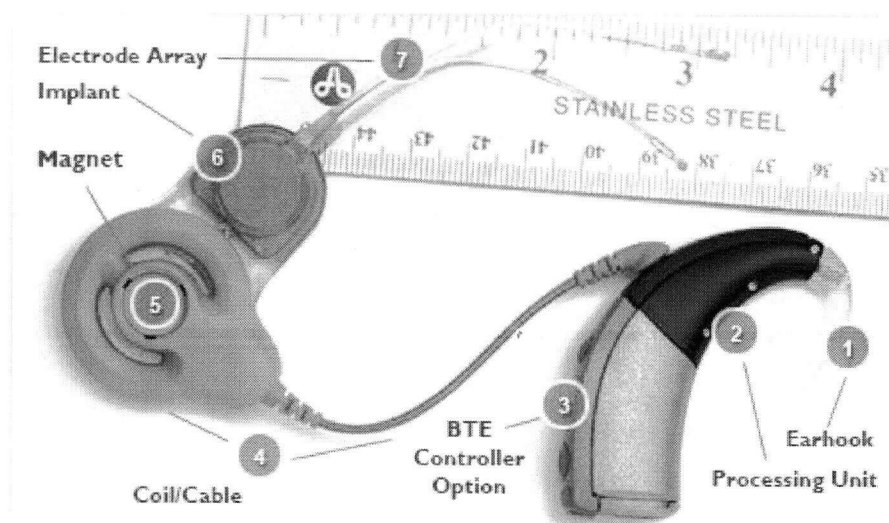


Figure 1.3 Cochlear implant (Nucleus Freedom™).

**Note. 1. The Earhook** is soft and comfortable, and sits on top of the ear to hold the sound processor securely in place. **2. The Processing Unit** houses the main "computer" for the sound processing system. It easily attaches to a Behind-the-Ear option (as shown) or to a small connector that works with the Bodyworn controller. It features microphones that help to pick up sound from speech and from the environment. **3. BTE Controller Option** sits behind the ear and features buttons which allow you to adjust volume, programs and sensitivity. **4. Coil/Cable** unit connects the sound processing unit to the implant on the other side of the skin. It help to transmit the electric impulses that enable you to hear. **5. The Magnet** sits in the middle of the Coil and connects with a magnet on the other side of the skin. This connection between the magnets helps to conduct sound to your hearing nerve. **6. Cochlear Implant body** is made of titanium and silicone, and is the most reliable cochlear implant available today. **The Electrode Array** extends from the main body of the implant into the Cochlea. This is the main piece of the implant that delivers sound to your hearing nerve.

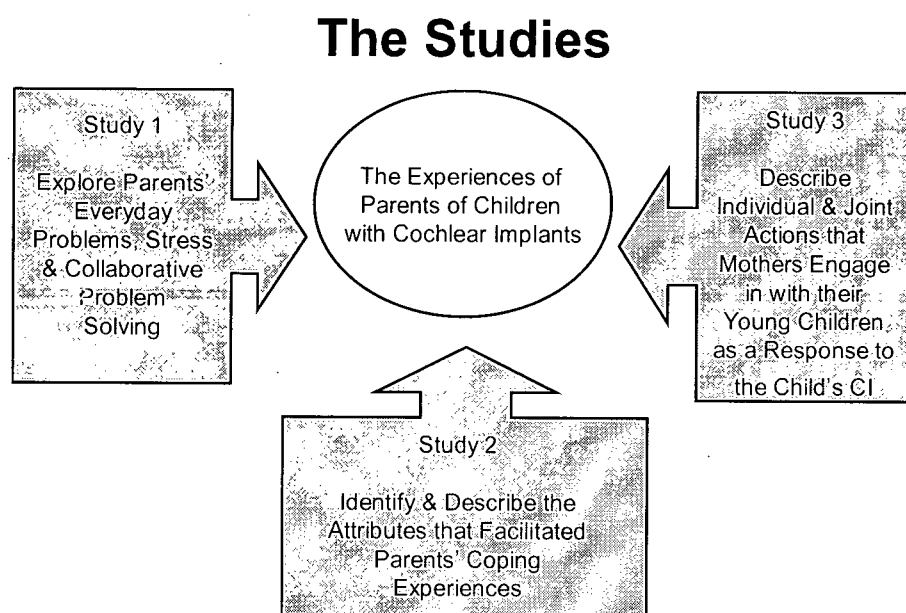


Figure 1.4 The experience of parents of children with CIs: The dissertation studies

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## **Chapter 2**

# **Everyday Problems and Stress Faced by Parents of Children with Cochlear Implants**

A version of this chapter has been submitted for publication. Zaidman-Zait, A. (under review). Everyday Problems and Stress Faced by Parents of Children with Cochlear Implants.

## Introduction

Cochlear implants are surgically-implanted electronic devices that enable children who are profoundly deaf to experience some sensation of sound. Pediatric cochlear implantation (CI) has become a commonly selected rehabilitation option for children who are deaf (Spencer & Marschark, 2003). CI was first approved for U.S. children in 1990, and, by 2002, the U.S. Food and Drug Administration had lowered the minimum age for implantation to 12 months (Spencer & Marschark, 2003). According to data from the National Institute on Deafness and Other Communication Disorders and the Food and Drug Administration, 100,000 adults and children around the world were using implants in 2005 (National Institute on Deafness and Other Communication Disorders, 2006). A growing number of studies have demonstrated the vast positive benefits of CI for children's speech perception, speech production, language, and communication (Bat-Chava, Martin, & Kosciw, 2005; Blamey, Barry et al., 2001; Blamey, Sarant et al., 2001; Connor, Hieber, Arts, & Zwolen, 2000; Geers, Nicholas, & Sedey, 2003; Kluwin & Stewart, 2000; Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000), for children's social competence (Bat-Chava & Deignan, 2001; Bat-Chava & Martin, 2002; Bat-Chava et al., 2005; Christiansen & Leigh, 2002), and for children's reading ability (Tomblin, Spencer, & Gantz, 2000).

Importantly, successful outcomes following CI are neither conclusively assured nor instant (e.g., Geers, 2004), and continuing rehabilitation efforts are necessary after CI in order to make the procedure effective (Christiansen & Leigh, 2002). Moreover, great variability is often reported in children's outcomes following CI (Bat-Chava et al., 2005; Purdy, Chard, Moran, & Hodgson, 1995; Sach & Whynes, 2005; Spencer, 2004; Spencer & Marschak, 2003; Svirsky et



al., 2000). This variability indicates that children may continue to demonstrate hearing and communication difficulties after CI. The aforementioned long-term rehabilitation and continued difficulties after CI, even in light of its major benefits, may generate various sources of stress for parents and can present specific challenges to the parenting role associated with raising an implanted child. Moreover, the parents' role throughout the implantation and rehabilitation processes is of great importance for enhancing the benefits of implant use and eventually for the child's progress (Allegretti, 2002; Geers & Brenner, 2003; Spencer, 2004). Thus, parental experiences and adjustment hold vast importance.

Previous research has shown that parents of children with implants not only experience more psychological distress than parents of children with normal hearing (Quittner, Steck, & Pouiller, 1991) but they also experience more distress than parents of children who are deaf but use conventional hearing aids (Burger et al., 2005; Spahn, Richter, Burger, Löhle, & Wirsching, 2003). Several studies revealed that parents' psychological distress levels differ at various points in time over the course of the implanted child's treatment (Perold, 2001; Purdy et al., 1995; Quittner et al., 1991; Richter et al., 2000; Spahn et al., 2003), with peaks noted when receiving information about the implant, during the pre-surgery examination, during surgery, and at the first appointment to adjust the implant (Burger et al., 2005; Spahn, Richter, Zschocke, Löhle, & Wirsching, 2001). Nevertheless, inconsistent research results have emerged regarding whether parents' stress decreased postoperatively (Quittner et al., 1991; Incesulu, Vural, & Erkam, 2003; Richter et al., 2000; Weisel, Most, & Michael, 2007). It may be that parental stress does not decrease over time, even if the child's performance and functioning improve after CI, due to the child's continuing hearing difficulties that lead to communication breakdowns and other associated problems (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Weisel et al., 2007), or

because of the realization of the continued need for intensive rehabilitation efforts (Weisel et al., 2007).

According to Lazarus and Folkman's (1984) stress-coping model, stress is individuals' cognitive evaluation of the stress associated with an event or ongoing situation and their appraisals of their specific external and internal resources affecting their coping ability. Parenting stress, suggested to be qualitatively different from stress in other distinct domains (Creasey & Reese, 1996), is defined as the aversive psychological reaction to the demands of being a parent (Deater-Deckard, 1998). Abidin (1995) conceptualized that parental stress stems from three sets of factors: those inherent in the child, those inherent in the parent, and those related to the parent-child interaction. Moreover, according to the contextual model of stress, research must examine stressors embedded within a specific context, including factors related to the child, the family, and the specific tasks and demands that must be mastered for successful functioning (Quittner & DiGirolamo, 1998). Thus, another important aspect in the context of parental stress is the impact of day-to-day childrearing experiences (Crnic & Low, 2002). Daily hassles can be conceptualized as bothersome events that occur during one's daily interactions with the environment (Kanner, Coyne, Schafer, & Lazarus, 1981).

In the present case, parenting a deaf child can make some of the common parenting demands more challenging, thereby establishing a completely new set of unique daily demands. For example, reading a storybook, a common everyday shared activity between children and their parents, can become a challenging task for parents of young deaf children because of difficulties in communicating the story to the child and the child's early literacy skills (Aram, Most, & Mayafit, 2006). Hence, it is important to consider the specific problems and concerns experienced by parents of deaf children (Lederberg & Golbach, 2002; Quittner, Glueckauf, &

Jackson, 1990). The experience of such everyday frustrations may leave parents with a diminished sense of competence and satisfaction and eventually may render an adverse effect on the quality of parenting, the parent-child relationships, and the child's functioning (Belsky, Woodworth, & Crnic, 1996). More comprehensive understanding of parental stressors may positively impact children's rehabilitation by empowering parents to develop competence and involvement in their child's education and development (Dunst, Trivette, Boyd, & Brookfield, 1994; Meadow-Orlans & Sass-Lehrer, 1995; Minke & Scott, 1995; Winton & DiVenere, 1995)

A limited number of studies have explored the specific contextual stressors associated with parenting a child with a cochlear implant. First, making the decision to implant was reported to be one of the most stressful and taxing of the steps faced by parents (Incesulu et al., 2003; Li, Baid, & Steinberg, 2004). Subsequently, the surgery itself evokes considerable anxiety and fear (Perlod, 2000). Overall, research has suggested that the child's hearing loss and implantation introduce many unique obligations and demands to the parenting role. For example, parents must obtain multifarious information with regard to available treatment, education, and communication options for their children (Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001); gain knowledge about implants and learn how to troubleshoot them (Incesulu et al., 2003); maintain involvement in their child's extensive rehabilitation (Spencer, 2004); and manage associated costs and time demands (Sach & Whynes, 2005). Furthermore, studies also indicated that specific challenges associated with parenting deaf children were linked with parents' feelings of distress (Incesulu et al., 2003; Quittner et al., 1991; Zaidman-Zait & Most, 2005). Parents' higher stress levels correlated with their child's more severe communication difficulties and their less satisfactory relationships with professionals (Zaidman-Zait & Most, 2005). Children's communication difficulties have a negative impact on daily interactions between parents and

their children and lead to frustrations (Freeman, Dieterich, & Rak, 2002; Hintermair, 2000). In turn, these everyday problematic transactions might lead to cumulative parental stress. The identification of specific types of everyday problems, in comparison to the assessment of general parental stress, offers the most direct application for effective interventions to support the adjustment of families of children with implants.

In sum, previous research provided preliminary evidence regarding some potential stressors linked specifically with parenting a child with a cochlear implant. However, information remains limited on the daily problems/stressors that these parents face and on parents' associated feelings of stress. Thus, the current study aimed to explore the specific types of everyday problems associated with parenting in these families.

Coping is best understood as a process that enables the individual to reduce the emotional reaction that the stress induces and to manage its imposed behavioral demands (Lazarus & Folkman, 1984). Lazarus and Folkman's stress-coping model presented an "individual" approach to coping but disregarded the fact that individuals cope with stressors collaboratively with other individuals (Berg, Meegan, & Deviney, 1998). Inasmuch as everyday problems occur in rich, multifaceted social contexts (Berg & Klaczynski, 1996), the problems are often managed with other individuals' assistance and feedback (Berg, Strough, Calderone, Sansone, & Weir, 1998; Strough, Berg, & Sansone, 1996). A second, related aim of the current study, therefore, was to investigate the interpersonal relationships that serve as a coping resource for parents in collaboratively solving their everyday problems. Collaborative problem solving can have various functions that could serve as a pathway to successful parental involvement and commitment in rearing a child with an implant. Collaborative problem solving has not been examined for this population, but research on other adults showed significant benefits (e.g., in aging older adults,

collaborative problem solving compensated for age-related restrictions and losses, leading to more successful aging; Dixon & Backman, 1995).

Last, the current study examined the effect of parental problems and feelings of stress on parents' sense of satisfaction with their lives. Previous studies demonstrated that parental stress had both a direct and an indirect effect on parents' life satisfaction (Hintermair, 2004; Lederberg & Golbach, 2002) and psychological adjustment (Quittner et al., 1991). In sum, the present study examined the following questions:

1. What are the specific types of everyday problems associated with parenting in the CI context?
2. What interpersonal relationships serve as a coping resource for parents in collaboratively solving their everyday problems?
3. What are the associations between parents' everyday problems, parental stress, and child and family characteristics (including child's communication ability)?
4. What are the associations between parents' everyday problems, parental stress, and parents' sense of satisfaction with their lives?

## **Method**

### **Participants**

Participants comprised 26 hearing mothers and 5 hearing fathers of children who had undergone CI surgery. Regarding parents' education level, 77.4% ( $n = 24$ ) of the mothers and 56.6% ( $n = 17$ ) of the fathers had at least 1 year of university or college education.

Participants reported that in most of the 31 homes, mothers (74.2 %;  $n = 23$ ) and fathers (67.7%;  $n = 21$ ) had been born in Canada. The remaining parents had immigrated to Canada at least 3 years earlier, at an average of 16.9 years earlier for the mothers ( $n = 8$ ) and 23.0 years

earlier for the fathers ( $n = 10$ ). Twenty-five of the parents reported that the language spoken at home was English, 3 parents indicated bilingual homes (i.e., English and an additional spoken language), and the remaining 3 parents reported speaking only a language other than English at home (e.g., Cantonese, German), although the last group had been in Canada for 5 years or more. Most of the families (83.9%) resided in urban areas, while the remaining (16.17%) lived in rural areas. Regarding family size, 35.5% had only one child – the child with hearing loss. Most of the remaining families (48.4%) had two children. Four families reported having a second child with hearing loss; 8 families reported other immediate family members with hearing loss. In terms of their approach to communicating with their deaf child at home, the majority of parents (54.8%) reported using only spoken language, 32.3% reported using speech with some sign language support, and the remaining parents (12.9%) reported using equal amounts of spoken language and signs.

The children, 17 boys and 14 girls, ranged in age from 12 months to 13 years ( $M = 6.32$  years;  $SD = 3.93$ ). Hearing loss had been diagnosed at an average age of 13.08 months ( $SD = 12.24$ ). This relatively late age for diagnosis likely stems from the lack of a newborn hearing screening program in British Columbia, Canada, at the time of data collection. Mean age of implantation was 3.53 years ( $SD = 3.17$ ). According to parent reports, 6 children had been diagnosed with an additional problem other than hearing loss (e.g., learning disability, lung disease). During the first year post-implantation, all children had received speech and language intervention, in a variety of settings: 61.4% in an early intervention program, 29% in the preschool or school system, and 9.6% in treatment with a speech-language pathologist either at home or at a local health center. At the time of data collection, 38.7% attended an early

intervention program for young deaf and hard of hearing children, 12.9% attended a regular preschool, and most children (48.4%) were in a primary school setting.

## Measures

**Demographic background.** The demographic questionnaire tapped information on family demographics, including parents' education level, number of children, place of residence, and siblings' and parents' hearing status. In addition, this questionnaire tapped information on the implanted child: age, gender, etiology of deafness, communication modality, educational setting, age at implantation, intervention/educational setting, and any additional known disabling conditions. (See Appendix B1).

**Everyday problems, associated stresses, and collaborative relationships.** Parents responded to an open-ended question modified for the purpose of this study, asking them to describe in detail the types of everyday problems they encountered within the specific context of parenting a child with an implant. An open-ended method was chosen, rather than providing parents with a list of different types of problems, in order to better capture the problems most salient to parents. This evaluation of everyday problems was used previously with adults (e.g., Sansone & Berg, 1993; Strough, Patrick, Swenson, Cheng, & Barnes, 2003). Content analysis of these problems is described in the Results section. In addition, parents were asked to answer three questions about the problems they reported. First, parents were asked to rate how stressful they perceived each problem on a 7-point scale, from *minor annoyance* (1) to *extremely stressful event* (7). Second, parents were asked to indicate those individuals with whom they worked to resolve their everyday problems, from a list of six possible relationship options: family member, spouse, friend, professionals, other parents, and "other." Any number of relationships could be

marked. Parents who marked "other" were asked to specify the relationship to the additional person(s) with whom they collaborated in everyday problem solving. Third, an open-ended question asked parents to indicate with whom, from the relationships listed before, they most preferred to solve their problems collaboratively. Two scores were computed, namely the total number of problems reported and a stress score, which reflected the mean stress level associated with the problems reported. For collaborative problem solving sources, the frequencies of the different relationships mentioned by parents were counted. (See Appendix B2).

**Parental stress.** The Parental Stress Index / Short Form (PSI/SF; Abidin, 1995) was designed to assess stress broadly within the family context, focusing on issues of general parental distress and children's difficulties, including three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child, each containing 12 items. The Parental Distress subscale measures the distress a parent feels due to personal factors related to parenting, such as an impaired sense of parenting, lack of social support, or presence of depression. The Parent-Child Dysfunctional Interaction subscale assesses whether the parent perceives his or her interactions with the child as reinforcing to the parent or as a negative element in the parent's life. The Difficult Child subscale measures the behavioral characteristics of children that make them either easy or difficult to manage, due to either temperament and/or noncompliant, defiant, or demanding behavior. The total PSI score is an indicator of the parent's experience of overall parental stress. Parents rated each of the 36 items on a 5-point scale ranging from *strongly disagree* (1) to *strongly agree* (5). The 90<sup>th</sup> percentile of the PSI represents the percentage at which parental stress might be considered clinically significant (Abidin, 1995), creating a clinical cut-off score for examining parents' stress levels. The PSI was shown in empirical studies to be a valid and reliable measure when used with parents of typically developing



children (Abidin, 1995) and also when examining parents of children with hearing loss (Hintermair, 2006). Abidin reported internal reliability coefficients (Cronbach alpha) of .80 to .87 for the three subscales. The present internal reliability coefficients (Cronbach  $\alpha$ ) were .88 for the Parental Distress subscale, .81 for the Parent-Child Dysfunctional Interaction subscale, and .88 for the Difficult Child subscale.

**Parents' life satisfaction.** The Life Satisfaction Scale was used to measure parents' overall life satisfaction or subjective well-being. Parents responded to two items (How satisfied are you with your life as it is right now? How satisfied are you with the way you feel right now?) on a 5-point scale, from *very dissatisfied* (1) to *very satisfied* (5). This measure was used previously by Hintermair (2004) with parents of children who are deaf. The current internal reliability coefficient (Cronbach  $\alpha$ ) was .97.

**Child's communication ability.** The communication scale of the Parent Outcome Profile from Pediatric Cochlear Implantation (PVECIQ; Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002) was used to assess the communication ability of the child with hearing loss. Previous examination of this scale's psychometric properties (Nunes, Pretzlik, & Ilıcak, 2005; O'Neill, Lutman, Archbold, Gregory, & Nikolopoulos, 2004) provided support for the questionnaire's reliability and validity. Based on the psychometric work of Nunes et al., the recommended 4-item communication scale was used in the present study, including items related to the child's speech quality and ability to communicate orally and in face-to-face situations. Parents were asked to indicate their agreement with each statement on a 5-point scale ranging from *strongly disagree* (1) to *strongly agree* (5).

## Procedure

This study was part of a larger research project examining parental experiences following pediatric cochlear implantation. The study was reviewed and approved by the university Research Ethics Board. Parents were recruited from the Cochlear Implant Services program at B.C. Children's Hospital (BCCH).<sup>1</sup> The program coordinator distributed information about the study to all 75 families of children who had received services from the center during the study period. The researcher mailed the following documents to parents who expressed interest in participating: (1) a parental consent form detailing the purpose of the study, the study's procedures, information regarding confidentiality, and contact information if the parents had questions; and (2) the study questionnaire set. Thirty-six parents completed and returned the consent form and questionnaires to the researcher, representing a 48% response rate. However, 5 parents were excluded because their implanted child did not meet the study's age criterion (a child who is younger than 13 years of age). This age restriction was due to the age scales in the Parent Stress Index questionnaire. None of the parents accepted the offer of translation services necessitated by English language difficulties.

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<sup>1</sup> BCCH, founded in 1988, operates the only pediatric cochlear implant program in British Columbia. In January 2004, B.C. Ministry of Health funding was increased from only 6 pediatric cochlear implantation surgeries to up to 30 surgeries per year (Juck, 2005).

## Results

### Descriptive Findings on Daily Problems

Two researchers (the author and another researcher), both with expertise in early intervention with children who are deaf and hard of hearing and their families, conducted a content analysis of the everyday problems reported by the parents. Each rater separately read the problems and categorized each problem into an appropriate domain derived from the content. For example, a problem related to difficulty in having conversations with the child about complicated topics was categorized as a communication difficulty. Final categorization of the problems into domains was determined by consensus between the two researchers. To establish inter-rater reliability of the categorization, two research assistants each sorted 50% of the problems independently into the different domains. Agreement level found between the two assistants' sorting and the two researchers' sorting was 94%, indicating that these problems could be reliably be sorted into these domains.

As shown in Table 2.1, parents reported an average of 4.65 problems ( $SD = 3.05$ ) with an associated mean problem-related stress level of 4.53 ( $SD = 1.24$ ) on a scale of 1-7. The content analysis procedure yielded a total of 137 problems across nine domains, including: implant drawbacks, communication difficulties, child's behavior/character, child's social competence, rehabilitation demands and parenting role, financial difficulties, services, educating others/advocacy, and child's academic concerns. Four problems describing specific issues could not be categorized into the above domains (e.g., concerns about the information exchange with the child's school). Table 2.2 describes and exemplifies the nine domains and, in descending order of frequency, indicates the percentage of parents who identified at least one problem in the domains. As shown in the table, the most frequently reported domain for everyday problems was

implant drawbacks (58.1%). Next were communication difficulties (38.7%), child's behavior/character (35.5%), and child's social competence (29.9%).

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Tables 2.1 and 2.2

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### **Collaborative Relationships**

As seen in Figure 2.1, among the different types of interpersonal relationships that parents named as resources for collaborative problem solving, professionals were by far the parents' most frequently cited (90.3%), followed by spouse (80.6%), other parents of children who are deaf (48.4%), family members (38.7%), and friends (32.3%). Regarding parents' preferences among these collaborative partners, parents most frequently reported that they liked to resolve problems together with both a specified professional (61.3%) and with their spouse (51.7%), followed by other parents of children who are deaf (25.8%).

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Figure 2.1

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In their open responses, parents indicated that their choice of collaborative partner depended on the type of problem they faced. Furthermore, parents stated that professionals were important resources for problem solving because of their availability, their continuous role and

involvement in the child's life, their professional knowledge and experience, their provision of emotional and instrumental support, and their external point of view and perspective. Parents indicated that they valued collaborative problem solving with their spouses because the problems were shared ones; they acknowledged the importance of a joint decision-making process; they viewed the relationship with the spouse as a partnership; they had spouses who acted as a sounding board; and they valued their spouses' familiarity with the child, the problem, and the context. Finally, parents mentioned that other parents of deaf children shared similar experiences; were familiar with many of the problems; were able to provide emotional validation; and were valuable resources for making suggestions, comparing solutions, and discussing options.

### **Parental Stress**

The PSI results revealed significant correlations among all three parental stress subscales, with the amount of variance accounted for ranging from 23% to 41%. Similar correlations also emerged in previous studies of stress among parents of children with hearing loss (e.g., Pipp-Siegel et al., 2002), which supported the decision to analyze the parental stress subscales separately. In the current study, 16.1% ( $n = 5$ ) of parents scored at or above the clinical cut-off for the total PSI score. This figure was lower than that reported by Meadow-Orlans (1994) and higher than those reported by Pipp-Siegel et al. (2002) or Lederberg and Golbach (2002). The relatively late age of the children at diagnosis (due to the lack of early hearing detection and intervention in British Columbia at the time of the study) may affect parental stress scores (Pipp-Siegel et al., 2002). The percentage of parents who scored at or above the clinical cut-off for

each subscale was: Parental Distress, 22.6% ( $n = 7$ ); Parent-Child Dysfunctional Interaction, 9.7% ( $n = 3$ ); and Difficult Child, 16.1% ( $n = 5$ ).

### **Correlations among Everyday Problems, Parental Stress, and Demographic Variables**

Correlations were conducted between the child and family background characteristics and the number of everyday problems, the associated problem-related stress levels of the everyday problems, and the PSI-based parental stress. The child's current age, age at diagnosis, age at implantation, and duration of time subsequent to implantation did not correlate significantly with number of everyday problems or with their associated problem-related stress levels ( $p > .05$ ). Two significant positive correlations emerged for one of the parent stress subscales, Parent-Child Dysfunctional Interaction, with the child's current age ( $r = .46, p < .05$ ) and with age at implantation ( $r = .48, p < .05$ ). In other words, parents' level of stress related to their interaction with their children increased as children were older at the time of the cochlear implantation and at the time of the study. No significant correlations emerged between parents' education level, daily problems, and stress.

With regard to children's communication ability, a child who had an implant longer was reported as having better communication skills ( $r = .38, p < .05$ ). Parents who perceived their interaction with their child as dysfunctional (PSI) also reported their child as having a lower ability to communicate orally and in face-to-face situations ( $r = -.38, p < .05$ ). No other significant correlations emerged between children's communication ability and parents' experience of daily problems and stress.

## Correlations among Everyday Problems and Psychological Variables

To explore the interrelations among everyday problem scores and other psychological variables of interest, Pearson correlations were calculated (see Table 2.3). Correlations between parents' everyday problems scores and the three PSI subscales revealed that parents who reported a larger number of everyday problems also noted being more distressed themselves on the PSI ( $r = .38, p < .05$ ) and were more stressed (PSI) due to their perception of their children as more difficult ( $r = .45, p < .05$ ). In addition, those parents who perceived their children as being difficult (PSI) also rated their everyday problems as more stressful ( $r = .41, p < .05$ ).

Next, the relations between parental life satisfaction and parental experience of daily problems and stress were examined. Findings indicated that parent distress (PSI) correlated strongly and negatively with life satisfaction ( $r = -.62, p < .01$ ). In addition, parents who experienced stress (PSI) related to their dyadic interaction with their children ( $r = -.37, p < .01$ ), who reported a larger number of daily problems ( $r = -.38, p < .05$ ), and who revealed higher problem-related stress levels ( $r = -.42, p < .05$ ) also experienced lower satisfaction from life.

To further explore the relations between parents' feelings of stress due to factors associated with the parent or the child and parents' life satisfaction, a regression approach was chosen to test mediating effects (Baron & Kenny, 1986; Holmbeck, 1997). This tested whether the PSI parental distress subscale mediated the relations between child-related stress (based on the Difficult Child and Parent-Child Dysfunctional Interaction PSI subscales), everyday problem-associated stress, and parental life satisfaction. In other words, child-related stress was expected to increase parent distress, leading to a decrease in life satisfaction. This causal ordering of the variables was based on previous studies that examined the relations among stress

and adjustment (Lederberg & Goldbach, 2002; Quittner et al., 1990). Note that although the mediating effect cannot rule out alternative causal explanations, it has the advantage of providing important information about the relations between the tested variables. A negative direct effect emerged between child-related stress and life satisfaction ( $r = -.37, p < .05$ ), with child-related stress accounting for 14% of the variance in the life satisfaction score. However, as can be seen in Figure 2.2, a significant mediating relationship was also observed. When parental distress was entered into the model, the effect of child-related stress was reduced ( $r = .02$ ). In other words, an increase in child-related stress was associated with parent distress, which in turn decreased parents' life satisfaction. A similar mediating pattern was obtained for the stress level associated with the variable of everyday problems in parenting a child with an implant. A positive direct effect emerged between problem-related stress and life satisfaction ( $r = -.42, p < .05$ ). Once again, as can be seen in Figure 2.3, when parent distress was entered into the model, the effect of stress from everyday problems was reduced ( $r = -.24$ ).

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Figures 2.2 and 2.3

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## Discussion

### Problem Domains

The primary objective of the current study was to investigate the salient domains of everyday problems that parents encounter while parenting a child who undergoes CI. The



problems that the parents described, which were categorized into nine different domains, will be discussed next in descending order of frequency: implant drawbacks, communication difficulties, child's behavior/character, child's social competence, rehabilitation demands and parenting role, financial difficulties, services, educating others/advocacy, and academic concerns.

**Implant drawbacks.** The most frequently indicated everyday problem, cited by more than half of the respondents, concerned parents' technical difficulties in equipment maintenance and troubleshooting of their child's implant. There appeared to be two aspects to this problem, first, the parents' own frustration at lacking necessary skills or tools to complete the repairs successfully and expeditiously, and second, their children's inability to hear when the implant was malfunctioning. Research has shown that parents of implanted children expressed concerns about possible device failure and equipment maintenance (Incesulu et al., 2003). Sach and Whynes (2005) also reported that 34% of parents in their sample were surprised by the technical challenges that the implant presented, such as device failures and the need to replace parts. These parent-reported difficulties are compatible with research findings that parents of implant candidates/recipients attributed high importance to information pertaining to implant structure and functioning (Most & Zaidman-Zait, 2003). This intense focus on equipment may also impact parenting as parents of young deaf children have reported that most of the time they spend with their young deaf children concerns dealing with the hearing loss such as maintaining hearing aids and performing therapy-related activities (Calderon, Bargones, & Sidman, 1998).

**Communication difficulties.** Almost 40% of the parents indicated that communication problems between their children and themselves were major sources of everyday difficulty. Many parents related this challenge to the child's immature speech perception and production competence and language level. On the other hand, some parents viewed this from a dyadic

perspective, expressing dismay that they and their children did not share an easily understood, mutually accessible language. The overall result was frequent frustration, with misunderstandings on the part of both parent and child.

Research has shown successful speech and language outcomes following CI (Blamey, Barry et al., 2001; Blamey, Sarant et al., 2001; Connor et al., 2000; Geers et al., 2003; Svirsky et al., 2000), as well as parental satisfaction from their children's post-CI language and communication outcomes (Beadle, Shores, & Wood, 2000; Chmiel, Sutton, & Jenkins, 2000; Christiansen & Leigh, 2002; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). In line with these prior findings, a notable 60% of the parents in the current sample did not indicate their child's communication abilities as problematic. At the same time, it should be emphasized that, after CI, children may continue to demonstrate communication difficulties and variability in their development of spoken language (Purdy et al., 1995; Sach & Whynes, 2005; Spencer, 2004; Spencer & Marschak, 2003; Svirsky et al., 2000). Bat-Chava et al. (2005) suggested that this variability may be evident in two situations: first, in the poor acoustics of listening conditions in which children find themselves (e.g., with background noise), and second, in differences in individual functioning between implanted children. In addition, children's progress is a long-term process; for example, speech intelligibility does not appear to improve greatly in the first few years following implantation (Miyamoto et al., 1997; Tye-Murray, Spencer, & Woodworth, 1995). Instead, it continues to significantly improve over an extended period of time, even beyond 5 years after implantation (Chin, Tsai, & Gao, 2003; Tobey, Geers, Brenner, Altuna, & Gabbert, 2003; Peng, Spencer, & Tomblin, 2004). These earlier results are consistent with the current finding that the longer children had the implant, the better their communication abilities. Furthermore, Incesulu et al. (2003) found that parents of implanted children continued to express

concern about their children's speech and language development, and Freeman et al. (2002) noted that parents were bothered that their implanted children were missing information due to a lack of mutually accessible communication.

**Child's behavior/character.** Approximately one-third of the respondents indicated child behavior problems associated with typical developmental challenges, such as "the terrible twos." Daily interactions with children can present numerous situations that parents may perceive as minor irritations or annoyances (Crnic & Greenberg, 1990). The problems described by parents may reflect developmental changes in the child (Crnic & Booth, 1991). During developmental transitions (e.g., from infancy to early childhood and from middle childhood to adolescence), children's increasing autonomy and developing sense of self may pose specific challenging behaviors for parents. Although these behavior challenges are frequently noted among typically developing children, when the challenges occur in combination with childhood hearing loss they often render already existing communication problems more complex. As a consequence, it is often difficult for parents to distinguish between the confounds of hearing loss and development.

**Child's social competence.** Slightly less than one-third of the parents cited their children's immature social competence and lack of peer relationships as problematic. Previous research has provided preliminary evidence that children's social relationships improve as a result of implantation (Bat-Chava & Deignan, 2001; Bat-Chava & Martin, 2002; Bat-Chava et al., 2005; Christiansen & Leigh, 2002). It is assumed that implants' facilitation of children's communication skills can result in more satisfying socialization skills (Bat-Chava et al., 2005). This assumption corresponds with the finding that 70% of the parents in the present study did not report any problems related to their children's social skills or peer relationships. However, socialization outcomes do vary across children (Bat-Chava & Martin, 2002; Bat-Chava et al.,

2005). For example, Bat-Chava et al. reported that many children in their study still functioned below age level in their socialization skills, even after years of implant use. Likewise, Knutson, Boyd, Reid, Mayne, and Fetrow (1997) found that children's social interaction difficulties in a peer group had not improved 8-12 months after they received their implant.

Another issue to consider with regard to communication is that following CI many deaf children are placed in mainstreamed settings (Holden-Pitt, 1998). Indeed, 83% of the school-age children in the current sample were fully mainstreamed. Previous studies showed that deaf and hard of hearing children who relied on oral communication and attended mainstreamed settings often reported being lonely and experienced few, if any, close relationships (Stinson & Whitmire, 1992). Although successful implantation should ultimately broaden social horizons for deaf children, the variance in age at implantation and the sometimes idiosyncratic rates of rehabilitation processes may predict varying social outcomes.

**Rehabilitation demands and parenting role.** Approximately one-quarter of the parents expressed the concern that the heavy demands of rehabilitation caused them to fall behind in other areas of importance to them and their families, most notably in their work responsibilities and household chores. This is consistent with Evans (1995), who found that parents of newly implanted children may deal with increasing time demands due to therapy and related appointments, such as hearing assessments and programming appointments. Parents of children with implants have expressed surprise at the efforts and demands that rehabilitation required (Sach & Whynes, 2005). In addition, parents have reported needing extra time to learn new skills, such as acquiring new communication methods (Evans, 1995; Freeman et al., 2002). These increasing time demands reduce parents' available time to devote to parenting their other children (Kashyap, 1986), and, as reported by the parents in the current study, may also reduce

the time available to attend to competing, but important, responsibilities. Moreover, parents reported concerns and uncertainty about adequately fulfilling their parenting roles as supporting their child's rehabilitation. For example, some parents reported feeling that they were not doing enough to support their children and ensure their successful rehabilitation, thus corroborating prior research documenting parenting concerns expressed by parents of deaf children (Bodner-Johnson, 2001; Jackson & Turnbull, 2004). Overall, given the additional rehabilitation demands of implants, parents of implanted deaf children may face the paradoxical situation of feeling that they are not meeting their children's needs while facing more responsibilities than prior to the implantation. Confidence threats related to parenting abilities constitute one of the major stressors with potentially vast effects on patterns of family interaction, which in turn may mediate children's developmental outcomes (Guralnick, 2001). For instance, DesJardin (2004) found that mothers of implanted children who held high self-efficacy beliefs regarding their ability to influence their children's language development were more likely to follow through with the intervention strategies taught by their early interventionist than did mothers with low self-efficacy scores. Furthermore, parents of children with implants identified parenting confidence as a personal coping resource (Zaidman-Zait, 2007). Parents felt that their self-confidence increased both their commitment toward their child's rehabilitation and their feelings of hope for their child's progress in the future.

**Financial difficulties.** Even for parents whose medical plans include some coverage of expenses related to their child's implant surgeries, considerable additional expense is incurred in terms of replacement parts, traveling to medical and audiological appointments, and accessing rehabilitation services. Almost one-quarter of the parents in the present study (22.6%) cited financial issues related to the implant as everyday concerns. This is not surprising, given that

Meadow-Orlans and Sass-Lehrer (1995) found costs associated with children's hearing loss to be a major concern for parents of young deaf children. However, the concerns for parents of implanted children may well be intensified, given the frequent schedule for traveling to mapping sessions and the need for intervention in the months following surgery. Sach and Whynes (2005) reported that one of the negative experiences parents mentioned following implantation was costs related to their child's implant and rehabilitation.

**Services.** Almost 20% of the parents reported difficulties in accessing needed support services as a source of everyday problems. Likewise, Sach and Whynes (2005) reported that parents described challenges in obtaining services for their implanted child; for example, 31% of the parents in that earlier study had difficulties obtaining speech-language pathology services for their child. Furthermore, recent evidence has pinpointed a lack of sufficient numbers of professionals with specialized training in working with deaf infants and their families in early intervention services (Arehart & Yoshinaga-Itano, 1999; Arehart, Yoshinaga-Itano, Thomson, Gabbard, & Stredler Brown, 1998; Freeman et al., 2002).

**Educating others/advocacy.** The incidence of severe to profound bilateral sensorineural hearing loss is 1 per 1000 births (Hyde & Riko, 2000). Due to the relative infrequency of deafness, parents of deaf children hold much of the responsibility for explaining their children's deafness and communication needs to others. Equally important, parents of deaf children are often required, *de facto*, to be advocates for the services and accommodations their children need. Almost one-fifth of the parents in the present study cited the demands of educating others and serving as advocates to be everyday problems. Likewise, Spencer (2004) indicated that parents must undertake an advocacy role to educate others who have contact with their child or to struggle for services for their child. The present findings also substantiate previous research in

which parents expressed the need for guidance in educating others in the community, such as their child's teachers (e.g., Dromi & Ingber, 1999; Zaidman-Zait, 2007). Possibly, the common media portrayal of implants as a "cure" for deafness may leave parents in the position of having to correct the frequent misperception that their implanted child can now hear. Thus, parents of implanted children may have an additional layer of education and advocacy that they did not confront prior to the CI surgery.

**Academic concerns.** Almost 10% of the respondents expressed concerns about their implanted child's academic performance, thus corroborating prior research (Archbold et al., 2002; Sach & Whynes, 2005). Sach and Whynes' parent sample reported that 13% of implanted children had problems with basic skills, such as reading, writing, or mathematics.

Overall, the present findings indicated that parents of children with implants may experience various stressors that are specifically associated with raising an implanted child. These stressors may stem from contextual factors, factors related to the child, and factors associated with parenting a child with an implant. The current results enhance understanding regarding the contextual specificity of stressors associated with raising deaf children with a CI and can serve as a first step in the development of stress assessments specific to this population, which, in turn could buttress investigations of the mechanisms linking stressors, coping behaviors, and adaptation (Quittner et al., 1990).

## **Collaborative Relationships**

Parents in the current study appeared to draw from a variety of interpersonal relationships, both formal (professionals) and informal (family and friends), to support their problem solving as parents of a child with an implant. This finding coincides with the findings of

previous studies, which showed that parents of children who are deaf received support from multiple sources (Beadle et al., 2000; Calderon & Greenberg, 1999; Hintermair, 2000; Lederberg & Golbach, 2002; Meadow-Orlans & Steinberg, 1993; Quittner et al., 1990; Zaidman-Zait, 2007). The results of the present study also substantiate Berg, Meegan, and Deviney's (1998) assertion that everyday problems are managed in collaboration with other individuals within the social context.

Parents identified three key collaborative partners, namely professionals, spouses, and other parents of children who are deaf. Each of these interpersonal relationships, along with the unique supportive features of these relationships that parents of implanted children considered to be facilitative of their parental coping experiences, were reported and described in a recent study (Zaidman-Zait, 2007).

**Professionals.** The substantial preference for professionals as collaborative partners supports previous findings that parents of deaf children rely greatly on professionals as sources of support (Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Meadow-Orlans et al., 2003; Quittner et al., 1990). Furthermore, this finding underscores the importance of the parent-professional partnership and the significant role of professionals in intervention programs for deaf children and their families. Parent-professional relationships are essential for the parental adaptation process and the resulting progress of the child. Less satisfactory relationships with professionals were linked with higher stress levels among mothers of a child with an implant (Zaidman-Zait & Most, 2005).

**Spouse.** The parent-reported preference for spouses as collaborative partners lends support to the belief that married couples have collaborative expertise (Dixon & Gould, 1998; Margrett & Marsiske, 2002). Similarly, older adults reported their spouses as their preferred



partners for problem solving (Strough et al., 2003). The current findings suggest that parents believe that working jointly with their spouses will enhance their solutions to their problems. Factors contributing to spousal preference may include familiarity and reassurance. In a recent study, parents of children with implants indicated the importance of marital partnerships in making crucial decisions, achieving goals, sharing responsibilities, and communicating with the health care system (Zaidman-Zait, 2007). Current findings suggest the importance of paying attention to the marital relationship when working with families. Nevertheless, further research is needed to investigate the impact of this relationship on parental coping.

**Other parents.** The significant supportive role of other parents who face a similar situation corroborates findings of previous studies where parents of children who are deaf (both with hearing aids and with cochlear implants) highlighted the importance of making connections with other parents (Dromi & Ingber, 1999; Hintermair, 2004; Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001; Zaidman-Zait, 2007). Some of the qualities that parents have identified as valuable in other-parent collaborators include: compassion and complete understanding; knowledge of relevant information, community resources, and tools for learning and growth; round-the-clock availability and mutuality of support; and sources of models and strategies for coping (Ainbinder et al., 1998; Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Christiansen & Leigh, 2002; Zaidman-Zait, 2007). Altogether, this preliminary evidence regarding collaborative problem solving among parents suggests that it may comprise a fruitful area of inquiry for future research. Exploring the joint actions and coping strategies of parents with professionals, spouses, and other parents in resolving specific everyday problems may explain some of the variance both in child outcomes and in parents' well-being and may assist in improving interventions with families.

## **Everyday Problems, Stress, and Child Characteristics**

Not surprisingly, parents whose children were less able to communicate using spoken language reported increased stress due to difficulties in their interactions with their children, when compared to parents who reported greater oral communication abilities in their children. This finding is consistent with previous studies that have reported increased parental stress associated with lower child language ability, both among parents of deaf children in general (Chaffee, Cunningham, Secord-Gilbert, Elbard, & Richards, 1990; Frey, Greenberg, & Fewell, 1989; Pipp-Siegel et al., 2002) and among mothers of a child with an implant in particular (Zaidman-Zait & Most, 2005).

Parents in the present study with children who were currently older, or who had been diagnosed or implanted at later ages, appeared more stressed due to problems in interactions with their children than did the other parents. Previous studies also have reported a significant positive association between stress and child age (Konstantareas & Lampropoulou, 1995; Lederberg & Golbach, 2002; Pipp-Siegel et al., 2002). One possible explanation is that children who were diagnosed late and received an implant at an older age demonstrated less satisfactory speech and language outcomes, which led to increasing difficulties in establishing effective interactions with their parents. The fact that the child age variable did not explain variance in parents' stress level or reported everyday problems or in the child's communication ability provides further support for the notion that age at intervention (i.e., implantation) – rather than chronological age -- may have affected stress indirectly through its effect of variance in CI outcomes. In support of this, research has consistently identified age at implantation as a factor significantly impacting individual differences in outcomes (Spencer & Marschark, 2003). For

example, children who were implanted earlier revealed better speech and hearing outcomes in comparison to later-implanted children (Svirsky et al., 2000; Waltzman & Shapiro, 1999).

Further research is needed to understand the effects of age on stress among parents of implanted children.

With regard to reports of everyday problems, a larger number of reported problems was linked to higher levels of personal parental distress and higher levels of stress due to their perception of their children as being more difficult. In addition, as described before, the majority of problems parents faced were related to parent-child communication breakdowns and child behavior. Hence, it is not surprising that these parents may also have perceived their children as being more difficult to manage. Parents who attempt to cope with various child-related problems, without adequate support and resources, may experience a threatened sense of competence in their parenting skills, increased levels of depression, and feelings of isolation. Similarly, Pipp-Sigel et al. (2002) found that parents of children with hearing loss who experience everyday parenting hassles related to their young children also experienced general feelings of stress, whether attributed to factors in the parent, child, or parent-child interactions. Previous research has demonstrated that among parents of children with various health conditions, children's difficulties were connected to high parental stress levels and to difficulties in other areas of parents' lives (e.g., Carson & Schauer, 1992; Forgays, Hasazi, & Wasserman, 1992, Frank et al., 1991), and children's everyday problems such as sleep and feeding issues were also associated with parents' high stress levels (Goldberg et al., 1997; Ostberg, Hagekull, & Wettergren, 1997; Thunström, 1999). A recent intervention study focusing on everyday child-related problem solving demonstrated a reduction in the general level of parental stress. This

intervention increased parents' feelings of competence and reduced the parents' sense of restrictions due to parental responsibilities (Östberg, Hagekull, Lindberg, & Dannaëus, 2005).

The results of the current study suggest that parents' satisfaction with their lives is strongly affected by parenting-related stress, which is comprised of feelings of incompetence, a sense of lack of support, and the presence of depression. Moreover, child-related stress showed only an indirect effect on parents' life satisfaction through its significant relations with parenting-related stress. These findings replicated those of Lederberg and Golbach (2002), coinciding with their argument that parenting-related stress is the single most important variable affecting parents' satisfaction with their lives. Lederberg and Golbach claimed that if parents feel they are coping with the child-related problems (doing a good job as parents, being supported), these stressors do not seem to affect parents' feelings of well-being. The overall important effect of parental stress on life satisfaction was also found in Hintermair (2004).

Although conclusions about causal processes cannot be drawn, the present results appear to point to several potential ways to reduce stress and break recurring cycles in the family. For instance, to reduce stress, intervention could focus on helping parents cope with the specific everyday problems they face related to their child, such as behavioral problems or struggles related to the child's implant, and at the same time could empower parents to acquire specific competencies in efficiently solving problems and coping with their various parenting demands. Emphasizing the hearing parents' strengths and abilities to parent their children with hearing loss has been suggested as an important component of early intervention (Lederberg & Prezbindowski, 2000). Overall, intervention should be targeted at both reducing parental distress, especially for parents who are above the clinical cut-off for stress, and building intervention goals related to specific day-to-day problems occurring in the context of the family.

With regard to limitations of the current study, the assessment of everyday problems was conducted via an open self-report questionnaire. This assessment approach has been used previously and reported as being reliable and valid (Sansone & Berg, 1993; Strough, Patrick, Swenson, Cheng, & Barnes, 2003). At the same time, it would be useful to incorporate multiple methods of data collection in order to provide various kinds of detailed descriptions of problematic situations such as, for example, interviews with parents and parents' daily dairies. In this connection, daily dairies are expected to elicit more minor everyday problematic situations based on findings from previous research using similar procedures (e.g., Quittner et al, 1996). In addition, future research should collect more detailed information regarding the individual and collaborative corresponding parental coping strategies associated with the various everyday problems.

Furthermore, the sample of participants in the current study was relatively small and heterogeneous in terms of children's ages and the time interval since cochlear implantation. It is reasonable to assume that issues related to everyday problems in the family context and parental stress levels are influenced by children's ages and development, and the sample size and heterogeneity of the sample may not have allowed an in depth examination of these age related issues. The domains of everyday problems identified in this study should be considered not as definitive but, rather, as a preliminary set of domains. It should be noted that, although the domains of everyday problems identified are expected to be stable, it is anticipated that a replication study using a larger sample size could result in more trustworthy domains and perhaps in the identification of new domains of everyday problems. Because of the relatively small sample size used in this study, the numerical results may not be stable as the domain descriptions, and, accordingly, the referential statistics should be treated cautiously. The

generalizability of the results is limited by the unique composition of the study's sample, which is indicative of the unique context of cochlear implant services in British Columbia. It is unclear to what extent this sample is representative of a broader population of parents of children with CIs.

Larger future samples would enable more homogenous samples and statistical analysis of demographic variables. Further research could also examine parents' everyday problems according to children's age groups, time following implantation, and children's various outcomes following implantation. In addition, due to the sample size, the relations between parental stress and specific domains of everyday problems were not tested – a direction that future research can explore.

Table 2.1

Means, Standard Deviations, and Ranges for Everyday Problems, Parental Stress Scales, Life Satisfaction, and Child's Communication Ability (n = 31)

	<i>M</i>	<i>SD</i>	<i>Scores' Range</i>
Number of everyday problems	4.65	3.05	0 - 9
Stress level of everyday problems	4.54	1.29	1 - 7
<i>PSI</i> - Parental Distress	25.44	8.65	12 - 60
<i>PSI</i> - Difficult Child	25.91	8.75	12 - 60
<i>PSI</i> - Parent-Child Dysfunctional Interaction	17.63	5.28	12 - 60
Life satisfaction	4.03	0.69	1 - 5
Child's communication	3.68	0.83	1 - 5

Table 2.2

Everyday Problems: Domain Descriptions and Examples, and Percentages of Parents Who Identified at Least One Problem in the Domain (n = 31)

Domain	Description	% of parents	Sample problems given
1. Implant drawbacks	Equipment breakdowns and failures, maintenance of parts, troubleshooting, device's limitations (e.g., can't be used in water, at playground, or during night; effect of background noise)	58.1	<i>She can't hear when she is swimming, in the tub/shower, or when the batteries suddenly die on her</i>
2. Communication difficulties	Communication breakdowns in child-parent interactions, children's speech perception and production competence, language level, home language considerations	38.7	<i>I often don't understand his speech</i>
3. Child's behavior/character	Children's interactive behaviors and temperament	35.5	<i>Child's discipline is very challenging</i>
4. Social competence	Children's social competence, social status, peer relationships, social inclusion.	29.9	<i>He does not have "set" friends, doesn't get invited out</i>



Domain	Description	% of parents	Sample problems given
5. Rehabilitation demands and parenting role	Demands and responsibilities placed on parents due to rehabilitation needs and parents uncertainty regarding fulfillment of their role in rehabilitation.	25.8	<i>I'm falling behind in work and household chores as a result of extra work with child</i>
6. Financial difficulties	Costs associated with the cochlear implant device, traveling for rehabilitation or appointments, need to change residence (in order to access services)	22.6	<i>We have lots of related expenses, replacement of CI parts that are without medical coverage</i>
7. Services	Limited support services, accessibility of services	19.4	<i>We see a speech therapist only once in a couple of months</i>
8. Educating others / Advocacy	Need to explain child's hearing loss and communication needs to others and to advocate for services and/or accommodations	19.4	<i>We constantly have to answer questions about the child's hearing loss and cochlear implant from everyone</i>
9. Academic concerns	Concerns about child's academic performance	9.7	<i>We're worried that he might not be keeping up with his school work</i>

Table 2.3

Intercorrelations between Everyday Problems, Parental Stress, Life Satisfaction, and Child's Communication (n = 31)

	Subscale	Everyday problems		PSI			Life satisfaction	Child's communication
		No.	Stress level	Parental distress	Difficult child	Parent-child dysfunctional interaction		
Everyday problems	No.	---	.92**	.38*	.45*	.17	-.38*	.11
	Stress level		---	.36	.41*	.11	-.42*	.04
Parental Stress Index	Parental distress			---	.61**	.48**	-.62**	-.21
	Difficult child				---	.64**	-.32	-.31
	Parent-child dysfunctional interaction					---	-.37*	-.38*
	Life satisfaction						---	.27

\*  $p < .05$ . \*\*  $p < .01$ .

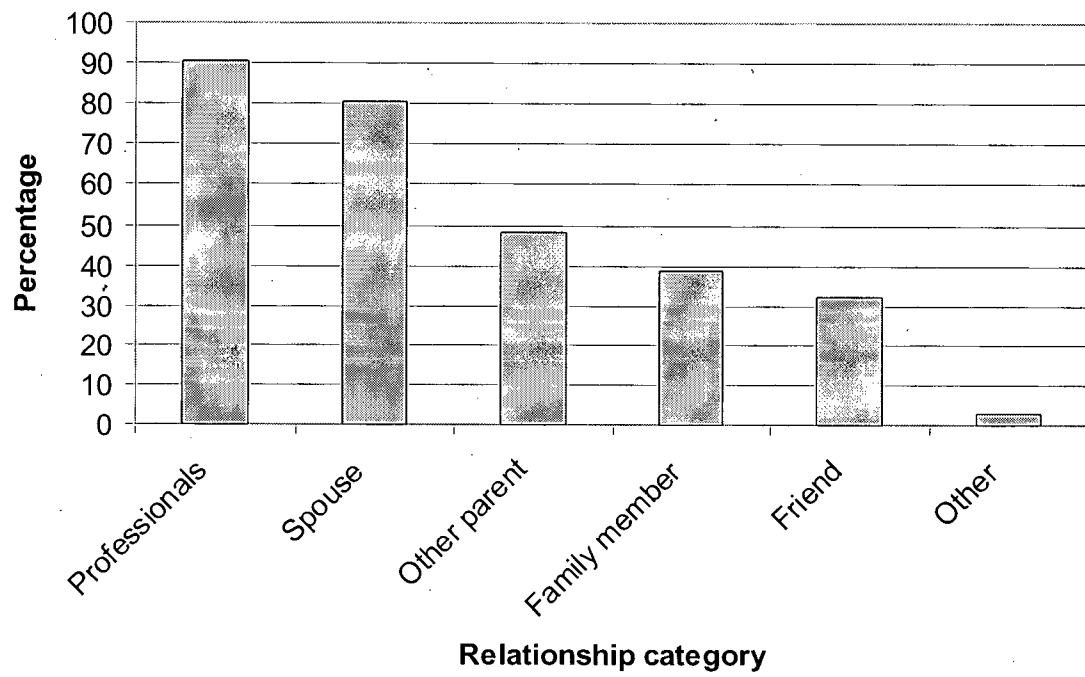
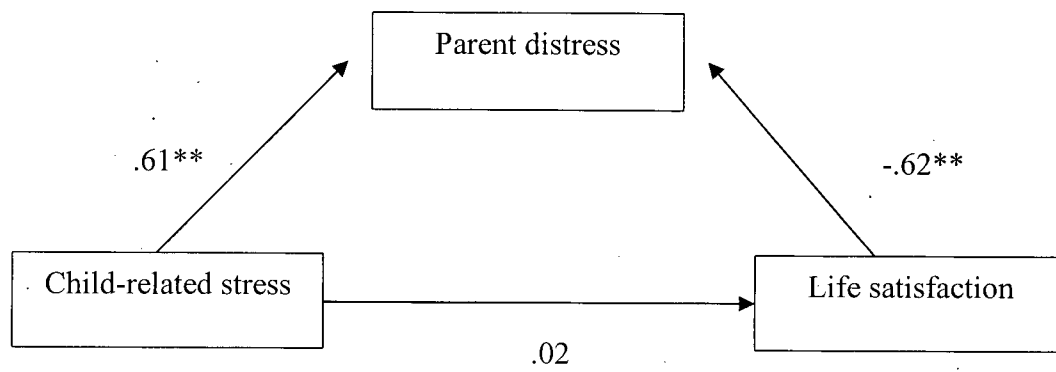


Figure 2.1 Percentage of parents citing collaborative relationships for solving child-related everyday problems.



\*\*  $p < .01$ .

Figure 2.2. Mediating effect of parent distress (direct effect of child-related stress on life satisfaction,  $r = -.37$ ,  $p < .05$ ).

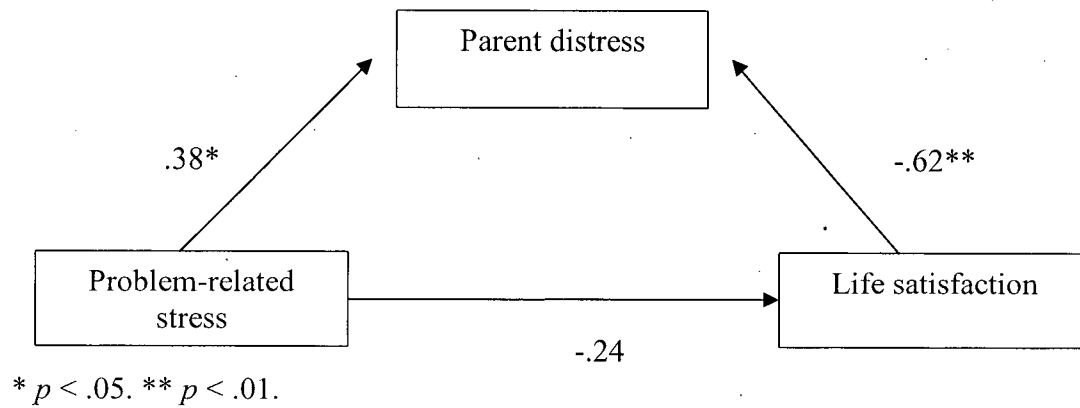


Figure 2.3 Mediating effect of parent distress (direct effect of problem-related stress on life satisfaction,  $r = -.42$ ,  $p < .05$ ).

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## **Chapter 3**

# **Parenting a Child with a Cochlear Implant: A Critical Incident Study**

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## Introduction

The identification of a child's hearing loss is a distressing time for parents, often eliciting intense emotional responses to the diagnosis (Koester & Meadow-Orlans, 1990). Following these initial responses, parents must undergo a process of adaptation to the various challenges uniquely associated with raising a child who is deaf, which include modifying communication strategies, becoming involved in medical and educational decision making, working with professionals across a range of disciplines, learning about technological supports, obtaining appropriate intervention programs and services, and dealing with additional financial and childcare pressures (Calderon & Greenberg, 1993; Meadow-Orlans & Sass-Lehrer, 1995).

Today, one of the first rehabilitation decisions that parents must face is whether to select a cochlear implant (CI) as the sensory aid of choice for their child who is deaf – an increasingly common pediatric rehabilitation option (Spencer & Marschark, 2003). Following the stressful, taxing decision to implant their child (Incesulu, Vural, & Erkam, 2003; Li, Baid, & Steinberg, 2004; Ruben, 1995; Spencer, 2004), these parents confront other unique challenges. They must cope with considerable anxiety and fear prior to and during their child's surgery (Chute & Nevins, 2002; Perold, 2001), followed by an extremely demanding rehabilitation process that requires extensive parental involvement (Christiansen & Leigh, 2002; Chute & Nevins, 2002). Parents must also gain knowledge about cochlear implants' maintenance and troubleshooting (Incesulu et al., 2003).

In a recent study, parents reported various stressors that they face in conjunction with caring for their implanted child: adjusting to the needs and behaviors of the implanted child; time and effort demands; childrearing demands that cause marital stress; difficulties in obtaining formal child care; the need to make changes in employment patterns; associated costs, efforts,

and stress induced by the child's intervention program; and difficulties in obtaining supportive services (Sach & Whynes, 2005). These multiple parenting challenges may lead to increased parental stress. Hence, parents need to find adaptive ways to cope with the various demands in their parenting role, which in turn will promote their own adjustment and functioning and lead to better child outcomes. In line with research promoting human strengths and parents' quality of life, with the goal of shaping health professionals' training for effective prevention (Hintermair, 2006), research is vitally important to identify factors that promote successful coping with the demands faced by parents of a child with a CI.

Accounts by parents of children with cochlear implants (CIs) have been of interest for some time. Yet, previous studies examining parents' evaluations have concentrated largely on parents' views and satisfaction regarding their children's outcomes following cochlear implantation (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Campisi, James, Hayward, Blaser, & Papsin, 2004; Incesulu et al., 2003; Nunes, Pretzlik, & Ilıcak, 2005; O'Neill, Lutman, Archbold, Gregory, & Nikolopoulos, 2004). These evaluations, generally using closed-format questionnaires, pertained to issues like children's communication skills, social relationships, and general functioning. The majority of parents expressed high satisfaction with the implant's various outcomes (Beadle, Shores, & Wood, 2000; Chmiel, Sutton, & Jenkins, 2000; Christiansen & Leigh, 2002; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). These findings coincide with research on parental expectations, which indicated that parents tend to hold relatively high expectations regarding the implant's outcomes for their child (Nikolopoulos, Lloyd, Archbold, & O'Donoghue, 2001; Richter et al., 2000; Zaidman-Zait & Most, 2005).

Research on the needs of the parents themselves has shown that parents of children who are implant candidates or recipients expressed a strong need for a wide range of information

pertaining to medical, educational, technical, communication, and other concerns as well as a need for emotional support and psychosocial interventions (Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001; Spahn, Richter, Zschocke, Löhle, & Wirsching, 2001).

This diversity of parental needs reflects the broad variety of stressors associated with parenting a child with a CI. Previous research has demonstrated that parents of children with CIs experience more psychological distress than parents of children with normal hearing (Quittner, Steck, & Pouiller, 1991) or parents of children with conventional hearing aids (Burger et al., 2005; Spahn, Richter, Burger, Löhle, & Wirsching, 2003). Psychological distress levels also differ at various points in time over the course of the child's treatment (Beadle et al., 2000; Perold, 2001; Purdy, Chard, Moran, & Hodgson, 1995; Quittner et al., 1991; Richter et al., 2000; Spahn et al., 2003; Zaidman-Zait & Most, 2005), with peaks noted when receiving information about the CI, during the pre-surgery examination, during surgery, and at the first appointment to adjust the implant (Burger et al., 2005; Spahn et al., 2001). As mentioned above, making the decision to implant was reported to be one of the most stressful and taxing steps for parents (Incesulu et al., 2003; Li et al., 2004). In addition, the fact that parents' stress did not necessarily decrease postoperatively was attributed to unrealized expectations, the necessity of parental involvement in rehabilitation, and restrictions in parents' pursuit of their own personal activities (Quittner et al., 1991; Richter et al., 2000). Zaidman-Zait and Most (2005) found that mothers' higher stress levels correlated with more communication difficulties with the child and with less satisfactory relationships with professionals. Furthermore, parents of children with CIs report concerns related to speech and language development, possible device failure, and maintenance of the implant equipment (Incesulu et al., 2003).

Although previous research has explored the difficulties and challenges associated with parenting a child with a CI, very little is known about parents' coping experience and about the factors that may reduce their psychological distress and promote their effective functioning as parents. Coping is best understood as a process that enables the individual to reduce the emotional reaction that the stress induces and to manage its imposed behavioral demands (Lazarus & Folkman, 1984). Coping efforts are oriented at either altering the situation itself (problem-focused coping) or managing the negative emotional reactions that accompany such situations (emotion-focused coping). In addition, in their coping efforts, individuals draw upon social and personal resources (Pearline & Schooler, 1978), which may also be described as external and internal resources (McWilliam, 2005). Personal, internal resources include parents' psychological characteristics and strengths (e.g., self-efficacy, optimism) that promote effective coping. Social, external resources include the formal and informal sources of support that parents receive from their social network (e.g., friends, professionals, other parents). External resources also go beyond social resources, to include the availability of services, community activities, materials, and informational resources. Resources presumably contribute to individual differences in stress-related experiences, coping efforts, and outcomes (Holahan, Moos, Holahan, & Brennen, 1997; Ptacek, Pierce, & Ptacek, 2002). A resource-based approach has been used in early intervention to map out the assets available to families (Dunst, 2001). Furthermore, recent models of stress and coping have underscored the importance of understanding the physical, psychological, and social contexts in which coping efforts occur (Berg, Meegan, & Deviney, 1998; Park & Folkman, 1997; Ptacek et al., 2002; Somerfield & Curbow, 1992).



Investigation of parental coping experiences and adjustment is important for several reasons. First, previous research demonstrated that parents' stress is not a direct outcome of their child's deafness and that individual differences in parental stress stem from different characteristics of the context, the child's hearing loss, and the parents, including parental perceptions and coping resources (Lederberg & Golbach, 2002; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Second, parents are the chief decision makers concerning cochlear implantation for their child. When making such an important decision, parents often feel it would help them to know more about the experiences of parents whose children were already implanted (Nunes et al., 2005). Third, the importance of the family context to childhood development has been acknowledged by early intervention researchers and professionals for many years (Bruder, 2000; Dunst, 1999; Guralnick, 1999). In addition, the experience of having a child with a disability often has a significant impact on the family (Bailey & Powell, 2005). These notions of reciprocity have led to family-centered models of intervention, which deliver services not only for the child but for the parents as well. The philosophy of family-centered intervention proposes that professionals' provision of information, guidance, and support will empower parents to build a collaborative partnership in order to develop competence and involvement in their child's education and development (Dunst, Trivette, Boyd, & Brookfield, 1994; Meadow-Orlans & Sass-Lehrer, 1995; Minke & Scott, 1995; Winton & DiVenere, 1995). Recent models of early intervention (Guralnick, 2001, 2005; McWilliam & Scott, 2001) are based on Bronfenbrenner's (1979) ecological theory, emphasizing the notion that the child and family exist within a series of complex contexts of interaction between the child's disability, the individual, and the systems internal and external to the family. Finally, parents can offer comments of great value to implant teams and policy makers (Nunes et al., 2005).

One useful framework for assessing the coping experience is the critical incident technique (CIT) (O'Driscoll & Cooper, 1994). CIT was originally developed by Flanagan (1954) to study U.S. Air Force pilots during World War II. The CIT aims to generate descriptive qualitative data of experiences that remained mostly uncharted in the literature, to highlight awareness about human experiences, and to elicit specific factors that helped or hindered a particular process (Woolsey, 1986). The CIT consists of a set of interview procedures for collecting information from people about their direct observations of their own or other people's behaviors (Woolsey, 1986). The information collected provides descriptive accounts of events that facilitated or hindered a particular aim. CIT is valuable for many fields of research, particularly due to its flexibility as well as its applied nature of providing direct practical implications. Although the CIT approach is consistent with a constructivist approach to human psychology, it incorporates both qualitative and quantitative elements into a single method (Bedi, Davis, & Williams, 2005), and provides the opportunity to examine how the social context affects the phenomena under investigation, through an exploration of subjective meaning (Camic, Rhodes, & Yardley, 2003). Flanagan's CIT has been implemented with some modifications to study psychological states and phenomena in different studies in a variety of disciplines (e.g., Alfonso, 1997; Bedi et al., 2005; Borgen & Amundson, 1984; Borgen, Hatch, & Amundson, 1990; McCormick, 1994). Noted for its rigorous validation procedure, the CIT offers a rich, comprehensive category system to represent the information gathered.

In sum, the experiences of parents of children with CIs have been of interest for some time, but research to date has heavily emphasized the exploration of the challenges and the stress parents are experiencing while to some extent disregarding the variables fostering parents'

coping processes. Furthermore, most research has used quantitative evaluations that limit our understanding to a restricted set of variables.

Thus, the current research utilized the CIT qualitative, holistic inquiry method, to provide detailed data permitting analysis of multiple aspects within the topic studied. The present study aimed to qualitatively investigate the phenomenological experience of parenting a child who is deaf and has undergone cochlear implantation and to develop a comprehensive categorical system that represents the facilitating resources that parents identified and attributed to their parenting coping experience. By utilizing CIT, this study asked: What attributes facilitated mothers' and fathers' coping with this parenting experience?

## **Method**

### **Participants**

Participants comprised 15 hearing mothers and 13 hearing fathers (including 12 married couples) whose children had undergone cochlear implantation surgery. Mothers' average age was 34.46 years ( $SD = 5.01$ ), and fathers' was 35.50 ( $SD = 4.97$ ). Regarding parents' education level, 20% of mothers and 46.7% of fathers had one or two years of higher education; 53.3% of mothers and 33.3% of fathers had a university degree. Most mothers (73.3 %) and fathers (71.4%) were born in Canada. The remaining parents immigrated:  $M = 18.5$  years earlier for mothers ( $n = 4$ ) and  $M = 12.75$  years earlier for fathers ( $n = 4$ ). Families resided in urban areas (55.3%) or rural areas (44.7%). Regarding family size, 40% had only one child – the child with hearing loss. Most of the remaining families had 2 children (53.3%). Two families reported having a second child with hearing loss; three families reported other family members with hearing loss.

Children were 7 boys and 8 girls who were deaf and had undergone cochlear implantation, with a mean age of 3.53 years ( $SD = 1.06$ ;  $Range = 2$  years & 2 months to 5 years & 11 months) at the time of the study. This sample ( $n = 15$ ) was relatively large in light of the number of pediatric surgeries undergone per year in British Columbia (Juck, 2005)<sup>1</sup>. All the children had at least a severe to profound degree of hearing loss, which was diagnosed at  $M = 12.37$  months ( $SD = 5.61$ ). Mean age at implantation was 24.22 months ( $SD = 12.01$ ). Only one family reported complications associated with the CI surgery, namely, the healing of the scar. According to parent reports, only one child had been diagnosed with an additional problem other than hearing loss, namely, a weakened hamstring in one leg. The average age at onset of educational-rehabilitational intervention was 14.86 months ( $SD = 7.64$ ). Regarding communicational modality at home, the majority of parents (60%) reported using simultaneous communication (speech and signs) with their children; 13.3% of parents reported using speech with some signs to support spoken language, and 26.7% reported using speech only.

## Measures

**Background questionnaire.** This questionnaire tapped family demographics (parents' education level, number of children, place of residence, hearing status of siblings and parents); information about the child (degree of hearing loss, age, gender, etiology of deafness, communication modality, educational setting, age at onset of intervention, and additional problems); and information on the cochlear implantation (date of surgery, complications). (See Appendix C1).

**Retrospective parental experience questionnaire.** This open-format self-report asked parents to recall specific incidents in their parenting experiences that helped their coping. This questionnaire was developed for the purpose of this study in order to prepare parents for the

upcoming critical incident interview , both of which were based on a retrospective report of incidents and experiences. In addition, completion of this questionnaire was expected to allow parents to consider what they would feel comfortable disclosing during the upcoming interview. Each mother or father completed this questionnaire separately. (See Appendix C2).

**Critical incident interview.** Each participant was individually interviewed by the researcher using a semi-structured format following Woolsey's (1986) critical incident interview protocol. The interview includes two parts, an orientation and an elicitation of facilitating experiences. The orientation involved establishing rapport, explaining the purpose of the study, addressing confidentiality issues, and describing the interview procedures. In the elicitation portion, participants were first presented with the aim and context of the activity: "Please focus on your coping during the experience of raising a child who is deaf and has a CI, from the time of diagnosis to the present." Second, to elicit participants' recall of significant incidents (including behaviors, thoughts, and feelings) that had facilitated their experience, the researcher asked: "What helped you cope with the experience of parenting/raising a child who is deaf? Please describe particular incidents or experiences in this period of time that facilitated your coping with parenting your child. Take your time to think of a specific incident or an experience in as much detail as you can." This question was followed by probing questions, along the interview, to encourage participants to provide maximal information and detail regarding their experiences, such as: "What was happening to you after this incident/experience?"; "What were the general circumstances leading up to this event?"; "How did you feel about it?"; "What were you thinking?". This process continued until the parent was no longer able to recall any other experiences.

## Procedure

The study was reviewed and approved by the university's research ethics board. Parents were recruited from two early intervention centers for children who are deaf and their families in British Columbia, and from the Cochlear Implant Services at the British Columbia Children's Hospital (BCCH).<sup>2</sup> Program coordinators in these three settings distributed information about the study to parents who met the following criteria: normal hearing in mothers or fathers of a child 5 years old or younger who had received a CI in the last 2 years. Mothers and fathers who were interested in participating received a parental consent form from the early intervention centers' directors detailing the purpose of the study, the interview questions, the criteria for participant selection, information regarding confidentiality, and contact information if they had questions. Completed consent forms were returned to the researcher. Next, the background questionnaire and the retrospective parental experience questionnaire were sent to each interested parent, and an interview was scheduled for each parent (100%) who had demonstrated initial interest in the study. Interviews were conducted by the researcher in the participants' home or at the early intervention center/hospital in accordance with parents' convenience. In cases where couples were interviewed, the interviews were conducted consecutively, in random order, without the spouse present and with no time for conversation between the two interviews. Each interview lasted approximately 60 to 90 minutes. All interviews were audiotaped and orthographically transcribed.

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<sup>2</sup> BCCH, founded in 1988, is the only cochlear implant program operating in British Columbia. In January, 2004, BC Ministry of Health funding was increased from only 6 pediatric cochlear implantation surgeries to up to 30 surgeries per year (Juck, 2005).

## Data Analysis

The written responses to the self-reported retrospective parental experience questionnaire as well as the audiotaped/transcribed interviews were subjected to extraction of critical incidents using NVIVO software. To extract incidents from the interviews, I read the transcripts while listening to the audiotapes, to avoid losing vocal nuances.

Criteria for extraction of parenting incidents followed Flanagan's (1954) two criteria: (1) The incident must comprise an actual and detailed behavior reported and judged to be critical by the participant; and (2) The behavior must be relevant to the general aim of the activity, which, in the present case, was parenting a child who is deaf. However, Flanagan emphasized the need to observe only manifest behaviors that accomplish a specific aim, whereas the current study extended Flanagan's criteria to the observation not only of external behaviors but also of internal processes that included emotional and cognitive states.

Each incident was extracted and coded for three features: (1) its source – who was involved and what the event's context was, (2) the action taken – what happened that was helpful, and (3) the outcome – the incident's effect. Next, each incident was given a descriptor to capture the meaning of that unit, in other words, to describe the helpful, facilitative action. In cases where the participants returned to the same incident more than once in the course of the interview, the incident was extracted and counted only once. To test the reliability of the extraction procedure, an independent researcher (a third-year doctoral student specializing in measurement, evaluation, and research methodology in educational psychology) separately analyzed a random sample of 25% of the interviews. An inter-rater reliability of 87.8% was achieved in extracting and describing the critical parenting incidents.

Another recommended validity measure for the rater's extracted critical incidents was participants' cross-checking (Butterfield, Borgen, Amundson, & Maglio, 2005), also referred to as testimonial validity (Stiles, 1993) or as a credibility check (Elliot, Fischer, & Rennie, 1999; Maxwell, 1992). This examination assessed the agreement between the raters' interpretation of the collected data and the participants' intended descriptions of their experiences. A randomly selected 50% of the participants received a summary report describing the extracted critical incidents that facilitated their coping with their parenting experiences, based on the interview and on the self-report. Participants were asked to review the summary report, to determine the accuracy of the critical incidents' descriptions, and to add, delete, or amend the incidents as needed. All participants stated that the report represented their parenting experiences accurately. Two participants added information to the recorded incidents to enhance their accuracy.

Next, the extracted incidents were subjected to an open-ended, inductive process of categorization to develop a comprehensive map of mutually exclusive categories (Flanagan, 1954; Woolsey, 1986) that would provide a rich description summarizing experiences across participants while indicating the facilitative attributes, their meaning, and their consequences, in line with the recommendations made by Alfonso (1997) and McCormick (1995). In this categorization process, as described above, after the incidents were extracted and coded for source, action, and outcome, the incidents were sorted into similar groups according to the facilitative action taken. Participants may have identified similar facilitative actions but have affiliated them with different consequences. This phenomenological, holistic, comprehensive category map can be used for development of theory, for test construction, for practical programs, and for further study of the categories (McCormick, 1995). According to the CIT qualitative methods, the purpose of the reported findings was to provide a comprehensive map of



the category system (source, action, and outcome). After the development of the categorization, three additional recommended credibility checks (Butterfield et al., 2005) were conducted – independent sorters, participation rate, and expert validation – as described in the results section.

## **Results**

A total of 430 critical incidents were elicited concerning what facilitated these 28 hearing parents' coping with the experience of raising a child who is deaf and has received a CI. The categorization procedure produced 20 categories. Table 3.1 presents the incidents' distribution among the categories, as well as the percentages of participants (mothers, fathers, and overall) who identified at least one incident in the categories. The following section presents each category based on parents' descriptions, explanations, and attributions of meaning to their experiences, using excerpts from their interview transcripts and their self reports. Then, the categorization validation procedures will be presented.

### **20 Categories of Facilitating Incidents**

**1. Identifying progress and success.** This category, the only one mentioned by 100% of the parents, referred to parents' identification of their child's progress and accomplishments throughout the rehabilitation process, especially noted after the child had undergone the CI surgery. When the surgery was successful (without complications) and/or the implant was successfully activated, parents described strong emotional responses and a sense of relief. Later, parents expressed amazement at their child's reactions to sounds, and appreciated their child's progress in speech perception, speech production, and language skills (even though these were

lengthy processes). Subsequent to such facilitory events, parents felt that all their investment efforts had been worthwhile and felt confident in their decisions, actions, and goals. In addition, parents were pleased with their children's ability to independently point out problems with their CI and children expressed satisfaction with the CI.

Example: The audiologist gave us such a good idea of the kind of sounds that he was getting that it made us feel very confident about how it was working for our child. And then with all the therapy we were getting, we were getting more and more confident that he actually was hearing. That he could hear a spectrum of sounds. He may not even have turned as quick as you would read. Some kids would turn to a fire engine in the first week that they had the processor on, but we knew that he could hear all those sounds... It was outstanding... it was quite exciting to start getting the feedback.

**2. Sharing experiences with similar others.** This category, mentioned by almost all (92.6%) of the parents, addressed making connections and communicating with similar others – that is, with parents of children who are deaf. Parents established connections with other parents through support groups, the Internet, and contact lists provided by the early intervention center. Parents reported that other parents offered the kinds of support that best matched their emotional and practical needs. Specifically, they noted other parents' trustworthiness and firsthand experience in the daily childrearing of a child who is deaf ("24 hours a day"), as well as their freedom from political or organizational agendas that might influence the information they delivered (in contrast to professionals). Parents expressed curiosity regarding other children's progress and other parents' actions, and they appreciated hearing other families' stories and

sharing their own experiences with others. Thus, communicating with other parents provided an opportunity to share information, knowledge, and resources; to collaboratively think through concerns and face challenges; and to discuss potential solutions and ideas. Parents felt that peer support helped them gain practical parenting skills, acquire new perspectives, and become better equipped for the future. In addition, they reported that such opportunities were encouraging and reduced their anxiety level and concerns. Other families also functioned as a social group that contributed to parents' sense of belonging, which also reduced their sense of loneliness and normalized the experience of parents and children dealing with deafness.

Example: You're actually talking to somebody who's been through it, or is going through it. I mean, your friends and family are awesome, but they're not the one with the child, and they're not the one who lives all day long with a child with a hearing loss ... These people can actually feel with you, and understand with you. Give advice and give a good pat on the shoulder. They understand. ... I don't know what I would do sometimes without the parent support group because after, you know, a couple of weeks of not seeing them, it's like, oh good, I get to talk to somebody about this, this, this and this, and right now we're in the potty training stage, and it's like oh my god, I don't know what I'm doing.

**3. Professionals' support.** This category, mentioned by almost all (92.6%) of the parents, comprised parents' receipt of support from different professionals such as surgeons, speech language clinicians, teachers for the deaf and hard of hearing, and so on in the following functional domains: emotional, tangible, and informational support. Emotional support referred

to incidents where professionals calmed parents during stressful situations (e.g., before the child's surgery), cared for parents, showed empathy, listened to parents' concerns, expressed understanding of their situation, and encouraged parents throughout the process of diagnosis, surgery, and rehabilitation. Tangible support referred to incidents where professionals monitored children's progress and reported it to parents, thus reassuring parents that their child was "on the right track" and progressing as expected. Informational support referred to incidents where professionals provided parents with information and advice that helped parents make decisions, answered parents' questions, provided explanations, and presented parents with numerous resources. Informational needs appeared to change over time, with the most critical period described as the time following diagnosis when faced with the decision of whether to choose cochlear implantation. In all, professionals' diverse supports were evaluated as decreasing parents' levels of stress and anxiety and as helping parents gain knowledge and experience a sense of control and competence.

Example: I remember one of the teachers from the intervention center phoning me after I had gotten home, which was very nice. She just phoned because she realized that my wife and the kids were going away and we had just found out about our child's hearing loss, and so she called me at home just to see how things were going. So that was good, having emotional support.

**4. Family's/friends' consistent involvement.** This category, mentioned by 74.1% of the parents, addressed parents' receipt of support from family members and friends in the following functional domains: informational, tangible, emotional, and rehabilitation support. Informational

support referred to incidents where friends and family members took an active part in obtaining information about hearing loss, intervention options, and the CI. Parents appreciated others' involvement in the information seeking process, especially following the child's diagnosis and before making the decision about cochlear implantation when parents lacked experience and knowledge related to deafness and faced the challenge of absorbing a considerable amount of new knowledge in a short period of time. Collaboration with family and friends helped the parents think through options, concerns, and decisions as well as construct their cognitive appraisal of the child's deafness and needs. Tangible support referred to incidents where family members and friends helped parents maintain daily life tasks. Childcare by these family members and friends freed parents to manage various tasks, like attending medical appointments, and gave parents "a break" at stressful times. Emotional support referred to incidents where family members' and friends' involvement provided a source of emotional support. Caring, encouragement, and companionship were valuable (e.g., the company of close family during the child's surgery). It was also important to parents that their extended family and friends gain understanding of what was involved in raising a child who is deaf and that they acknowledge parents' difficulties. Rehabilitation support referred to incidents where family members and friends became directly involved in the child's rehabilitation, such as participating in therapy sessions or working with the child on specific learning tasks.

Example: I went back to working two days a week. It's busy, but D. goes to my mom and dad's house. My mom has done a few sessions with her speech therapist and so she's got a good idea of, you know, what we kind of do and what our philosophy is. She tries to keep that going, those two days.

**5. Intervention services.** This category, mentioned by 70.4% of the parents, comprised services that parents received for their child and family, such as speech language therapy; supportive sign language services (like home classes and guidance for the day care setting); and CI-related services, like easy access to parts, candidacy for surgery at an early age, and a shorter waiting list for surgery due to increased health funding. Parents noted that service provision in the family home was convenient in terms of scheduling, enabled both parents and other family members to participate, and helped them learn how to work with their child in their everyday home context.

Example: Having the signing class available to us in our home was very helpful, even if it was just once a week. It took a lot of the burden off. And in fact it allowed the family to participate. Family members sort of felt they were more welcome, they'd have tea so it was a bit of a social thing as well as learning sign. So it made it a little easier than having to go out to night class every Wednesday or Tuesday.

**6. Taking action.** This category, mentioned by 70.4% of the parents, involved parents' decisions to engage in a problem solving approach and to take active steps toward learning how to best support their child. These parents described how they had intentionally decided not to be held captive by their intense emotional reactions to their child's deafness, but rather to respond practically and rationally. Parents' actions included extensive research and information procurement from multiple sources (e.g., websites and online discussion forums) to increase their knowledge base concerning hearing loss, rehabilitation options, CIs, as well as the early

intervention context of children with hearing loss (e.g., politics, different philosophical approaches, biases), and so forth. As a result, parents gained better understanding, which, in turn, informed their decision making, oriented them toward the future, empowered them, and gave them a sense of control in facing something over which they had no control – their child's disability.

Example: We were at the point where we just wanted to do whatever we could for our child and whatever it takes ... We just dove in and made decisions, figured out what needed to be done and started ... It was very hard, but we are the type of people who, instead of dwelling on it and getting upset, too upset or feeling too sorry for yourselves, we do whatever we can for our boy...

**7. Personal resources.** This category, mentioned by 63% of the parents, depicted parents' personal resources such as their profession (e.g., a physician), previous knowledge (e.g., about child development), previous experience (having another child with hearing loss), religiosity, time available, and family composite (e.g., having one child).

Example: We go to church and this gives me a lot of strength. This helps me so much. I just pray lots. And I knew that a lot of people prayed for us ... in our church, we depended on it.

**8. Gaining positive perspectives on deafness.** This category, mentioned by 56% of the parents, addressed parental cognitive appraisals of their child's deafness that facilitated parents'

coping with the experience of raising a child who is deaf. Parents described that they had accepted the fact that their child had a hearing loss and its consequences. Some were relieved when they compared deafness to other medical conditions and felt blessed that deafness is not a life-threatening disability, that their child had no severe additional disabling conditions, and that their child would be able to have an independent future life. Parents described a holistic view of their child, referring to their child's hearing loss as only one aspect of the child's uniqueness and, hence, they treated the child as any other child. Some parents felt enriched by the experience of raising a child with deafness and felt it introduced a new meaning and perspective to their lives.

Example: It was a traumatizing diagnosis, but it wasn't, like... I mean, I'd much rather her have this than be autistic, and that was our comfort throughout. Like, thank god she's deaf, that's what we kept saying.

**9. Professionals' guidance.** This category, mentioned by 55.6% of the parents, involved parents' benefit from professionals' direct and indirect guidance. Direct guidance was provided regarding the complex tasks of raising a child who is deaf in domains such as communicating with the child, working on language development, and troubleshooting with the CI. Indirect guidance was given to other service providers (e.g., preschool teachers) or individuals in contact with them or their child, regarding how to work with their child, to manage their assisted listening devices, and to support their child's intervention goals and language development. Parents reported that receiving guidance and feedback increased their sense of self-efficacy and their confidence and self-esteem in their parenting roles and skills, and promoted and motivated their participation in their child's rehabilitation.



Example: All the guidance from the infant development worker and the teacher for the deaf through the intervention center ... sort of set up my life for me because I didn't know what to do and I had another child and I thought how much can you do for one, and yet our whole life was focused on communicating in a new way and learning sign language.

**10. Belonging to an early intervention community.** This category, mentioned by 55.6% of the parents, comprised participation in an early intervention program, as a helpful resource in two domains of functioning: social and instrumental. In terms of social functioning, the intervention center served as a meeting place and provided opportunities to establish social connections with other families. This, in turn, promoted a sense of belonging and supportiveness. Coming to the center, parents felt they were part of a community which understood them; they no longer felt alone or lost. The parent support groups at the center also facilitated the promotion of social connections between families. In terms of instrumental functioning, the early intervention program provided a central source of professional services and resources to parents, such as sign language classes, a resource library, and speech therapy.

Example: We were fortunate; this facility here has been great. When we found out that she had a hearing problem, all the staff started coming, almost overwhelmingly, and everybody said, "You've got to get the ball rolling." It was great, to have this service set up and provided for you. Without it, as a parent, I wouldn't know what to do.

**11. Utilizing sign language.** This category, mentioned by 48.1% of the parents, addressed incidents related to use of sign language for communicating with the child. (It appeared from parents' descriptions that "sign language" actually refers to the use of signs, rather than to a distinct sign system or American Sign Language). The incidents parents relayed suggested that the first priority in parents' minds was finding a way to communicate. Parents expressed great satisfaction, relief, and motivation when their child started to comprehend parental communicative intent and to respond and produce signs. Parents reported that they found it helpful to start using sign language following diagnosis, especially due to the fact that they did not know yet if their child would be a suitable candidate for implantation or if the implant would help their child. In addition, even following the cochlear implantation, when parents aimed to establish oral communication with their child, they found it helpful to continue using signs in three ways: as a bridge during the lengthy transition to oral communication; when the child could not use the implant (e.g., in the bathtub, swimming pool, park, in bed at night); and to prevent frustration during communication breakdowns.

Example: We decided to use sign language because ... we weren't [yet] sure if T. was going to be a candidate for an implant after getting meningitis. We weren't sure how extensive the damage was to his nerves. We immediately started signing... he acquired signs very quickly. I mean, by the time we left the hospital we could get him started on signs like "light on," so it was extraordinary to see that and... very comforting to know that he would be able to communicate with us.

**12. Observing children with cochlear implants.** This category, mentioned by 44.4% of the parents, comprised parents' benefit from observation of children who already have CIs, mostly in incidents that occurred preoperatively. Observing other children influenced parents' perceptions of the implant as an efficient rehabilitation option for their child. The observation established parents' expectations regard their child's outcomes, helped them set rehabilitation goals, and gave them hope that their child would be capable of listening and speaking. These incidents influenced parental decision making processes and increased parents' confidence in their decision. Parents felt encouraged, optimistic, and less concerned regarding their child's future adjustment.

Example: We met a bunch of these kids who were three or four years old and had CIs for a little while, and I was talking to a four-year-old and I didn't even know he had one because he had big moppy hair. And you see this kid, he's talking, he's listening to me and then he's got this little wire hanging down and you think, hey, this thing will work, you know. And so you get this real big hope, that's where you start to feel... everything might, I think this will be good.

**13. Supportive workplace.** This category, mentioned by 44% of the parents, dealt with parents' work schedule flexibility, as well as employers' and co-workers' support and thoughtfulness. These factors enabled parents to take time off to attend their child's various medical and/or intervention appointments, a parent support group, a sign language class, etc. In some cases, mothers left their jobs altogether or moved to part-time positions. Parents attributed such decisions as facilitating management of their child's daily schedule and improving

outcomes following cochlear implantation due to the mothers' increased availability to work with their children. Parents appreciated when work colleagues were empathetic, expressed interest in their child, and tried to encourage them.

Example: All these appointments and assessments, especially before the implant, and meetings and looking for interventions, are so time consuming when you work full-time. I was lucky to be working at that time in a job where people would understand if I needed to take some time off and go to appointments and so on. So that wasn't a stress at all to, you know, missing work and so on. I had that flexibility.

**14. Incorporating rehabilitation into daily life.** This category, mentioned by 37.1% of the parents, touched upon integrating the child-related activities into the family's daily routine. Parents appreciated mundane daily activities (e.g., exercising sound discrimination while riding in the car or cooking dinner) as opposed to structured ones that promoted their child's language and communication skills. Parents expressed the goals of making language practice enjoyable and not restraining the family's routine. Siblings' involvement in language activities and interactions with the child with hearing loss were identified as contributing significantly to the child's progress and, therefore, supporting parental goals. Parents did not want to feel stressed about promoting their child's outcomes.

Example: Her brother helped her a lot. I think it was always a game. We sat together, we three, and did the games. Or when my husband had time, we all four sat together and played the games or looked at the animal pictures.

**15. Child's characteristics.** This category, mentioned by 33.3% of the parents, encompassed parents' identification of aspects of their child's personality, behavior, attitudes, and other specific characteristics that helped them adjust to the situation and make the rehabilitation process easier.

Example: J. has always been a fighter; he's always bounced back from everything. He helped us, honestly. What really got us through that dwelling on the "why me?" was him. His positive attitude, his personality, that's what really got us through. The fighter inside him to just keep going every time they knocked him down with a test or an operation, a needle, whatever, he just, you know, looked at you and got up again. He didn't just curl up in a shell and... feel sorry for himself ... he would just get up fighting every time. So we said how can we be upset and look at him, he's doing great through everything.

**16. Marital partnership.** This category, mentioned by 33.3% of the parents, dealt with incidents concerning the marital relationship. Parents indicated the importance of having each other at stressful time points (diagnosis, surgery), during challenging situations (difficult interactions with the child), and throughout the demanding rehabilitation process. They described the benefit of jointly making crucial decisions, working together toward their goals, sharing responsibilities, and communicating with the health care system. This unity, in turn, enabled both parents to be involved in their child's intervention, increased their self-confidence, eased the adjustment process, reduced stress, and even brought them closer. For some fathers, the joint understanding that the mother was taking a leading role in meeting the child's special

needs and in delivering information to the father was reassuring. In sum, a cognitive, emotional, and practical sense of collaboration and partnership was reported as an essential resource for parental coping with the child's deafness.

Example: We didn't have anything like ... other couples [who said]: "My husband wanted the CI and I didn't, so we had to ... get through that together as a couple before we could even move on." Whereas, I guess we were really blessed that we just kind of both thought the same way [about the implant] ... we were on the same page. I can't imagine not seeing this the same way as my husband and having to convince him, or him having to convince me. That would have just been such a strain, you know, on our marriage.

**17. Supportive childcare setting.** This category, mentioned by 29.6% of the parents, comprised parents' satisfaction with their child's educational setting (e.g., day care, preschool). Parents expressed high appreciation of the settings' support for their child's needs and encouragement of their child's inclusion in mainstream tracks. Support included teaching other (hearing) children to use some signs, collaborating with the child's speech language pathologist, supporting the child's intervention goals, and working with the child to promote language development.

Example: The preschool was willing to do whatever we needed to help J. They bent over backwards, made a lot of changes, hung signs up, taught the other children some sign language. He is the only hard of hearing one, there are 20 other children in the preschool

and they all are learning sign.

**18. Connection with adults who are deaf.** This category, mentioned by 25.9% of the parents, depicted the opportunity to meet and establish relationships with adults who have hearing loss (with or without CIs). Parents met adults who are deaf through the intervention center, through professionals who worked with their child, or via the Internet. Parents who had the opportunity to learn from these adults' experiences and hear their life stories reported that it increased their understanding of what it is like to live with deafness and to use a CI. Adults who are deaf supported parents' efforts to learn sign language, helped parents improve their interaction patterns with their children, and, in some cases, served as a role model. They gave parents hope for the future.

Example: An adult woman who is deaf came and hung out with me and my kid, taught me some basic sign language. It was just to see a productive, active person with this disability. We've maintained a friendship ever since. It's amazing to know that a person who has a hearing loss can actually grow up and succeed. It helped when I was able to speak with an adult who is deaf, and she was able to describe what it's like...

**19. Parental confidence in decisions.** This category, mentioned by 22.2% of the parents, consisted of parents' self-confidence regarding their decisions (e.g., regarding implantation, rehabilitation approach) and their espousal of a positive future orientation. When parents felt they were giving their child the best chances to succeed in life, they reported that their self-

confidence increased their commitment toward their child's rehabilitation process as well as their feelings of excitement and encouragement toward the future.

Example: We were confident about our decision that this was the right thing to do. Ah, I think any parent wants to be able to give their child the best life they can have. And, to be able to give R. the ability to hear, although not as you and I hear, but hear nonetheless – it was our responsibility to give that to her.

**20. Financial support.** This category, mentioned by 18.5% of the parents, addressed parents' appreciation of financial support that helped cover their child's treatment and related expenses. For instance, financial aid helped families living in remote areas, who had to travel with their child to reach preoperative medical appointments, to attend mapping sessions (especially during the first year after surgery), and to access intervention services.

Example: We have the support of our community, which is well aware that we travel up and down the island. And my husband's work office has been wonderful. They have handed over money a few times now for us to pay for our gas to get down to Vancouver.

### **Categorization Validation Procedure**

Three recommended credibility checks (Butterfield et al., 2005) were conducted after the categories were established: participation rate, independent sorters, and expert validation.



**Participation rate.** As seen in Table 3.1, to determine the representation of each category among the study participants, participation rate (the percentage of participants who mentioned incidents) was examined. Categories with a high endorsement (e.g., identifying progress and success, with a 100% participation rate, or professionals' support, with 92.6% endorsement) can be considered to have a broad level of relevance. However, categories with a low level of endorsement (e.g., parental confidence in decisions, with only a 22.2% participation rate, or financial support, with only 18.5% endorsement) should not be considered invalid, but rather signify that the incidents comprising this category are less typical and may be extreme or highly idiosyncratic (Andersson & Nilsson, 1964).

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Table 3.1

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**Independent sorters.** Inter-rater reliability was examined by two judges' categorization of a random 10% sample of the incidents from each category. Thus, each judge categorized 43 incidents. The judges first received a brief written description of all 20 categories as well as the set of 43 transcribed incidents presented randomly on 43 separate index cards. The judges were asked to write down which of the 20 categories suited each card (only one category per card). The percentage of agreement for categorizing the incidents was 97.72% between the researcher and the first judge and 93.18% between the researcher and the second judge, providing an overall average inter-rater reliability of 95.45%. It has been suggested that a category system should attain at least 75% agreement (Andersson & Nilsson, 1964; Flanagan, 1954).

**Expert validation.** To determine whether these categories were valid and useful in the context of the field (Butterfield et al., 2005; McCormick, 1994), a summary of the category system was submitted to two experts in the field of early intervention for children who are deaf and their families. The first expert was the educational director of an early intervention center's preschool program over the last 30 years, and the second expert was a faculty member in a teacher preparation program in education of the deaf and hard of hearing, a position she had held for the last 18 years, with experience in research in early intervention. The experts were asked to separately review each category description and to comment on whether it was manifested in the practical context of early intervention. The experts confirmed each of the categories as useful and valid to therapeutic practice. This examination provided a link between research and practice.

## Discussion

Study results indicated that the coping experience of parenting a child with a CI was determined by various sources of influence associated with social contextual aspects, with the parent himself or herself, and with the child. This pattern of findings is consistent with conceptual ecological models of parenting, such as Bronfenbrenner's (1979) ecological approach, which outlined multiple factors that may influence parenting, and Belsky's (1984) process model that provided a framework for addressing three domains of determinants of parental experience and functioning, including: contextual sources of stress and support, parents' personal psychological resources, and the child's characteristics. The findings of the study will be discussed according to these domains.

Findings of the current study were also consistent with findings from meta-analyses examining the most significant factors in the coping process among parents of children with disabilities (Scorgie, Wilgosh, & McDonald, 1998; Yau & Li-Tsang, 1999). Those studies summarized that relevant factors relate to the parent and family characteristics and status (e.g., appraisals, marital relationships, time schedules, problem solving skills, family composition), the child characteristics (e.g., temperament, degree of disability), and external resources (e.g., social network support, collaboration with professionals).

### **Contextual Sources of Support**

The significant role of social and emotional sources of support stems largely from the unique challenges and demands associated with parenting a child who has a CI. Regarding social support to parents of children who are deaf, the current findings whereby parents received support from multiple sources, both formal and informal, corroborated previous research (Beadle et al., 2000; Calderon & Greenberg, 1999; Hintermair, 2000; Lederberg & Golbach, 2002; Meadow-Orlans & Steinberg, 1993; Quittner, Glueckauf, & Jackson, 1990). These sources included friends, extended family, intimate relationships, co-workers, other parents, adults who are deaf, professionals, and the community. In addition, similar to the current findings, these prior studies found that perceived social support was a beneficial resource for parents and was associated with parental well-being and adjustment. Notably, in these quantitative studies, social support was mainly defined as social network characteristics (availability, size, frequency, and satisfaction). In contrast, the current qualitative study provided in-depth descriptions of the unique functions of social support for this group of parents. Functional domains of social support refer to the degree to which interpersonal relationships serve particular functions (Sherbourne &

Stewart, 1991). In citing social supports, parents in the current study most often mentioned functional domains such as emotional or instrumental aid or tangible information and advice, companionship, and validation (Krause & Markides, 1990; Sherbourne & Stewart, 1991).

In many facilitating incidents, parents described types of support that facilitated their parenting experience along with the unique source of support that each relationship was able to offer. In other words, other parents, professionals, family members, adults who are deaf, and other sources in the parental social context each offered special features that supported parents in their coping processes.

Sharing with other parents of a child who is deaf uniquely offered a source of compassion, full understanding, and a level of mutual trust that was not reported for parents' other supporting relationships. As a result, other parents were considered a reliable ally for sharing relevant information and community resources, furnishing tools for comparison and learning, and providing good partners for collaborative problem solving. These findings from the present study coincide with those of Ainbinder et al. (1998), who found comparable qualities of support from other parents of children with special needs, including: perceived sadness, comparison that enables learning and growth, round-the-clock availability of support, mutuality of support, and personal growth. Similar outcomes were also suggested by Barnett, Clements, Kaplan-Estrin, and Fialka (2003) among parents of children with special needs. Moreover, parents of children who are deaf (both with hearing aids and with CIs) have highlighted the importance of making connections with other parents in similar situations (Dromi & Ingber, 1999; Hintermair, 2004; Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001) and of such contacts' positive effect on parental emotional experience (Dunst & Trivette, 1990; Hintermair, 2000; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). For example, similarly to the current

findings, Hintermair (2000) found that meeting other parents of children who are deaf reduced parents' social isolation, strengthened emotional bonds with their child and acceptance of their child, and improved interactional responsivity in child-parent interaction.

Another unique source of support reported by parents was professionals. Findings indicated that parents appeared to rely on professionals mainly for informational support, advice, and guidance. Receiving information from professionals appeared to be a valuable resource for parents. The present outcomes confirmed previous research reporting that parents of children who are deaf (both with hearing aids and with CIs) expressed a strong need for a wide range of information (Bernstein & Barta, 1988; Dromi & Ingber, 1999; Most & Zaidman-Zait, 2003). In addition, as was also indicated by others researchers (Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olsen, 1997), information plays an important role in parents' coping process and adjustment to their child's hearing loss.

Professionals' practical guidance was also reported here as helpful for parents. As reported previously, the present mothers of children who are deaf expected to receive guidance regarding a range of practical matters and direct instruction with regard to communication and interaction skills in order to advance their children in the process of learning language (Dromi & Ingber, 1999; Dromi & Ringwald-Frimerman, 1996; Horowitz & Shfatia, 1987; Pipp-Siegel et al., 2002). Moreover, the positive effect of parental guidance on parents' coping ability and on self-confidence in the parental role also emerged in previous research (Able-Boone, 1993; Fallon & Harris, 1991; Laughton, 1994). Zaidman-Zait and Most (2005) attributed the correlation found between parent-child communication difficulties and parents' lower level of satisfaction from professionals to the latter's lack of direct guidance for parents on how to develop better communication strategies with their child who is a CI user. In addition, consistent with previous

findings (e.g., Dromi & Ingber, 1999), parents in the current study also expressed a need for guidance delivered to others in the community, such as teachers who work with their child. The current findings support the notion that raising a child with hearing loss does not occur in social isolation; in many cases, parents play an advocacy role in which they must campaign for services for their child or educate other people who have contact with their child (Spencer, 2004).

It appears that parental satisfaction from professional informational support and guidance was not simply a matter of the delivered content but also the manner in which it was delivered. The importance of professionals' counseling qualities indicated by the parents (e.g., empathy, honesty, openness to parents' ideas, acceptance of parental decisions, willingness to listen, caring) were also found in previous studies that explored mothers' expectations and perceptions about their interaction with professionals in the field of deafness (Dromi & Ingber, 1999; Sjoblad, Harrison, Roush, & McWilliam, 2001). Moreover, similar to the importance of various helpgiving characteristics reported previously (Dunst, Trivette, & Hamby, 1996), parents in the current study identified significant helpgiving characteristics that led toward empowerment outcomes such as: supporting decision-making, promoting competence, trustworthiness, information sharing, useful advice giving, honesty, and understanding of concerns. It seems that the consequences of professionals' counseling practice reported by parents are consistent with the concept of effective helpgiving, that is, a process that provides individuals with opportunities to learn skills and develop a sense of control, leading to solutions for problems and concerns (Dunst, Trivette, & LaPointe, 1992). Likewise, the association described by parents between helpgiving practices and parents' sense of control was also reported by Judge (1997).

Parents described ways in which family members, spouses, friends, and other parents not only supported their coping efforts, but were actually involved in a collaborative coping effort,

where the child's deafness was perceived as a property of a social unit. This finding reflects Berg et al.'s (1998) thesis that stressors occur within a social context and are appraised and managed in collaboration with other individuals. As described by Berg et al., others' participation in parents' coping occurred by means of joint problem solving, collaborative thinking, division of labor, mutual influence, and dialogues. Examples from the current findings included parents co-constructing the meaning of having a deaf child together with others and parents sharing childrearing tasks such as seeking information related to CIs, taking care of their child, and promoting their child's outcomes following the cochlear implantation. In addition, parents solved problems related to their child's deafness in a collaborative manner, and had others involved in their decision making process.

### **Parents' Personal and Psychological Resources**

Another group of attributes that parents found relevant to their effective parental coping experience when raising a child with a CI reflected parents' personal resources (e.g., coping style, sense of competence) and parents' cognitive appraisals. According to some parents in the current study, it was helpful to adopt an active problem-focused coping style that included efforts that were oriented at responding to and altering the situation itself, i.e., the child's deafness. Parents' problem-focused coping mainly included parents' active information- and solution-seeking behavior related to various issues surrounding their child's condition and the CIs. According to parents' reports, information-seeking behavior was an effective coping strategy. The positive contribution of parents' active style of acquiring information about CIs was also found in previous research (Spencer, 2004), where it was associated with parents' satisfaction with their decision to choose a CI for their child and with the children's post-implant

performance. Similarly to the current findings, Sach and Whynes (2005) found that some parents went further than the information received from professionals by undertaking their own research.

The multiple sources of information from whom the current parents sought information were also reported by Christiansen and Leigh (2002) and included other parents of children with CIs, implanted children and adults, and health professionals such as pediatricians, audiologists, speech/language pathologists, and the Internet. Overall, the results of the current study suggest that parents appeared to go through a great deal of information gathering and fundamental thinking processes before deciding on rehabilitation options for their child (Li et al., 2004; Sach & Whynes, 2005; Spencer, 2004).

Parents' actions were also intended to regulate the intense negative emotions they were experiencing. One of the process that helped parents in altering their negative emotions included parents' intrapsychic process. Parents' appraisals of their child's deafness were modified over time and gained new meanings. Parents gradually began to feel that their child's deafness was manageable and even enriched their life experience. According to parents' reports, changes in their perceptions and thoughts regarding their child's deafness were modified by the interactions they had with others. As indicated by Berg et al. (1998), a dynamic process of appraisals and reappraisals occurs while individuals engage with the people in their social network.

Parents' confidence in their decisions and choices and their positive consequences were another helpful attribute mentioned by parents. One example of helpful choices that parents mentioned was the utilization of sign language to establish communication with the child following diagnosis, or even for occasional or transitory uses (e.g., at bedtime or bath time). Greenberg (1983) reported that mothers who were part of an intervention program that supported total communication expressed less stress than mothers who relied solely on oral



communication. Parents' motivation to incorporate sign language, even when choosing the CI for their child and aiming for oral communication, in some cases stems from uncertainty about the potential cochlear implantation outcomes. This uncertainty is probably related to the reported variability in outcomes (Dowell, Blarney, & Clark, 1997; Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000), limited generalized research evidence (Nicholas & Geers, 2006), and conflicting opinions among professionals. The acquisition of spoken language abilities following CI takes time (see review in Nicholas & Geers, 2006), during which an alternative mode of communicating can be beneficial. In addition, parents' description of children's decrease in production of signs and increase in production of spoken words over time is similar to preliminary evidence reported by Yoshinaga-Itano (Yoshinaga-Itano, 2006).

### **Child's Characteristics**

Parents described their child's personality characteristics and progress as fundamental to their experience. The current parents' reported satisfaction from CI outcomes is consistent with previous parent satisfaction levels (Beadle et al., 2000; Chmiel et al., 2000; Christiansen & Leigh, 2002; Meadow-Orlans et al., 2003; Sach & Whynes, 2005; Zaidman-Zait & Most, 2005) and with recent research demonstrating successful speech and language outcomes following cochlear implantation (for a recent review, see Nicholas & Geers, 2006).

### **Perceived Positive Outcomes of Existing Coping Resources**

Consistent with previous research, it appears that the parents of children with CIs in the present study experienced stress (Burger et al., 2005; Quittner et al., 1991; Richter et al., 2000; Spahn et al., 2003). Particularly stressful experiences reported by the parents included the child's

diagnosis, obtaining information, decision making, and the surgery. The current findings repeatedly demonstrated how various personal, social and external resources such as social support, personal psychological characteristics, child's progress, and the existence of services led to a decrease in parental stress, suggesting that high levels of stress are not inevitable and are linked to the availability of resources. Similarly, previous research also reported the influence of various resources on parental stress, including the amount of educational support children and parents received (Lederberg & Golbach, 2002), children's progress and communication abilities (Chaffee, Cunningham, Secord-Gilbert, Elbard, & Richards, 1990), parent psychological characteristics (Hintermair, 2006), and social support (Hintermair, 2004; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Pipp-Siegel et al., 2002; Quittner et al., 1990).

Adequate social services resources were reported as leading to additional cognitive and self-perception outcomes, such as parental sense of competence, self-efficacy appraisal, and sense of control. These qualities have been associated with parents' descriptions of empowering outcomes following helpgiver-helpseeker exchanges (Dunst et al., 1992). By receiving information, guidance, and emotional support from multiple sources (e.g., other parents, professionals), parents in the current study reported having opportunities to learn new skills and to develop a sense of empowerment, leading to resolution of concerns, solutions of problems, and the achievement of desired goals (Dunst et al., 1992; Zimmerman & Warschausky, 1998). In addition, according to parents' descriptions, it seems that these outcomes (parental self-efficacy and sense of competence) become, in turn, self-resources for parents, demonstrating that resources are both an end and a means (McWilliam, 2005). Research examining the effect of different cognitive coping resources among parents of children who are deaf found that maternal problem solving was associated with child adjustment (Calderon & Greenberg, 1999); sense of

coherence reduced parental stress (Hintermair, 2004); and, in mothers of children with CIs, perceived knowledge and competence in their children's speech-language development was associated with strategies employed during mother-child interactions (DesJardin, 2004). Overall, parents engage in dynamic processes of coping, where the utilization of resources promotes parental coping and fosters the acquisition of new resources and appraisals, which, in turn, lead to improved parental functioning and adjustment in response to the challenges of raising a child who is deaf.

### **Study Limitations and Future Research**

The categorization system developed in this study should be considered as a preliminary set of categories that describe coping as understood by parents. Because of the relatively small sample size, the current numerical results (i.e., percentage of participants mentioning at least one incident in a category, and incidents' distribution and range within categories) are probably less stable than the categories themselves and may not be generalizable. Nevertheless, a previous large-sample study examining parental perceptions about their child with a CI revealed findings resembling those of prior studies with very small sample sizes (Sach & Whynes, 2005).

Replication studies using larger sample sizes could establish the reliability of the current categories, identify new categories, and perhaps permit the examination of differences between mothers' and fathers' coping processes. In addition, knowing what assists parents in their coping processes does not completely reflect the obstacles that parents face. Hence, it is important to examine, too, what hinders the parental coping process. Knowing the positive and negative aspects of parenting experiences will be useful in planning effective preventions and services for deaf children and their families.

Furthermore, recent outcomes and advances in implant technology and implementation of newborn hearing screening may affect parents' coping experience. Hence, future research should continue to examine parental experiences and their implications for practice. Moreover, the current complex set of findings raises a multitude of future research questions, such as how parents' reported coping experiences reflect their actual behavior and its association with the child's progress over time. In addition, future research should adopt recent theoretical models of coping in social contexts and integrate perspectives of coping and social support when exploring family adjustment. Finally, research should employ various qualitative approaches to advance the understanding and consequences of parenting a child with a CI and to highlight issues that require researchers' and practitioners' attention.

The current research substantiates the soundness of implementing early intervention models such as the developmental system model (Guralnick, 2001) and the support approach to early intervention (McWilliam & Scott, 2001), which are consistent with ecological theory and recognize that families need various combinations of resources, social support, information, and services to help them address the stressors associated with parenting in general and parenting a child with special needs in particular. Early intervention programs that strengthen parental perceptions of control, support, and coping are likely to be successful at helping parents provide the types of behaviors that will support their children's development.

Table 3.1

Percentage of Participants Mentioning at Least one Incident in Category, and Incidents' Distribution and Range Within Categories

Category description		% participants who			No. of incidents given for category	Incidents per parent	
		mentioned incident(s)				Range	<i>M</i>
		Total ( <i>n</i> = 28)	Mothers ( <i>n</i> = 15)	Fathers ( <i>n</i> = 13)			
1	Identifying progress and success	100.0	100.0	100.0	56	1 – 5	2.0
2	Sharing experiences with similar others	92.6	93.3	91.7	32	0 - 2	0.6
3	Professionals' support	92.6	93.3	91.7	68	0 - 7	2.1
4	Family/friends consistent involvement	74.1	73.3	75.0	36	0 – 4	1.2
5	Intervention services	70.4	80.0	58.3	31	0 - 3	1.0
6	Taking action	70.4	66.7	75.0	29	0 – 3	0.9
7	Personal resources	63.0	53.3	75.0	23	0 – 4	1.0
8	Gaining perspectives on deafness	56.0	53.3	58.3	18	0 - 2	0.7
9	Professionals' guidance	55.6	73.3	33.3	20	0 - 2	0.8
10	Belonging to early intervention community	55.6	46.7	66.7	15	0 - 1	0.5
11	Utilizing sign language	48.1	46.7	50.0	14	0 - 2	0.6

Table 3.1 (continue from previous page)

Category description	% participants who			No. of incidents given for category	Incidents per parent	
	mentioned incident(s)				Range	<i>M</i>
	Total ( <i>n</i> = 28)	Mothers ( <i>n</i> = 15)	Fathers ( <i>n</i> = 13)			
12 Observing children with cochlear implants	44.4	40.0	50.0	12	0 - 1	0.5
13 Supportive workplace	44.0	33.3	58.3	14	0 - 2	0.6
14 Incorporating rehabilitation into daily life	37.1	40	33.3	12	0 - 2	0.6
15 Child's characteristics	33.3	33.3	33.3	10	0 - 2	0.6
16 Marital partnership	33.3	20.0	50.0	9	0 - 1	0.5
17 Supportive childcare setting	29.6	40.0	16.7	9	0 - 2	0.5
18 Connection with adults who are deaf	25.9	33.3	16.7	8	0 - 2	0.5
19 Parental confidence in decisions	22.2	20.0	25.0	8	0 - 2	0.6
20 Financial support	18.5	20.0	16.7	6	0 - 2	0.5
Total	—	—	—	430	—	—

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## **Chapter 4**

# **Parental Involvement in the Habilitation Process following Children's Cochlear Implantation: An Action Theory Perspective**

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## **Introduction**

The habilitation process following pediatric cochlear implantation rests heavily on parental involvement in a number of important dimensions, many of which are considered in the current research. First, parents are actively involved in the habilitation process of their children. Second, parents engage in daily intentional behaviors over time, envisioning an end-result for their child. Third, these behaviors have meaning for parents. Fourth, parents' actions do not occur in a vacuum. Rather, both parents and their children engage together in activities/pursuits. In addition, it seems that others, such as professionals, are also involved in the habilitation process. In the current study, we used two cases to illustrate an action theoretical perspective of these dimensions of parenting children with cochlear implants (CIs). The action theoretical perspective (Valach, Young, & Lynam, 2002) and its related action-project method are proposed in this study as heuristics for researching parenting children with CIs and parents' involvement in their children's habilitation process.

### **Parenting Children with Cochlear Implants**

Cochlear implantation has become an increasingly common habilitation option for children who are deaf (Spencer & Marschark, 2003). There is an increasing body of research demonstrating an improvement in children's functioning after cochlear implantation, in particular their spoken language and ability to communicate (e.g., Bat-Chava, Martin, & Kosciw, 2005; Blamey, Barry, Bow, Sarant, Paatsch, & Wales, 2001; Connor, Hieber, Arts, & Zwolén, 2000; Geers, Nicholas, & Sedey, 2003; Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000). It is important to note that successful outcomes following cochlear implantation are neither conclusively assured nor immediate (e.g., Geers, 2004), and significant variability in children's

outcomes following cochlear implantation has been reported (Bat-Chava et al., 2005; Purdy, Chard, Moran, & Hodgson, 1995; Sach & Whynes, 2005; Spencer, 2004; Spencer & Marschak, 2003; Svirsky et al., 2000). Continuing habilitation efforts are necessary after cochlear implantation in order to help make the procedure effective (Christiansen & Leigh, 2002).

It has been suggested that the role of parents throughout the habilitation process is one of the many factors found to enhance the benefits of CI use and eventually the child's progress (Allegretti, 2002; Geers & Brenner, 2003; Spencer, 2004). Moreover, Desjardin, Eisenberg, & Hodapp (2006) suggested that parental involvement and self-efficacy are two family factors that account for the variance in children's communication development following cochlear implantation. In trying to understand parents' influence on children's outcomes, Spencer (2004) examined different behavioral indicators of parental involvement related to their children's education and development both before and after cochlear implantation. Findings indicated an association between high levels of parental involvement, for example, learning sign language, advocating for their child's needs, devoting time and effort to take their child to the CI clinic for follow-up and monitoring children's language achievement. In a study of parents' perceptions of their involvement related to their children's CI use and early intervention services, Desjardin (2004) found that mothers' higher sense of involvement with their children was associated with mothers' enhanced language-facilitation strategies and their children's improvement in language abilities.

The above-mentioned studies on parental involvement emphasize its positive effect on children's language outcomes following cochlear implantation. Likewise, these studies underline the importance of understanding what parents are doing in their day-to-day life with their children, as well as parents' perceptions of their own involvement. At the same time, the studies

relied only on parents' retrospective accounts, and did not account for parents' intentional actions as oriented toward reaching goals specific to the parents' role in their child's habilitation and the promotion of his/her outcomes following cochlear implantation. Nonetheless, Dix and Branca (2003) highlighted the important role of goal-directed behavior in understanding parenting in their theoretical model. According to this model, goals have an organizational role in guiding parenting actions and change in actions, and as such they are pivotal in determining parenting practices (Dix, 1991; Kuczynski, 1984). Moreover, the research on parental involvement has centered around causal explanations and avoided looking at the unfolding nature of parents' and their children's joint processes over time. Finally, without doubting the importance of examining only parents' behaviors, it is vital to consider simultaneously parents' subjective internal process (i.e., cognitions, emotions and meaning) that accompany parents' behaviors and practices. The consideration of parents' internal process can be extremely valuable in gaining a better understanding of parents' behaviors and experiences following their children's cochlear implantation. For example, in trying to explain the low scaffolding abilities of hearing mothers of deaf children, Jamieson and Pedersen (1995) suggested possible explanations that are based on mothers' internal process, that is, mothers' emotional response to their child's deafness and maternal sense of competence.

Previous research looking at parents' internal experiences demonstrated that caring for a child with a CI and executing habilitation requirements have been found to affect parents' emotional and cognitive experiences. Parents of children with CIs have been reported to experience distress at various times over the course of the child's habilitation (Beadle, Shores, & Wood, 2000; Purdy et al., 1995; Quittner, Steck, & Pouiller, 1991; Richter, Spahn, Zschocke, Leuchter, Laszig, & Lohle, 2000; Spahn, Richter, Burger, Löhle, & Wirschang, 2003; Wiesel,

Most, & Michael, 2007; Zaidman-Zait & Most, 2005). In addition, parents reported various challenges that they face, such as adjustments necessitated by the needs and behaviors of the implanted child, time and effort demands, and stress induced by the child's intervention program (Sach & Whynes, 2005). It seems that previous research on parents' internal experiences mostly has employed a stress and coping standpoint. This standpoint has important implications for both theory and intervention; nonetheless, it limits our understanding and knowledge of other complex emotional and cognitive processes that are involved in parenting children with CIs. For instance, parents were found to hold positive views and be satisfied regarding their children's communication skills, social relationships, and general functioning following cochlear implantation (Beadle et al., 2000; Chmiel, Sutton, & Jenkins, 2000; Christiansen & Leigh, 2002; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003); at the same time, parents might experience difficulties when interacting with their child, and might modify their expectations accordingly. It seems that research exploring parental emotional experiences has disregarded the various internal experiences that might be included in parents' daily joint engagement with their children.

In sum, in order to increase our knowledge of parenting responses to having a child with a CI and parents' involvement and influence on their child's progress over time, a wider perspective that examines parents' behaviors in the context of their daily life and integrates behavior, meaning, function, internal process, and structure, and strives to capture process, is needed.

### **Action Theoretical Conceptual Framework**

Our view is that researching parenting children with CIs and parental involvement in the habilitation process following cochlear implantation from an action theory will provide a new



understanding of the complexity and intentionality of parents' and children's joint action in the context of the habilitation process. Action theory may be particularly useful for this because it is a framework and a language for understanding and researching applied tasks in which people engage in their everyday lives (Valach, Young, & Lynam, 1996). Action theory argues that human behavior is intentional and goal-directed, though not always rational (Valach et al., 2002). Action is understood as a complex multidimensional phenomenon. Three dimensions of action theory are involved in conceptualizing action and in research that is based on this theory (see Table 4.1): action systems, levels of action, and perspectives on action (Young, Valach, & Domene, 2005).

Action systems refer to individual action, joint action, and projects. Action consists of specific goal-directed behaviors that occur in contiguous time (Young et al., in press). Actions may be considered at the individual level in terms of goals, functional steps and specific behaviors. However, many of the same actions may also be considered as joint, that is, as occurring between people. When a series of actions, constructed as having common goals, are linked across a mid-term length of time, one may speak of a "project" (see Figure 4.1). A project is something that an individual or people jointly and intentionally work toward for a longer period. Projects encompass more than what can be accomplished in the immediate term and yet have some form of end point (i.e., when goals are accomplished). People engage in individual and joint actions to carry out their projects. The majority of projects that people engage in during their daily lives are social in nature and, therefore, involve more than one individual (Valach et al., 2002).

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Table 4.1

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The other two dimensions of action theory refer to the levels at which action and projects are organized and operate. Action is hierarchically organized: the goal of an action is considered at the highest level, and it represents the meaning of action processes. Goals are the overall intentions of the people who are engaged in the action (Young et al., 2005; Young et al., in press). Goals are defined by their cognitive qualities and social meaning and are structured as superordinate and subordinate, with some goals subsuming others. At the medial level of action organization are the functional steps. Functional steps are a sequence of contiguous specific verbal and non-verbal behavioral elements that have a common function. Functional steps are the intentional means (e.g., strategies, plans) by which people move toward their goals, steer and direct both the course of an action and its goal, and energize it with emotion.

At the lowest level are the specific conscious and unconscious verbal and non-verbal behavioral elements involved in the performance of a behavior (e.g., asking a question, shifting gaze, pointing). In addition, action theory emphasizes the relevance and consideration of resources, knowledge, and skills available in performing an action. These resources can either facilitate or inhibit the implementation of an action.

Action is also viewed from three distinct perspectives (see Figure 4.1), which occur in a non-hierarchical fashion. One may observe action as it manifests in verbal and non-verbal behavior, consider action based on the cognitions and emotions that steer, guide, and accompany

the action (i.e., internal process), and understand action from its social meaning as having goals and representing intentionality.

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Figure 4.1

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It seems that action theory and the action project method may be used as a conceptual framework to explore the specific intentional goal-directed individual and joint action of parents' and their children with CIs in the context of their daily life, while considering simultaneously different perspectives (manifest behaviors, internal process, and meaning) and striving to capture process over time. Action theory and the action project method can provide a way to extend our understanding based on the "causal" model of parenting behaviors and children's outcomes, by viewing parents' involvement in the habilitation process as a joint project comprised of a complex process of ongoing individual and parent-child joint actions embedded within context and occurring over time. Action theory and the action project method provide a research approach that allows investigation of the interactions between parents and children as they engage in joint activities in response to the child's cochlear implantation. Parents' goals are both prefigured and co-constructed through their joint interaction process with their children (Young & Valach, 2004). This notion is also reflected in the recent view of socialization as a process of mutual participation and involvement of children and their caregivers (Rogoff, 1991). Finally, as mentioned above, action theory has the advantage of simultaneously considering multiple perspectives on parents' action (manifest behavior, internal process and meaning). As such, it

can connect emotional processes, such as distress and anxiety, with parents' involvement and practices.

The purpose of the current research was to describe from an action theoretical framework the individual and joint action and projects that mothers engage in over time with their young children as a response to the changes and possibilities brought about by the CI. A central research goal was to demonstrate the way in which the action theory approach to social inquiry developed by Young, Valach and colleagues (e.g. Young, Valach, & Collin, 1996; Valach et al., 2002) enables an increased the understanding of the complexities of parenting a child with a CI.

## **Method**

This study was part of a larger research project examining parental experiences following their child's cochlear implantation. In the current study, we used two cases to illustrate the way in which action theory is able to increase the understanding of parental involvement and the complexities of parenting a child with a CI. The current study employed the instrumental case study method, which is important because it uncovers knowledge (Luck, Jackson, & Usher, 2005) and provides insight about the phenomena of interest (Stake, 2005). The study of the particular in case study research facilitates a necessary depth of understanding if we are to illuminate parenting action processes. Instead of an emphasis on generalization, here the purpose was to demonstrate an innovative theoretical framework that serves to facilitate our understanding of a larger phenomenon.

Within each case, a modification of the Qualitative Action-Project method developed by Young and colleagues (Young et al., 2005; Valach et al., 2002) was used. This method meets the standards for rigorous qualitative research. It involves collecting different types of data on the

same phenomenon: actual pertinent behaviors are video recorded and retrospective self-reports of the videotaped data are gathered through interviews; internal processes (cognitions and emotions) about these behaviors and meaning attributed to the data are gathered from participants by playing that data back to them and inviting their recollections on it; and participant feedback is also incorporated through interviews, including the telephone monitoring interviews.

It should be emphasized that the purpose of action-project method is to illuminate and describe the experiences of parents and their children and to generate a complete description of a phenomenon. As such, the method yields results that are descriptive rather than explanatory or predictive. Therefore, action theory research is unable to determine whether, and in what manner, the specific actions of parents and children are a *cause* of the child's progress (or hindrance). This does not, however, negate the valuable contribution that action theory is able to provide.

## **Procedure**

The study was reviewed and approved by the University's research ethics board. Mothers were recruited from the Cochlear Implant Services Program at British Columbia Children's Hospital (BCH). Background information on the participants will be provided in the findings for each case. Interviews and observations were conducted in the participants' home. Data collection involved the following stages, as shown in Figure 4.2:

**Stage 1: Completion of background questionnaire.** Mothers completed a *background questionnaire*. This questionnaire tapped family demographics (parents' education level, number of children, place of residence, hearing status of siblings and parents); information about the child (degree of hearing loss, age, gender, etiology of deafness, communication modality, educational setting, age at onset of intervention, and additional problems); and information on

the cochlear implantation (date of surgery, complications) (See Appendix D1). In addition, mothers reported on their children's vocabulary development using the MacArthur Communication Developmental Inventory (CDI), which has become the standard parent checklist for measuring early language development in hearing children (Fenson, Dale, Reznick, Bates, Thal, & Pethick, 1994) and has been used with parents of children with hearing loss (e.g., Mayne, 1998).

**Stage 2: Introductory interview.** In an introductory interview with each mother, guided by action theoretical framework, mothers were asked about their experiences of having a child who is deaf, about their current goals and concerns regarding their child and their parenting, the ways in which they address those concerns/goals, and about their daily activities. The mothers were also requested to comment on how they are involved in, and attempt to influence, aspects of their child's life. (Although each child was seen regularly by a Speech-Language Pathologist (SLP), only the mother and child were involved in the actual data collection.) (See Appendix D2).

**Stage 3: Mother-child joint activity.** Following the initial interview, mothers were invited to engage in a joint activity with their child in the absence of the researcher. The interaction session included two parts. First, mothers were given the freedom to generate and direct a typical interaction activity that they engaged in frequently with their child at home (for example, playing together, conducting language activities, reading a picture book) for approximately 10 minutes. Next, the researcher introduced set of toys to the mother and child. Mothers were invited to continue to engage in a joint activity with their child for an additional 10 minutes. The self-generated and self-directed nature of the interaction allowed the dyad to engage in a joint activity using their natural, ongoing style of interaction. The mother-child activities were videotaped.

**Stage 4: A video recall procedure.** Following the mother-child joint activity, mothers participated in a video recall procedure known as the "self-confrontation procedure" in action theory (i.e., individually viewing with the researcher a playback of the interaction they had had with their child). Mothers were asked to view the interaction and to stop the videotape whenever they wanted to comment on what was taking place. Alternatively, the researcher stopped the videotape at approximately one-minute intervals and explicitly asked the mothers to comment regarding their thoughts, feelings and actions at the time of the interaction. Video recall permits participants' internal processes to be accessed. Next, semi-structured follow-up questions were asked to explore any relevant topics that may have emerged. Subsequently, the interview, interaction, and the self-confrontation were transcribed and analyzed (described below). This preliminary analysis served as the basis for the development of a short summary of mothers' joint and individual actions and goals/project. The summary was presented at the beginning of the first follow-up conversation between the mother and the researcher.

**Stage 5: Telephone log monitoring procedure.** Four structured telephone interviews were conducted monthly with the mothers for four months. The purpose of these interviews was to collect additional information regarding the parents' individual and joint actions (projects) and to discuss their progress in achieving their goals. In the telephone conversations, mothers were asked about their current goals and concerns, to describe their joint activities with their children, to describe any thoughts and feelings that they were having, and to report on goals they achieved and any barriers that they have encountered.

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Figure 4.2

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## Data Analysis

The qualitative analytic protocol of the action-project method was used (for details see Young et al., 2005). The data were analyzed according to the three levels on which action is organized, that is, goals, action steps or functions, and action elements. The analysis of all data sources (interview, self-confrontation procedure, and mother-child interaction) occurred simultaneously. All data sources were transcribed and coded from both “bottom up” (i.e., coding of specific units that make up the action) and “top down” (i.e., identification of the intentional framework, or overall goal of entire sequence of action) perspectives.

**Analysis steps.** The videotapes of the mother-child interactions were coded utilizing Transana Software (available on line: <http://www.transana.org>). All mother and child verbal and non-verbal behaviors during the joint activity were transcribed. There were four general steps in the analysis process:

1. The identification of both the mother’s and child’s overall joint intention for the action, which we labeled as the intentional framework, based on a thorough reading of the mother’s interviews and the video recall transcript and viewing the videotape of the mother-child joint activity.
2. A detailed analysis of the language (verbal and non verbal) and behavior of the joint interaction. The mother-child interaction sequence was divided on the basis of the



intervals of the video recall procedure. Each interval was coded according to the three levels on which action was organized, that is, goals, action steps or functions, and action elements for both the mother and the child. The actual words, expressions, and behaviors used in the interaction (i.e., the elements) were coded using labels such as *asking question* and *showing*. Then the elements were grouped into functional steps or means that the participants used to reach their goals. The goal for each interval was identified, while incorporating both information from the participants' behaviors and, for the mothers, information from the video recall procedure. This process ensures the integration of manifest behavior, internal process, and social meaning in understating action. Furthermore, the mother and child joint action was analyzed at the dyadic level, where any change in goals and/or functional steps between the mother and the child were noted. This process resulted in description of the goal regulation process. (See example of the analysis in Table 4.2.)

3. An action theory content analysis of the transcripts of the telephone conversations. The final analysis was based on the whole data set for each dyad. The purpose of this analysis was to describe the process of the joint actions over time (5 months). The actions taken by the participants over time were identified. Attention was paid to each mother's reports on her emotions, cognitions and attributed meaning attached to actions and her evaluation of the progress of the project and its associated outcomes.
4. Summary of all the analysis steps, resulting in a narrative description of each dyad's overall project, goals, functional steps and outcomes and, similarly, at the level of the specific joint action of the observed mother-child interaction. Both broad and detailed analysis were brought together to form an understanding of the individual and joint

action of mother and their children. A summary of the result for each case was written using action theory framework. A shorten version of the narrative summary of the analysis is presented for each case in the finding section.

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Table 4.2

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### **Trustworthiness of the Research**

A discussed by Young et al. (2005), the action-project method meets Lincoln and Guba's (2000) arguments regarding validity and rigor in qualitative research. Having three distinct types of data, that is, behaviors, recollected internal processes, and attributed social meaning, the method readily meets the criterion of triangulation. In addition, the parents in the study had the opportunity to react in detail to their data and our interpretation of it on two explicit occasions. They reviewed their joint action with their child during the video recall procedure and they heard and responded to our initial identification of the joint action/project, based on the analysis of the video recorded action and the video recall interview, in the first telephone conversation.

Furthermore, the transcription was created by a well-trained transcriber and analyzed by the first author. Subsequently, verification step took place whereby a graduate student research assistant trained in action theory research checked the transcripts with the videos, and verified the consistency of the analysis process. Finally, the second author reviewed the analysis for integrity and consistency and correspondence with action theory. In addition, the analyses were repeatedly reviewed and discussed by the authors. Mothers had the opportunity to discuss the

data and findings throughout the monitoring periods, especially in the self confrontation and the first telephone interview, and were directly involved in the formulation of their own project.

## **Findings**

The findings presented here illustrate the dimensions of goal-directed individual and joint action and projects that two mothers engaged in over time with their young children following cochlear implantation. The action theoretical framework is used to report the findings for each of the two cases. Each case analysis is considered at each level of the hierarchy of action systems, structures, and perspectives, described above. First, for each case, the short-term mother-child joint action is described, as this joint action is considered as part of a series of actions that ultimately are in service of the overall project. Careful attention is given to the goal regulation process during the mother-child joint activity. Next, the summary of the mother-child individual and joint actions over time underlining the overall identified project occurring over a mid-term period of time, that is, from the beginning to the end of monitoring, for a total of 5 months, is described (based on all gathered data sources).

### **Narrative of Case 1: Hanna and her Mother**

Hanna, a 39-month-old girl, is an only child who lives with her parents. Hanna's profound hearing loss, the cause of which is unknown, was diagnosed when she was 10 months old. Hanna does not have any known additional disabling conditions. She had been participating in an early intervention program since she was 12 months old. She received a CI at 21 months of age, that is, 18 months prior to the start of participation in this study. The cochlear implantation surgery went well, without any complications. At the time of data collection, Hanna attended day care three times per week and visited the intervention center for speech therapy once a week.

Regarding communication modality at home, Hanna's parents initially focused on total communication. However, oral communication has gradually been used following the cochlear implantation. At the time of the study, they used speech with some signs to support her spoken language. Hanna's current productive vocabulary includes 512 words (based on her total score on the CDI). Hanna's mother is currently not working in paid employment, and her father works full time. Hanna's parents are both hearing.

**Illustration of mother-child joint action process.** The mother's overall goal in the joint action was to engage her daughter in a play activity that provided opportunity to expand the daughter's knowledge and promote her language development. This goal related to the mother's parallel goal of facilitating and supporting Hanna's learning and understanding according to her needs. The daughter's overall goal throughout the joint action was to engage with her mother in a play activity and to solve the different problems introduced by the activity. In addition, the daughter asserted her own independence and demonstrated other goals through her actions, including indicating and pursuing her own desires, choices, and plans, and expressing her needs.

The mother-daughter joint action was characterized by a high degree of cooperation and a positive tone. Both mother and daughter executed their goals by regulating their actions throughout the joint activity. In this goal-regulation process, the daughter moved between being responsive to her mother's leading and asserting her own goals. She then moved between her goal to engage with mom in play, by collaborating with her mother, following her plan, and listening and responding to her questions, and her goal to follow her own interest and choices by initiating and indicating her desires. The mother adjusted her actions based on Hanna's actions and feedback, for example, her expressed interest and needs and the mother's evaluation of her understanding. Evidence of this regulation process was found in the mother's consistent goal to

maintain her child's engagement and involvement in the joint activity. The mother attained her goal by following the daughter's interest and choices. As the mother stated in the self-confrontation: "I'm looking at her, when we're working with something to see if she's interested in it or not because I won't stick with it if she's not interested..." In this way, the mother tried to balance taking a lead and following Hanna's interest. For example, after introducing and reading the "Good Night Teddy" book, she followed her daughter's lead while Hanna explored the book independently, flipping through the book several times. Furthermore, to maintain Hanna's engagement, the mother recruited her attention, responded to her intentions, desires, and emotional states. She, expressed interest, requested and asked questions, provided encouragements, and actively played with Hanna.

Another component related to the process of goal regulation was for the mother to maintain Hanna's satisfaction and prevent frustrations. The mother provided support and assistance, took her daughter's perspective, and expressed warmth and humor whenever she corrected her (see example below, which includes the coding of elements in italics).

Hanna: points to an object on the board and raises her gaze toward mom [*asks for confirmation, responds, provides information*]

Mother: No [*disagrees*] that's an octopus [*provides information, labels*]. You don't wipe your face with an octopus [*provides explanation*] funny girl (touches child's cheek) [*uses humor, expresses warmth*]. Look [*directs attention, points*]. What's in this area? [*asks question*] This is the picnic table [*points on the board, directs attention, provides information*]

Furthermore, in the self confrontation the mother stated: "Even though she's put the eyes on the side of the head (playing with Mr. Potato Head), I think ... if that's what she wants, that's fine because that's her imagination. ...as long as she's happy and she's playing...she's doing fine."

Throughout the joint activity, the mother instigated additional actions, related to both her overall goal to expand Hanna's knowledge and her own perceived "teaching role" steered by the activity. For example, when Hanna played with Mr. Potato Head, the mother reflected in the video recall: "This is a great way for teaching her about body parts," or when reading the book "Good Night Teddy," the mother made associations to Hanna's daily life. As the mother reflected: "I was showing her that, you know other, other people do what she does before she goes to bed. Ah, so it, it's just a normal routine that every child usually does. ... to let her know that she's not the only one that does it, it's normal." It seems that the mother had an additional goal to convey to the daughter that she is not different from other children.

Mother: ...Teddy's having a bath like "Hanna" has. What's that? What's that?

Hanna: Quack. Quack.

Mother: Quack. Quack. Brushing, Teddy's brushing her teeth. You like doing that too, don't you? *(Pause)* Oh, Teddy's got to come out here. Teddy climbs on Daddy Bear's lap for a bedtime story. He's sitting on Daddy's lap, see. What you do? You sit on Daddy's lap.

Okay. Teddy gives Grandma Bear, mommy bear a big hug. Big hug That's what you do to Mommy, you know, too, at night.

Hanna: animates Teddy - puppet in the book - doing those actions as she reads

Mother: Teddy snuggles into bed all warm and snug. Goodnight Teddy.

The mother's actions reflected her cognitions about the way one should support the learning of children with CIs. As the mother mentioned in the interview, "You have to be in the

child's world, expose them to new experiences and information, visual learning, modeling, repetitions, opportunities to practice, support when frustration arise, positive reinforcement, feedback and, give them time to solve problems – be patient.” For example, when the daughter kept going over the book several times, her mother observed her actions, provided descriptions of Hanna's activities to her, made associations with Hanna's experience, and verbalized, labeled and narrated. In the self-confrontation, the mother said: “They say the biggest thing with a child is repetition. So that's why I think maybe where my patience comes in. Like it didn't bother me she could have done the book again, for a third time....”

**The joint project** of Hanna and her mother was characterized by various taxing subordinate goals including promoting Hanna's language development and enhancing her literacy skills, advancing Hanna's social interaction skills with peers and adults, raising Hanna's awareness of and teaching specific strategies regarding personal safety, and preparing Hanna for changes in her daily routine, that is, transition to school. All these goals and related actions over the period of the current study had a common goal as understood by the mother, that is, preparing Hanna for the near future specifically for the transition to pre-school and later on to the public school system. The project was delineated by the mother; however, it was a cooperative project, as both mother and daughter engaged in the actions which comprised the project, and Hanna was responsive to the mother's initiations and highly involved in the series of their joint actions.

**At the level of meaning**, the mother perceived her daughter as being “prepared” by Hanna's having adequate social skill and communication competence that together would enable her to achieve integration within a mainstream school environment and ensure her well-being. The project was emotionally energized by the mother's concerns and by her hopes for her

daughter's future. These concerns related both to Hanna's functioning and developmental process and the mother's role as a parent. The mother was especially worried about whether Hanna had the capacity to develop satisfying peer relationships, to fit in, for example, not be teased, and achieve full integration in the hearing world. She felt anxious about whether Hanna would succeed in school, both socially and academically, and receive appropriate services to support her progress. The mother stated, "I am sure that when she will go to regular school there will be challenges, because we heard that we have to advocate for her all the time, until she can do it for herself, which we will try to do at an early age."

The mother was worried and afraid for Hanna's safety. For example, the fact that Hanna cannot hear her from a distance when not using her implant when playing at the playground could present a potential risk factor. Consequently, the mother reported a goal of increasing Hanna's awareness of her surroundings and maintaining her signing abilities "as a safety precaution." The mother was also concerned about the adequacy of her parenting skills, often asking herself, "Am I even doing it right?" She described situations when she worked with Hanna on certain skills and saw no progress over time. As a result, she felt frustrated, discouraged.

It appears that the project had significant relevance for the mother's parenting identity, as part of her own *parenting project*, and for her daughter's identity. The mother perceived parenting a child who is deaf as both challenging and enriching and that there was a great need to be protective and persistent. She believed she has become a better parent and developed a deeper capacity to deal with challenges and "not to take things for granted." This mother experienced identity growth and development through engaging with her child. She also believed she had a significant role in Hanna's habilitation and that this role has contributed to Hanna's apparent



progress. Being involved in Hanna's habilitation process, the mother adopted a "teaching role." This new role fit alongside her "being her mother" role, where her main goal was to ensure Hanna's well-being. With regard to the daughter's identity, the mother's goal was for Hanna to have a strong character, for example, high self-esteem and self worth, believing that she could achieve anything she wanted to, and live her life as normally as other children.

**At the level of functional steps and steering process,** the mother functionally engaged in this project by involving her daughter in various activities where the latter had the opportunity to expand her knowledge, gain new experiences, and practice her abilities. In addition, the mother taught Hanna new skills according to goals she had jointly constructed with the professionals who worked with Hanna, for example, playing games to improve her speech production and expand her vocabulary. The mother orchestrated peer-interaction opportunities where she was able to guide her daughter to behave in a socially acceptable manner by sharing toys, taking turns, and repeating herself when she wasn't understood by others, and to practice the pragmatic use of language in everyday contexts, for example, greeting exchange. In addition, the mother made specific plans in preparing Hanna for upcoming changes by providing information, setting expectations, creating familiarity with both new environments and routines, for example, a different teacher, different teaching style, and school environment. Furthermore, the mother acted as an advocate for her, for example, requesting the local municipality to set speed bumps in their neighborhood and meeting with Hanna's future teacher to educate her about CIs. At the same time, Hanna was functionally engaged with her mother by participating collaboratively in mother-initiated activities and demonstrating interest and motivation.

**At the level of behavior, structural support, and resources,** there appeared to be several structural supports and resources to carry out this project. The most salient resource that was

explicitly identified by the mother was the availability of social support from both professionals and family. The mother's relationship with Hanna's SLP was helpful. The SLP offered reassurance, guidance, and helped the mother to refine her parenting and teaching goals. The mother also consulted with Hanna's day-care teacher, her spouse, her extended family, and other parents: "I have a very good team to work with – we (i.e., she and husband) are the lucky ones." Another resource was the availability of time the mother and daughter could spend together. In order to support Hanna's habilitation process, the mother quit her job and devoted herself full-time to supporting Hanna. In addition, Hanna's character and temperament supported the implementation of the mother's plans.

In terms of *process over time*, the project remained salient from the mother's perspective throughout the 5-month involvement in the study. Throughout the monitoring period, the mother reported continued progress toward achieving her goals. The mother described Hanna's progress as following: "It seems that you go along for a while, then you will get a spurt and then you will go along for a while. Nothing dramatic happens and suddenly – boom -- all these new words and actions are coming out." Thus, she indicated her understanding of this process as progressing in qualitative changes and not simply as the addition of individual language elements.

## **Narrative of Case 2: Jacob and his Mother**

Jacob, a 25-month-old boy, lives with his parents and an older brother, who also has a profound hearing loss and a CI. Jacob's profound hearing loss was diagnosed when he was four months old; the cause of the hearing loss is unknown. He does not have any known additional disabling conditions. He has been participating in an early intervention program since immediately following the diagnosis of his hearing loss. He received a CI at 15 months of age, that is, 10 months prior to the start of participating in this study. The cochlear implantation

surgery went well, without any complications. Regarding communication modality at home, Jacob's parents chose an oral communication approach, consistent with the approach of the early intervention program he attends. Jacob uses gestures and babbles when communicating with others and does not have any productive vocabulary. Jacob's mother is currently not working in paid employment, and his father works full time. Jacob's parents are both hearing.

**Illustration of mother-child joint action process.** The mother's overall goal in the joint activity was to increase her son's ability to discriminate between sounds while utilizing different strategies she had learned. A second coinciding goal was to elicit the child's engagement and interest in the initiated activities. Jacob's main goal throughout the joint action was to engage in a play activity according to his own interest and choices.

The mother-son joint action was characterized by Jacob's conditional cooperation and altering levels of enjoyment and satisfaction. This process was apparent in both the mother's and son's goals and in the regulation of their functional steps throughout the joint action. In this process, Jacob moved between being responsive to his mother's initiations or, although rarely, initiating joint engagement, that is, being involved, and asserting his own choices and interest mostly by engaging in solitary play, that is, not being involved. This course of action was energized by Jacob's emotional appraisal of the situation as pleasurable versus disagreeable. At the same time, the mother was challenged by her need to maintain Jacob's interest and enjoyment in order for him to engage in her action plan. In the first part of the joint action, that is, the mother's choice of activity, she had a very clear action plan, steered by her goal to practice speech discrimination while utilizing specific strategies. Functionally, the mother initiated the activity, took the lead, and controlled the sequence of the activity. She recognized the son's interest and accordingly regulated her actions. As she stated in the video recall

procedure: I replaced it because what I want is a reaction from him. And he's not giving it to me...he's not very interested. ... So, I move on.

The mother followed Jacob's interest as long as it was in the service of her goal. Otherwise, she restricted his action or tried to re-direct his attention. For example, when the mother and son practiced Ling's six sounds, Jacob chose to play with the snake instead of the airplane. In response, the mother followed his interest and joined him. However, when he chose to play with the horses and the barn, she did not join him and redirected his attention. At times, she had conflict around whether to continue repeating and practicing different sounds and feeling bored or changing the activity. She explained:

In this case he plays with the airplane and he plays and plays. I mean I can only say ahhh for so long and then you know you want to move on.... It is boring because you just have to keep repeating yourself. ... there's more interaction when a child can actually ask you something or wants to do something. ..in that way it's boring.

When the set of toys were offered to the dyad, the mother did not have a clear plan related to her overall goal. As she stated: "I let him play with it and I present whatever I can present, not that there's a specific goal or that I know what that I'm doing." In turn, she demonstrated more flexibility in her actions and more willingness to follow Jacob's lead, by having child-oriented goals and facilitating and supporting his actions (for example, putting glasses on Mr. Potato Head and not correcting when Jacob misplaced the arm on the top of the head of the Mr. Potato Head).

With regard to steering process, the mother utilized the auditory-verbal approach. She was aware of the abilities Jacob needs to acquire, and she was familiar with the specific exercises to practice those skills. During the video recall interview she explained:

This is one of my techniques for discrimination... In this case, drawing is a very nice way to indicate different sounds, by different lines. So the long lines are for ahh and the short lines are for buh buh buh.

The mother believed it was very important that her son continue to practice his skills. Hence, she believed that she should not force him to participate in activity against his will, but should find ways to keep his pleasure in those activities. She reflected her awareness regarding which activities increase his enjoyment and lead to further participation. For example, with regard to their play with a hopping frog, the mother said in the video recall:

He really enjoys that kind of activity. ...I see he's not interested in doing the activity where I say something and he has to imitate. He wants to see some sort of reward or, you know, something happen and that's why I, I took the frog.

The process was emotionally steered by the mother's expectations. As the mother explained in the self-confrontation, when she didn't expect her son to perform in a certain way, she felt more relaxed in comparison when she had clear expectations about his performance. When Jacob did not perform as expected, she questioned her parenting practices and skills and felt disappointment and frustration. She stated:

... it's either he's gonna do it and you'll be very happy and excited, or he's not gonna do it and there's gonna be a little disappointment. So there's a lot more emotion going on and you also feel that if you do something where he has, is supposed to do something and he's not doing it, that um, you're maybe doing it wrong, or you should do it more often, or maybe you should do it in different ways. So, your head starts to think about it a lot more and in these kinds of activities it's easier to, to do it. ...It makes me feel good that he ah, he's doing what he's supposed to do.

In addition, throughout the joint action the mother made choices based on her overriding goal of promoting Jacob's language competence. At the same time, she was aware when her actions were appropriate for his level and did not expect any particular response from him. During the self-confrontation interview she stated:

This is really advanced because here we're talking about body parts, which is something that come once, you know they're ready and they start to learn what are eyes, nose, ears. ... You know try and get the word in as much as possible. .. just repeating it. But .. I don't think he's ready for that yet... what I do is I present the names of the objects that I use. Try to repeat it as much as possible. Don't expect him to say anything or do anything, just listen basically.

The **joint project** of Jacob and his mother was about working together to promote the son's optimal oral communication competence by following and implementing clear intervention steps. The project was emotionally energized by the mother's continued hope and expectation for Jacob's eventual communication abilities and by a sense of concern and frustration around his progress. Approximately one-year post cochlear implantation, Jacob's mother had been expecting greater progress in his listening and speech production abilities than she had seen to date. These emotions of hope and expectation, in turn, motivated the mother's actions. During the self-confrontation the mother said:

I do feel frustration sometimes, we do a lot of practicing... it [language] has to come now. You do get a little bit worried, I mean after 10 months you want to see something, but I think because my experience with my other son, it is probably not as bad as some other parents who'll go through this the first time because I know the end result.

It seems that the joint project was intertwined with the mother's parenting project pertaining to the emotional regulation of her hopes and frustrations as the parent of a child with a CI.

**At the level of meaning,** the mother believed that she played a "supporting role" in helping Jacob to receive the maximum benefits from the CI and providing him the same opportunities as hearing children. She believed that in order for Jacob to benefit from his CI, he needed vast intervention. She also believed that this intervention was her responsibility in concert with professional support. Whenever she witnessed progress in Jacob's understanding or communication competence, she felt affirmed and relieved that "parenting has paid off." The meaning of the project was affirmed for her. However, she reported that parenting a child who is deaf presented various challenges and demands. She stated "being a parent of a child with a CI, there are always extra worries and there are extra concerns and extra costs...." Some of these challenges included the need to gain new knowledge about deafness and CIs and make wise decisions that had effects on both child and family life. In addition, she continued to learn to communicate with Jacob, promote his language development, and manage his CI. Emotionally, it was hard for her to accept that Jacob will "need more time to acquire language in comparison to his peers." The mother further articulated that she played the role of advocate and educator of those who are entrusted to care for her child, such as babysitters. At the same time, one important goal for the mother was to engage with her son "just for the sake of pleasure." During the introductory interview the mother said:

I want to have fun with him. I don't want to see it as a chore or a task or. So instead of, you know, those typical routine things, I like to just turn on the radio and sing and dance together or something like that.

**At the level of functional steps and steering process,** Jacob's mother increased his awareness of different sounds by practicing discriminating sounds -- specifically, Ling's six sounds -- through the use of toys. Also, she made sure Jacob wore his CI throughout the day. She had a clear plan and strategies around how she should go about reaching her goals. This plan was informed by Jacob's SLP, who instructed and guided her. The mother believed that in order to increase Jacob's motivation to take part in language-related practice activities, she needed to maintain her child's interest and pleasure.

Pertaining to her parenting project, in order to better cope with her challenging emotions of disappointment and frustration, the mother lowered her expectation of the rate of Jacob's progress. She justified his current achievements, for example, attributing Jacob's progress to his age, to his attitude and personality, or to the fact that "for some kids it takes longer." Moreover, the mother looked for reassurance that the CI worked for Jacob through hearing tests and trying different mapping programs. She became increasingly satisfied with any improvements, even when she perceived them as minor. For example, in the follow-up interview she stated:

Sometimes I would like to see him do more, he is 2 ½ almost and would like him to say his first word. Still it is encouraging to see that he is progressing even though he is very slow. It is not really frustrating, I know that it takes time and every child is different and as soon as he starts school, everything will go a lot faster."

When Jacob failed to demonstrate progress or accomplish a task according to his mother's expectations, she tended to question her parenting practices.

**At the level of behavior as well as structural support and resources,** Jacob's behavior at times worked counterproductively to the joint project. One issue the mother faced was Jacob's unwillingness to participate in speech-practice exercises suggested by his SLP: "He's not that



interested in doing this with me ... it's hard for me to do these kinds of exercises ... have him sit down and do what I want him to do -- that is almost impossible." The mother attempted to find her own way of dealing with certain things, including incorporating practice into daily routines: "You might have to sit down with him three times a day for short periods instead of, you know, for 45 minutes, what you normally do with the speech therapy." The mother worked at being more flexible and patient as she sought to find a balance between working with her son and maintaining her "own daily life [that she has] to lead."

The mother described another challenging aspect of coping as having to deal with Jacob's "tantrums," which encompassed situations in which he expressed his anger by removing the speech processor, taking the CI parts apart, and acting aggressively. These episodes fed into the mother's parenting project, leading her to question how she should react and regulate Jacob's behavior. Some of her strategies included insisting that son wear his implant and trying different techniques such as putting Jacob in a "time-out." Her goal at these times was for Jacob to learn to behave in an acceptable way. She explained that she saw some of this behavior as part of normal development, "the terrible twos." However, it was especially challenging in light of the communication barrier; as she indicated, she cannot use language "to calm him down or to explain certain things, it's sometimes very hard."

One perceived resource in carrying out the project is the mother's previous experience with her older child. This experience increased her assurance with regard to Jacob's future progress and provided her with necessary skills and knowledge in supporting Jacob. She stated, "I feel good about the way I work with him. I know better what I need to do." Having this experience lowered the mother's degree of anxiety and uncertainty. Another *resource* was Jacob's SLP, with whom the mother jointly defined goals and action plans around promoting Jacob's language

development. As the mother reflected: "We decide together what is the next step and what we should work on it, do it together. [The SLP] gives me an expert advice on language and as a mother; I fill her in, on what kind of child Jacob is."

### **Overall Findings**

The findings demonstrated that mother-child behavior together following a CI can be understood as goal-directed action. The mothers engaged in joint and individual meaningful processes that they understood as facilitating their children's progress and development following a CI. Thus, we were able to identify a joint parent-child project. In both cases the projects were determined by the mother, and the child was brought in at the functional level; for example, the children engaged in different tasks with their mothers, and at the behavioral level they produced words, imitated, repeated, and answered questions. In addition, it appeared that some of the meaning of the project for the mothers was constructed between the mothers, the professionals working with the child, and other members of the family, and this meaning had an influence on the parent-child joint process.

In both cases, the projects can be described as being "focused" that is, being well-defined, having explicit goals and congruent functional steps (Young, Logan, Lovato, Moffat, & Shoveler, 2005). Similar to previous research where parents' strong commitment was found to be linked with involvement in a focused project (Young et al., 2005), both mothers demonstrated a strong commitment to pursuing their goals, which included investment of time and effort in "working" with their child on skills development. At the same time, in Case 1, at the meaning level, the project had a broader intentional framework, envisioning the child's future life and well-being in the hearing world, whereas in Case 2, the project was operating under a narrower

intentional framework – the child's ability to use spoken language -- focusing on specific steps that needed to be achieved.

In the current study, in both cases, the mothers were also engaged in a parenting project, that is, "the series of goals and actions through which the parent's role as a parent was constructed" (Young, Ball, Valach, Turkel, & Wong, 2003, pp. 297-298). Both mothers constructed their parenting identity and role as having a child who is deaf. It seems that having a child with a CI altered the meaning of parenting, sometimes forcing the mother to be "the teacher" of her child, while at the same time maintaining images of the parent-child relationship that are not defined by the child's hearing capacity. For both mothers it was meaningful to establish a pleasurable "normal" mother-child relationship and to have an emotional connection with their child. In this regard, while Hanna and her mother shared this goal in their joint actions, Jacob and his mother experienced more challenges in the implementation of an action plan that focused on the quality and nature of their interactions. In addition, parenting projects encompass an evaluation function toward the construction of parenting identity. In other words, successful attainment of goals in the joint project operated as a resource in constructing positive perceptions of parenting competence and feeling pride and satisfaction in the parenting role. On the contrary, when the project wasn't productive, it provoked parents to question their parenting.

These cases provide evidence of emotion as having an important role in parent- child joint actions at different levels of action (Young, Paseluikho, & Valach, 1997). At the goal level, emotion influenced meaning; for example, Hanna and her mother's joint actions were driven by their shared joy while engaging with one another. On the other hand, Jacob's mother's frustrations around his progress and behavior posed a challenge for the project's progress. In both cases, it was also evident that emotion functioned as a steering process, guiding and

directing actions. In Case 1, the mother's investment and efforts in working with her daughter to support her language and social competence were guided by her caring for her daughter's emotional well-being and her concerns regarding her daughter's future functioning and inclusion in school. In Case 2, the mother's actions were guided by her continued hope and expectation for her son's eventual communication abilities and by a sense of concern and frustration around his progress.

Further, emotions also functioned in the self-regulation of behavior. In Case 2, the son was responsive to his mother's initiations based on his appraisal of the situation as being pleasurable versus displeasure. The mother decreased the level of interest in some of the activities and her concern in accomplishing other actions impeded her responsiveness and supportiveness of her son's initiations. In contrast, in Case 1, the mother adjusted her actions in order to promote her daughter's happiness and maintain her engagement in their joint action.

Lastly, the importance of the availability of resources for the projects was apparent in both cases. In Case 1, the mother's sources of social support, for example, family members and professionals, and the child's characteristics facilitated the project's progress over time. In Case 2, the mother's knowledge and previous experience helped her face various challenges and provided her with skills to construct goals and action plans. At the same time, in this case the child's tantrums and level of interest hindered the project's progress over time.

The findings suggest that parents of children with CIs share similar challenges faced by parents of deaf children in general, including modifying communication strategies, working with professionals across a range of disciplines, learning about technological supports, and obtaining appropriate intervention programs and services (Calderon & Greenberg, 1993; Meadow-Orlans & Sass-Lehrer, 1995). It seems that parents define their actions based on their children's needs,

whether they are learning American Sign Language or adjusting to hearing aid or to a CI. What seems to be different in the case of adjusting to a CI is the intensity of parental perceptions of their need to be involved in the habilitation process of their children and their high expectations for their child's progress. The current findings are consistent with a large body of research (e.g., Christiansen & Leigh, 2002) that point to the necessity of intensive, long-term habilitation efforts after the CI in order to help ensure the effectiveness of the whole procedure; the fact that parents perceive the habilitation program as very intense, demanding, and of long duration; and the sense that parents hold high expectations with regard to their child's communication, social, and academic abilities (Wiesel et al., 2007; Zaidman-Zait & Most, 2005). Moreover, the findings support the reflections of Wiesel et al. (2007) that "parents often invest tremendous effort in the CI process and tend to develop high hopes and expectations" (p. 62). This observation should be treated cautiously as our study was intended solely to describe the experience of parents of children with CIs. In addition, high parent expectations likely stem from very natural emotions – parents' hope that their child's cochlear implant will result in successful outcomes. These expectations and hopes serve a positive function. They operate effectively to inspire goal orientation and hence direct parents' future actions and motivation (Zaidman-Zait & Most, 2005).

## **Discussion**

In the current study we sought to elucidate the use of the action theoretical framework and the action-project method to describe the individual and joint actions and projects related to parents' involvement in their children's habilitation process following cochlear implantation. The findings are unique because for the first time the notion of intentional, goal-directed project

and joint activity as part of parental involvement have been identified and described. This work advances our understanding of parenting children with CIs by offering a practical and theoretically grounded description of processes at different levels of action.

The use of action theory and its related method in the current study represents a shift in epistemology in deafness studies. As stated by Young et al., (2005 p. 217) "at its heart, action is an epistemology rather than a method or conceptual framework," moving beyond the search for causal explanations (for example, parenting variables that affect children's language development). This shift illustrates an alternative approach to observing parents' and children's behaviors in the context of their daily life, looking at the processes through which parents construct meaning. In this way, action theory contains a system of knowing that underlines the notion that knowledge and meaning are provoked and constructed through action (Young et al., 2005). In addition, such an approach privileges parents' epistemological positions by enabling them to reflect on their personal and social meaning and their thoughts and feelings through their intentional engagement in projects. Parents implicitly or explicitly answered the question, "What is this (action) about?" (Young, Valach, & Marshall, 2007). Parents in the current study understood and engaged with their children in joint activities that they considered as goal-directed and meaningful. They interpreted their own and their child's behavior as intentional and goal-directed.

From the rich descriptions and analysis of the cases in this study, we can draw potentially illuminating implications for the "current thinking" in relation to parenting children who are deaf, and specifically children who are using a CI. The promotion of child outcomes project stands as the most salient joint projects identified in this study. This project relates both to the medium- and long-term effects on the child's progress including, for example, improving the

child's speech production at one end and achieving social inclusion in the hearing world at the other end. As suggested previously (Geers & Brenner, 2003; Spencer, 2004), parents play a significant role in the habilitation process. The findings of this study extend this notion by illustrating how parental involvement is manifested as a continuous joint process. Both parent and child are active agents contributing to, and bringing goals into, parent-child interactions and relationships. Furthermore, both parent and child affect and are affected by the other's behaviors in a given action and across time (Harach & Kuczynski, 2005) while utilizing strategies to achieve their goals (Kuczynski, Harach, & Bernardini, 1999), and are jointly engaged in the co-construction of meaning through action (Young & Valach, 2004).

Identifying and distinguishing between individual and joint goals and between goals and the functional steps to attain them offer important insights into the complexity of parental involvement in the habilitation process as it unfolds over time. For example, Spencer (2004) identified several indicators of parental involvement and later found an association between parental involvement and child language outcomes following cochlear implantation. Spencer's important insight into cochlear implantation outcomes is limited by reporting on parent manifest behavior from a unidirectional perspective. The results of the present study, however, describe involvement from a theoretically grounded method aimed at seeing how parents' involvement markers fit within the generation of ongoing goals, functional steps and elements. It is likely that the child's behavior, and the parent's available resources (knowledge, skills) and internal processes (perception of their parenting competence) serve to regulate this process. Another important component of these findings is an understanding of the process of parents' goal regulation over time and moment-by-moment during their action with their child. This coincides

with Dix and Branca's (2003) theoretical model of the organization of parent behaviors based on goal regulation systems.

The current findings illustrate that parents' actions were embedded in complex interweaving projects (i.e., parenting, parent identity, child competence, and child welfare) and goals. For instance, there was a unique challenge for parents to balance goals between those related to parental responsibilities evoked by the CI habilitation demands on the one hand and those around the maintenance of an overall enjoyable relationship with the child on the other. It seems that successful steps toward accomplishment of this balance served to enhance parenting projects and were related to the parents' sense of competence in their overall role. The complexity of projects has also been observed previously. Young et al. (2001) found that family career development projects had multiple goals and were embedded in the parent-adolescent relationship, parenting, adolescent identity, culture, and other projects. Validation of concurrent projects and the exploration of the dynamic interdependencies between projects will advance our understanding of the complexity of issues and demands faced by parents.

### **Methodological Strengths and Limitations**

There are substantial methodological merits in the use of the action project method (Young et al., 2005). In contrast to other qualitative research methods, in action theory data are sought from three perspectives rather than just one. Observing mother-child joint action provides primary access to the manifest behavior of the action and the self-confrontation procedure has the particular advantage of accessing internal processes and meaning. Finally, the interview provides access to a retrospective report of everyday activity and related meaning and internal process.



Although extensive and rich data were collected for each case, we acknowledge several limitations in the data collection protocol. In describing the parents' individual and joint action and projects over time, we have included only one observation session with a self-confrontation procedure. In addition, projects were monitored over a relatively short time period, utilizing a monthly interview. Hence, it is possible that the data collection may not have captured all of the pertinent actions that contributed to the projects described. Future research should seek to investigate projects over extended periods of time and include several observation sessions that include a self-confrontation and parents' written reports of their actions during the follow-up time period. Moreover, given the time that research of this nature takes to conduct, and the depth of analysis that occurs for each participant dyad, and the difficulty of recruiting subjects, it is somewhat impractical to use the procedure with samples that would be considered large by quantitative research standards. Conducting case studies is sufficient to obtain a good range of experience and suggest implications for practice. However, it is likely that some patterns and constructs underlying the experiences of different families will be missed due to limited sample size.

### **Directions in Future Research**

The current findings highlight the significant role of emotions at all levels of action (meaning, function and behavior), as energizing steering process, and in the regulation of behavior. The affective salience of parenting has recently been addressed (e.g., Dix, 1991, 2000; Stern, 1995). However, much of the previous research in deafness has explored only a narrow range of emotion-relevant constructs; mainly parenting distress, depression, and parental stress (e.g., Meadow-Orlans, 1994; Quittner et al., 1991) and has ignored the examination of parents' internal affective experience and specifically parents' emotional experience while interacting

with their children. The use of action theory and its method allows researchers to explore parents' affective experiences that are embedded in parents' actions and their interaction processes with their children. Understanding the affective experiences of parents might introduce possible explanations for the inconsistent findings regarding parental stress (Lederberg & Golbach, 2002; Pipp-Siegel, Sedey, Yoshinaga-Itano, 2002) and for parents' behavior while acting jointly with their children (e.g., Jamieson, 1995). Moreover, it might help in providing explanations that go beyond listing possible fixed factors that explain stress, such as the child's communication ability, availability of social support, and child's age. For instance, in the current study, it seems that children's responsiveness to parents' initiations increased parental satisfaction, whereas children's slow progress or disengagement led to parent disappointment and parental feelings of incompetence. Gaps or conflict between goals, functional steps, and behaviors that occurred in joint activities and projects might increase parental stress. The experience of stress could be related to the parenting project and the child's habilitation project, and might even act to energize these projects. Examining stress and emotional experiences from an action theoretical perspective would have significant contribution to both theory and practice. Furthermore, the action theory approach also has the advantage of being well suited to examining *processes*. Through the identification of projects and following them over time, one is able to identify changing perspectives, whether progress has been made, what kinds of activities parents and children engaged in, and how different projects meshed (Young et al., 2001).

### **Implications for Practice**

Based on parental accounts, it seems that parents and professionals also co-constructed joint projects that focused on the promotion of the child's outcomes following cochlear implantation. These projects also included constructing an understandable parental role in this

process. Indeed, previous literature indicates that close mutual relationships between families and professionals in early intervention are crucial for achieving both improved parental coping and involvement in the habilitation as well as improved outcomes for the child (Dromi & Ingber, 1999; Hadadian & Merbler, 1995; Minke & Scott, 1995; Vernon & Wallrabenstein, 1984). Moreover, it has been reported that parents of deaf children rely greatly on professionals as sources of support (Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Quittner, Glueckauf, & Jackson, 1990), that professionals facilitate parents' coping experiences (Zaidman-Zait, 2007), and that professionals and parents of children with CIs engage in collaborative everyday problem solving (Zaidman-Zait, submitted). The current results suggest further extending notions of the parent-professionals relationship to one that focuses on parents' and professional's co-construction of meaningful processes and outcomes through short-term joint actions and mid-term projects. The conceptualization and facilitation of parent-professional joint projects presents an intriguing and potentially heuristic direction for future research.

The philosophy of family-centered early intervention emphasizes families' strengths rather than deficits, the empowerment of parents to support their children's current and future learning and development, and the enhancement of parent-professional collaborative relationships (Bruder, 2000; Dunst, Trivette, Boyd, & Brookfield, 1994). If family empowerment is a desired outcome of early intervention programs, then, accordingly, adopting an agentic perspective in practice and research is warranted. As illustrated in the current study, action theory provides insight into the daily actions and processes of parents and children that foster the enactment of agency. Our view is that parents, in concert with important others (their children, family members, and professionals) take an active stance toward their parenting practices and the promotion of their children's outcomes following cochlear implantation. This understanding

allows professionals working with families to consider parent promotion of child outcomes and related projects as intentional, goal-directed, and hierarchically organized system process. From the perspective of promoting families' strengths, parental projects can be viewed through a positive frame, by asking what allows parents to be motivated in their projects and to find meaningfulness in their actions (Young & Valach, in press). Moreover, by using action theoretical language, professionals can empower parents by helping parents understand themselves as self-responsible, meaning-making, and goal-directed agents. Last, action theory integrates meaning, cognitive processes, and behavior in a way that is close to human experience and is, thus, highly useable in intervention with deaf children and their families. It presents important possibilities for helping deaf children and their families understand the habilitation process as it is situated within daily contexts, as well as a way to understand how ongoing actions serve to construct successful outcomes over time. The latter could be one of the most relevant advantages of using this approach in the professional support of such families. Sharing a conceptual frame, that is, adopting a conceptualization which is rooted in an everyday theory of action, helps professionals speak the same language as the parents and implement scientific knowledge in a way parents can apply in their everyday life.

Table 4.1 The Three-Dimensional Conceptual Framework of Action: Action Systems, Levels of Action, and Perspectives on Action.

	Concept	Definition	Example
Action Systems	Individual action	Specific goal-directed behaviors that occur in contiguous time by an individual	Reading information on a web-site
	Joint action	Specific goal-directed behaviors occurring between people	Having a conversation, playing a game.
	Project	Series of actions, having a common goal, linked across a mid-term length of time. A project is something that an individual or people jointly and intentionally work toward for a longer period.	The joint project between the son and his mother appears to be focusing on and developing the skills and abilities that will help the son to communicate easily with others.
Levels of Action	Elements	The specific conscious and unconscious verbal and non-verbal behavioural elements that are involved in the performance of behaviour.	The action of having a conversation may involve elements such as statements of opinion, question statements, smiles, sitting on a carpet.
	Functional steps	A sequence of contiguous elements that have a common function. Functional steps are the intentional means by which each participant moves towards their goals.	Functional steps in a parent-child joint action may include eliciting child engagement, directing child's attention, and regulating child's behaviour.

Table 4.1 (continue from previous page)

Concept		Definition	Example
Perspectives on Action	Goal	Goals are the general, overall intentions and purposes of people who are engaged in the action. A goal represents the meaning of action processes.	The goal of a parent during a play activity with his child may be to have enjoyable interaction.
	Manifest behaviour	The observable sequence of behaviour that is involved in carrying out an action.	Sorting cards game according to their colours, reading a book.
	Internal processes	The subjective thoughts and feelings that a person is experiencing during the action.	A parent/child might feel: Happy, frustrate, irritate, angry
	Social meaning	The explanations that people give when describing actions to others, including the intentions and purposes that they provide about the action in question.	A parent explains his actions: "I was trying to check whether my child can label the different objects in the picture."

Table 4.2. Interval from the joint activity of Jacob and his mother, Analysis, and Video Recall

Case 2: Interval #5 (coding of elements is in italics)	Mothers' functional steps and goal	Child's functional steps and goal	Mother's report on internal process
<p>M: What are you looking for? [asks question]</p> <p>J: looking at the toys in the box [investigates objects]</p> <p>M: What's that? [pick a cookie, asks question] Yummm. Yummm.[makes sounds] You want some? [asks question, offers object to child] (Pause) Yummm. [makes sounds, repeats]</p> <p>J: not responding to mother. [spreads the toys and pick the snake] Ahooooooo [makes/demonstrates sounds]</p> <p>M: Shhhhhh. Sssssss. [makes sounds]Don't bite me [requests]. Sssssss. [makes sounds]</p> <p>J: moving the snake towards his mother[operates the snake]</p> <p>M: Ow. Owwww [makes sounds] that hurts. [describes the effect of child's action]</p> <p>J: [stands and walk away ]</p> <p>M: Come over here sweetie [request,</p>	<p>Functional steps: Practice difference sounds, elicit engagement, respond to child's initiation, reflects and enact child's action, regulate child's behavior</p> <p>Goal: Increase child's level of interest, Engage child in joint activity, to learn to discriminate and produce different sounds</p>	<p>Functional steps: Animates object (makes sounds, operate object),</p> <p>Goal: Engage in play following his interest and to involve mom in play (at times).</p> <p>Note: The son shifts from engaging in solitary play with objects following his interests (e.g., playing with the horses, play with the toys in the box) and engages with mom when he is interested in the activity the mother initiates (e.g. the hopping frog) or when he invites mom to engage in his interest (e.g. snake)</p>	<p>I think he, he's just having fun especially if it's something where he can get a reaction from me....</p> <p>It's either he's gonna do it and I'll be very happy and excited, or he's not gonna do it and there's gonna be a little disappointment. So there's a lot more emotion going on and you also feel that if you do something where he has, is supposed to do something and he's not doing it, that um, you're maybe doing it wrong, or you should do it more often, or maybe you should do it in different ways. So, your head starts to think about it a lot more and in these kinds of activities it's easier to, to do it....</p> <p>Practicing with him sometimes comes natural because I went through the process already (with the other son)...sometimes I think, oh this is a good moment to</p>

Table 4.2. Interval from the joint activity of Jacob and his mother, Analysis, and Video Recall (continue from previous page)

Case 2: Interval #5 (coding of elements is in italics)	Mothers' functional steps and goal	Child's functional steps and goal	Mother's report on internal process
expresses warmth]. Come here [repeats request]. Come sit [rephrase request, situate child beside her]. Come play with me [requests, elaborates].			introduce...it's mainly in this way, where I just present sounds and not so much where I expect from him.
J: moves snake			I use the same objects as the speech therapist uses because I'm afraid if we differ too much then he will not really get the activity. So we have decided that the ooh sound will be a train etc.
H: Sssssssss. Sssssssss. Owwww. Sssssss [enact, parallel to child's action]. [makes sounds]Its gonna bite my finger [describes partners action]. Owwwww [makes sounds](Laugh)			
J: (Laugh)			



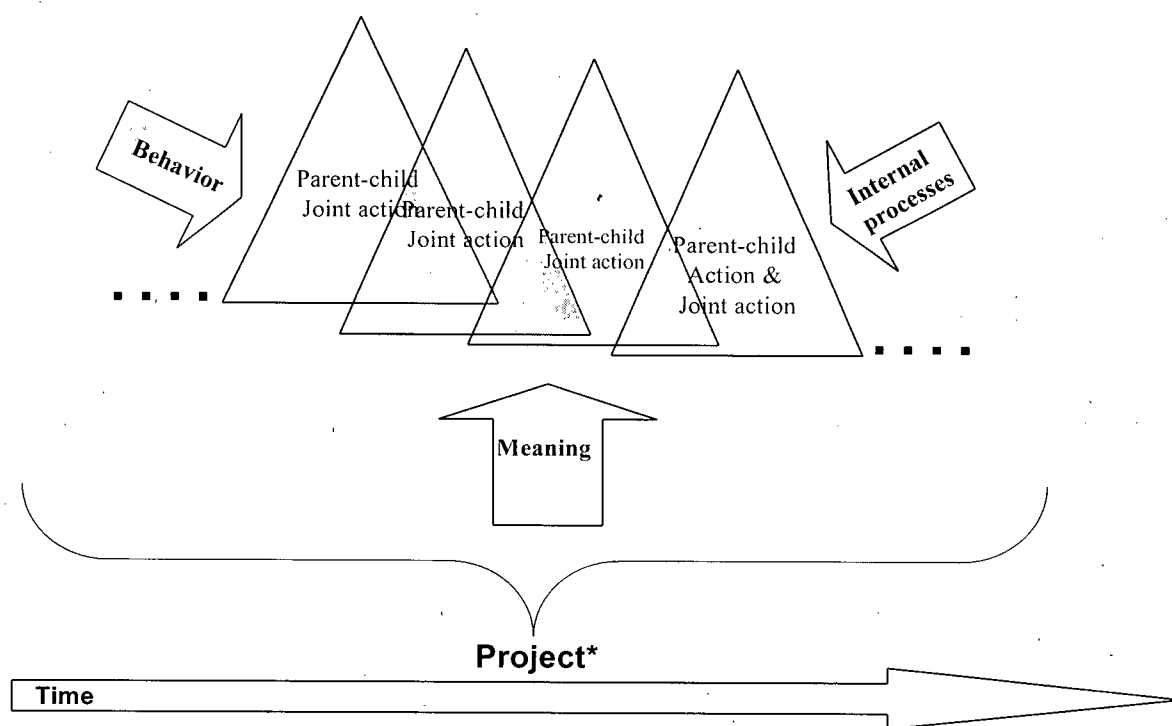


Figure 4.1 Joint actions across time from multiple perspectives.

\* **Project** refers to series of actions, constructed as having common goals, are linked across a mid-term length of time

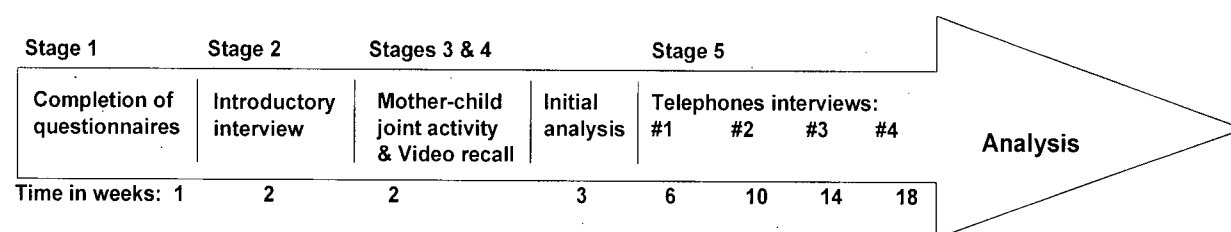


Figure 4.2 Stages of data collection across time.

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## **Chapter 5**

### **Discussion**

The central goal of the current dissertation was to investigate and describe the experiences of parents of children with cochlear implants (CIs). The first study (Chapter 2) explored parents' everyday problems and their experience of stress associated with parenting a child with a CI. Parents were asked to report, via open format, on their everyday problems within the specific context of parenting their children with CIs. In addition, parents were asked to describe with whom they jointly worked to solve their problems. The second study (Chapter 3) asked the question: What attributes facilitated mothers' and fathers' coping with this parenting experience? Mothers and fathers of children with CIs were asked to describe critical incidents that helped their coping process. The third study (Chapter 4) described the individual and joint actions that mothers engage in with their young children, over time, as a response to the changes and possibilities brought about by the CI. Mothers' actions were described from different perspectives, including their manifest behaviors, functions, internal processes and meanings. In the current chapter, I will describe some of the commonalities (described as themes) emerging from the findings of the three studies. These four overarching themes that emerged include a) parenting experience: taking context into consideration; b) interpersonal relationships: a coping resource; c) parental Self-appraisals and perceptions; and d) child behavior, parental stress and coping. The discussion of each of the themes will be followed with implications for practice related to each theme.

### **Parenting Experience: Taking Context into Consideration**

Taken together, the findings of the three studies strongly suggest that the experiences of parenting a child with a CI are determined by various sources of influence associated with social contextual aspects, with the parent himself or herself, with the child, and the interactions between them. This pattern of findings is consistent with conceptual ecological models of

parenting, such as Bronfenbrenner's (1979) ecological approach, which outlines multiple factors that may influence parenting, and Belsky's (1984) process model, which provides a framework for addressing three domains of determinants of parental experience and functioning, including contextual sources of stress and support, parents' personal psychological resources, and the child's characteristics. Examples from the studies reflecting the above-mentioned domains include: the importance of professionals' support, the key role of sharing experiences with similar others, access to intervention services, parental sense of competence, parental knowledge, and child characteristics. The studies' findings also highlight the importance of understanding the range of stressors that are embedded within a specific context (Quittner & DiGirolamo, 1998). Parenting a child with a CI can present unique tasks and demands that must be mastered or managed by the parents. For example, parents need to acquire knowledge and have skills in order to work with their child on his or her speech production. The importance of exploring parents' contexts has been demonstrated in previous quantitative studies, which indicated that parents' stress is not a direct outcome of their child's deafness and that individual differences in parental stress stem from different characteristics of the context, the child's hearing loss, and the parents, including parental perceptions and coping resources (Lederberg & Golbach, 2002; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002).

Although the findings of the three studies emphasize the importance and relevance of context to parents' experience, the studies in Chapters 2 and 3 take a different stance than that represented in the third study (Chapter 4), which takes an action theory perspective on context. Whereas ecological theory (e.g., Bronfenbrenner, 1986) provides an understanding of how individual lives are influenced by (and influence) their environment, action theory offers a framework for examining human process embedded in context. Here, the examination of context

does not distinguish between person and the environment, but recognizes that context 'runs in and through' individuals (Radley, 1996, in Young, Lynam, Valach, Novak, Brierton, & Christopher, 2000) or is embodied within action. Context can be understood not as a 'field for action,' but, rather, as the 'field in which action takes place'; it is the action that constitutes the field and vice versa (Valach, Young, & Lynam, 2002). The joint action processes of parenting a child with a CI are understood in relation to other individual and joint action processes within a parent's life. Parents' actions are surrounded by internal and external resources (Young & Valach, in press) and that the context of their daily lives is included in their understanding of meaning (Young et al., 2000).

### **Implications for practice**

The following specific recommendations for early intervention programs and professionals working with deaf children and their families are drawn from the findings concerning the importance of taking context into consideration:

- The current research substantiates the soundness of implementing early intervention models such as the developmental system model (Guralnick, 2001) and the support approach to early intervention (McWilliam & Scott, 2001), both of which are consistent with ecological theory. In addition, both models recognize that families need various combinations of resources, social support, information, and services to help them address the stressors associated with parenting in general and parenting a child with special needs in particular.

- According to the Developmental System Model (Guralnick, 2001), children's developmental outcomes are affected by the family characteristics and potential stressors created by the child's disability. These stressors are information needs, interpersonal and family distress, resource needs, and confidence threats. It is important the intervention program include continual assessments of specific stressors faced by parents of children with CIs and provide parents the needed support and proper intervention.

### **Interpersonal Relationships: A Coping Resource**

A common theme across the studies presented in the preceding chapters is that parents managed the various stressors, demands, and challenges associated with parenting a child who has a CI in collaboration with others in their social context. Parents appeared to draw from a variety of interpersonal relationships, both formal (professionals) and informal (family and friends). The key collaborative partners identified were professionals, spouses, and other parents of children who are deaf. The importance of social support corroborated previous research (Beadle, Shores, & Wood, 2000; Calderon & Greenberg, 1999; Hintermair, 2000; Lederberg & Golbach, 2002; Meadow-Orlans & Steinberg, 1993; Quittner, Glueckauf, & Jackson, 1990) that demonstrates the importance of social support to parents' well-being and adjustment. The three studies go beyond 'causal' indicators, such as size of social support network, frequency of contact, or level of satisfaction, by providing information regarding the unique functions and features of the various supportive relationships. For example, according to the study presented in Chapter 3, other parents of a child who is deaf uniquely offered a source of compassion, full understanding, and a level of mutual trust that was not reported in the other supportive relationships. Other parents were considered a reliable ally for sharing relevant information and

community resources, furnishing tools for comparison and learning, and providing good partners for shared problem solving. Moreover, parents seem to co-construct the meaning of having a deaf child together with others, solve problems related to their child's/children's deafness in a collaborative manner, have others involved in their decision making process, and share childrearing tasks. Similarly, in the study presented in Chapter 2, parents identified a preference of collaborating with other parents. An interdependent approach offered parents the strengths of sharing similar experiences with others who have familiarity with many of the problems and who can provide emotional support and validation. Parents also had the opportunity to trade suggestions, compare solutions, and discuss options.

Spousal support has generally been deemed important in studies of families with typically developing children (Belsky, 1990; Deater-Deckard & Scarr, 1996). In the area of studies concerning deaf children and more generally in the disability literature, however, spousal support has not been differentiated from other sources of support, and has been integrated into measures of the size of and satisfaction with one's support network. The current studies' findings suggest that spousal support may be particularly salient for parents of children with CIs.

The most commonly highlighted source of support mentioned by parents across the studies was professional support. The studies highlight the importance of the parent-professional relationship for parent coping processes and for everyday problem solving. In addition, it was found that parents and professionals co-construct the parents' ongoing goals and projects, such as their joint project with their child and their parent identity project (as was reflected in the two case illustrations in Chapter 4). The above-mentioned findings also help in understanding previous findings in which parents' higher stress levels were correlated with less satisfactory relationships with professionals (Zaidman-Zait & Most, 2005).

Overall, parents appeared to rely on professionals mainly for informational support, advice, and guidance. In the study presented in Chapter 2, parents stated that professionals were important resources for parents' problem solving because of the professionals' availability, their continuous role and involvement in the child's life, their professional knowledge and experience, their provision of emotional and instrumental support, and their external point of view and perspective. In the study presented in Chapter 3, parents indicated the importance of receiving guidance regarding a range of practical matters and direct instruction with regard to the communication and interaction skills needed to help advance their children in the process of learning language. Finally, the findings presented in Chapter 4 suggest that professionals were the most salient resource as explicitly identified by the mothers. Mothers and professionals co-constructed mothers' goals and action plans around the promotion of their child's development and their parenting. Accordingly, it seems that parents and professionals engage in joint actions and projects that focus on the promotion of the child's outcomes following cochlear implantation.

Overall, the findings across the three studies reflect Berg, Meegan, & Deviney's (1998) thesis that stressors occur within a rich, multifaceted social context and are appraised and managed in collaboration with other individuals. As described by Berg et al., others' participation in parents' coping occurred by means of joint problem solving, collaborative thinking, division of labor, mutual influence, and communication. The findings of Chapter 4 also support an action theoretical notion that people engage in individual and joint actions to carry out their various intentional life projects. The majority of projects in which people engage, during their daily lives, is social in nature and, therefore, involves more than one individual (Valach et al., 2002).



These preliminary findings regarding collaborative problem solving among parents and others in their social context (spouse, other parents, and professionals) will comprise a fruitful area of research by offering a deepened understanding of the complexity of the process of rehabilitation with deaf children in the context of interpersonal relationships. Exploring the joint actions and coping strategies of parents with professionals, spouses, and other parents may explain some of the variance in child outcomes and in parenting.

### **Implications for practice**

The following specific recommendations for early intervention programs and professionals working with deaf children and their families are drawn from the findings concerning the key role of interpersonal relationships as a coping resource:

- Professionals should be aware of the importance of the marital relationship to parent involvement in the rehabilitation process (e.g., making decisions regarding the child's rehabilitation, sharing responsibilities, and communicating with health care providers). Professional preparation should provide professionals with knowledge about the importance of marital relationships and the skills to highlight this in intervention planning.
- It is crucial that intervention programs provide parents the opportunity to meet other parents who have children with CIs, in order to facilitate meeting both informational and emotional needs.

- In order to provide quality services to the parents, and thus to the child, professionals should recognize the importance of taking a collaborative role with parents during the rehabilitation program, as well as recognize their own ability to enhance and/or add to the parental stress and coping process.
- Professionals should consider integrating into their training programs and clinical practice the various support functions and specific help-giving characteristics identified by parents as of paramount importance. Help-giving practices were found to be associated with families' feelings of self-confidence or self-efficacy (Judge, 1997; Trivette, Dunst, & Hamby, 1996).
- Professionals should consider parent promotion of child outcomes and related actions as intentional, goal-directed processes that occur jointly with others, including with the professionals.

### **Parental Self-Appraisals and Perceptions**

The third major theme is that parents' self appraisals and perceptions are a key facet of parenting stress and coping. In the study presented in Chapter 2, parents reported concerns and uncertainty about adequately fulfilling their parenting roles, specifically in terms of supporting their child's rehabilitation. For example, some parents reported believing they were not doing enough to support their children and ensure their successful rehabilitation. In the study presented in Chapter 3, parents of children with implants identified parental confidence, sense of competence, and self-perceptions as effective personal coping resources. Parents reported that

having a sense of confidence in their decisions and actions increased both their commitment toward their child's rehabilitation and their feelings of hope for their child's progress in the future. Furthermore, parental sense of competence and sense of control were also reported to be a result of having adequate external social resources. Last, in the study presented in Chapter 4, mothers expressed concerns as to the adequacy of their parenting skills. Mothers' sense of confidence was threatened when their child did not respond according to the mothers' expectations or when the mothers did not see progress being made in their child's abilities. Overall, parenting projects encompassed an ongoing evaluative function that related to the construction of the parent's identity. In other words, successful attainment of goals in the joint project operated as a resource in constructing positive perceptions of parenting competence and feelings of pride and satisfaction in the parenting role. On the contrary, when the project was not productive, anxiety and doubt about parenting practices were evoked.

In sum, lack of confidence in one's parenting abilities constituted one of the major stressors to the parents in the studies. Threats to confidence and distress have potentially vast effects on patterns of family interaction, which in turn may mediate children's developmental outcomes (Guralnick, 2001). In light of this finding, the concept of self-efficacy, that is, the specific belief about one's own abilities to perform successfully and competently in a particular task or setting (Bandura, 1989), emerges as an important construct relating to parental functioning, and appears to be a notable force behind the parenting experience (Coleman & Karraker, 1998). Given the additional rehabilitation demands following cochlear implantation, parents may face the complex situation of having more responsibilities in parenting, yet lacking the necessary skills to work with their children, and feeling unable to meet the child's needs. Indeed, parents perceived the rehabilitation program as very intense, demanding, and of long

duration (Zaidman-Zait & Most, 2005). In a recent study, DesJardin (2004) found that mothers of implanted children who held high self-efficacy beliefs regarding their ability to influence their children's language development were more likely to follow through with the intervention strategies taught by their early interventionist than did mothers with low self-efficacy scores.

With regard to parents' hopes and expectations, the studies support Zaidman-Zait and Most's (2005) suggestions that parents' high expectations may serve a positive function, operating effectively as an inspiring goal orientation or intentional framework and, hence, directing the parents' future actions and motivation. In the study presented in Chapter 3, parents' appraisals of their child's deafness were modified over time and gained new meaning. This process helped parents to alter their negative emotions. In one case presented in Chapter 4, the mother's high hopes and expectations of her child's progress served to motivate her to remain highly involved in joint rehabilitation actions with her son (Case 2). Research has consistently demonstrated that an optimistic outlook toward the future fosters motivation and successful performance, whereas pessimistic thinking dampens motivation to work toward important goals and hinders successful performance (Bandura, 1997; Taylor & Brown, 1988). It is suggested that parents' cognitions motivate and organize parenting actions and, furthermore, influence the effectiveness of childrearing practices (Goodnow & Collins, 1990).

There remains much to be done on research that explores the intersection of parenting cognitions and parenting behaviors embedded in social context among parents of children with CIs. The importance of such research direction is based on the notion that parents' cognitions are guiding and steering parents' behavior -- and thereby children's behavior and development. The current studies highlight the complexity and the dynamic nature of these processes. These processes point to the need for the examination of parents' and children's joint processes over

time as part of CI rehabilitation. For example, an important avenue of future research would include an examination of the construction of parent hopes, motivation, commitment and sense of competence through parents' ongoing interaction with their child, and how this process, in turn, affects and is affected by parent-child behaviour and child progress.

### **Implications for practice**

The following specific recommendations for early intervention programs and professionals working with deaf children and their families are drawn from the findings concerning the key role of parents' social cognitions and self-perceptions for parenting stress and coping:

- Professionals working with parents must emphasize the wide variability in outcomes following cochlear implantation and, most importantly, must clearly explain the rehabilitation process to parents. This, in turn, may help lower parents' frustrations and help to maintain a parental sense of competence.
- The established emphasis on the need for parental commitment, investment, and involvement in the intense rehabilitation following cochlear implantation for ensuring positive child's outcomes, can introduce major stress to the parenting role. Professionals in early intervention programs and in CI teams should devote attention to supporting and guiding parental involvement. Parents' major role in their child's rehabilitation should be based on parent-professional collaborative relationships, in line with the recommendations of family-centered intervention models (Dunst, Trivette, Boyd, & Brookfield, 1994; Meadow-Orlans & Sass-Lehrer, 1995; Minke & Scott, 1995; Winton &

DiVenere, 1995). Accordingly, a key goal for professionals should be to enable families by helping parents develop the skills they need to help both themselves and their children (Dunst, Trivette, & Hamby, 1996).

- Early intervention programs that strengthen parental perceptions of control, support, and coping are likely to be successful in helping parents provide the types of behaviors that will support development in their children.

### **Child Behavior, Parental Stress and Coping**

Findings across the three studies emphasized the child's influence on parental stress and coping processes. In the study reported in Chapter 2, the child's age at the time of implantation, the child's communication abilities and the child's related stress (both based on everyday problems in parenting a child with a CI and child-related stress in general) were associated with parental distress. According to the study presented in Chapter 3, parents identified their child's personality characteristics and progress as fundamental to their own coping experience. In the study presented in Chapter 4, it appeared that child responsiveness to the parent initiations increased parental satisfaction, whereas low child progress or disengagement led to parent disappointment and feelings of incompetence. Gaps or conflict between goals, functional steps, and behaviors that occurred in parent-child joint activities and projects increased parental stress. Overall, the studies' findings indicate that parents' experience their child's uniqueness are a critical component of the parenting stress processes. As reflected in the results of the three studies, these processes include parents' perceptions of their child's characteristics, personality, functioning, behavior, as well as their child's communication abilities.

Parents' perceptions of their children are the critical part of children's influence on parental emotional experience. Consistent with the findings of previous studies, more distress is involved when parents perceive their children as demanding and difficult than when the children are seen as compliant and cooperative (e.g., Harrison & Shfronoff, 2002). The identified stressors associated with the caregiving of children with CIs emphasize Abidin's (1992) theory of parenting stress, which highlights separate domains of distress that are tied to the parent's own attributes (sense of competence, anxiety, depression) and the attributes of the child's situation (e.g., communication problems, rehabilitation demands).

From an action theory stance (see Chapter 4), parents' appraisal of their child's characteristics and functioning can be manifested at different levels of action, that is, meaning, function, and skills and resources. For example, at the meaning level, a parent may appraise his child's difficult behavior as indicating a need to be more demanding in his parenting practices, although this goal might be conflicted with the parent's ongoing feeling of guilt associated with the child's disability. The parent appraisal also functions as a steering process, guiding and directing the parent's actions. For example, the parent may insist that the child will wear his CI; however, the parent may not show this behaviour consistently. Finally, at the level of skills and resources, the parent may appraise the child's difficulties in communication as stressful, because of his own poor skills in promoting the child's communication competence. This may be compounded by a lack of professional support in guiding the parent how to work with his child.

Furthermore, as was reflected in study 3 (Chapter 4), there is a wide range of emotions beyond stress that are expressed by parents. It seems that parents' appraisals of children's competence and behavior and of specific situations are also related to the positive and negative feelings parents hold toward their children. Future research should acknowledge parents'

appraisals, the meanings associated with their appraisals, parents' emotions, and parents' coping strategies and actions, in assisting parents to develop strength, expertise, and confidence in parenting their child with a CI.

### **Implications for practice**

The following specific recommendations for early intervention programs and professionals working with deaf children and their families are drawn from the findings concerning the child's influence on parental stress and coping processes:

- Children who undergo cochlear implantation are regularly assessed throughout their rehabilitation by professionals at the CI center and/or at the early intervention program. The assessments are usually focused on the child's speech perception and speech production abilities. The current studies highlight the importance in including ongoing formal and/or informal assessments of parents' views and perceptions with regard to their children's progress (for example, the "Parent Questionnaire, Children with Cochlear Implants: Parental Perspectives" recently developed by Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos (2002)). This kind of assessment can be used as a sounding board to check with parents about their meaning-making of their child's progress, their feelings regarding their child's progress, and their own parenting skills. This information helps inform professionals about parents' on-going needs and understandings, and, in turn, assists in determining who best to support both the children and their parents in their individual and joint actions.



- Professionals who work with parents of children with CIs must be aware continuously of how to recognize parents' difficulties in such areas as working with their children, engaging in parent-child interactions, and managing the child's behavior. Next, professionals should craft interventions aimed at improving parents' interactions with their children and providing them with strategies to promote their children's language acquisition and/or behavior.
- It is important that intervention programs incorporate assessment of parental stress. However, these measures should be specific measures developed for parents of children with CIs (see Meadow-Orlans, 1990, for measures developed specifically for use with parents of children who are deaf). In addition, it would be useful when assessing stress to employ Abidin's (1992) theory of parenting stress, which highlights separate domains of distress that are tied to the parent's own attributes and the attributes of the child's situation, and the contextual model of stress (Quittner & DiGirolamo, 1998), which emphasizes the notion that stressors are embedded within a specific context, including factors related to the child, the family, and the specific tasks and demands that must be mastered for successful functioning.

Collectively, the findings of the three studies highlight the complexity of the experience of parenting children with CIs. The findings shed light on the various dimensions and perspectives involved in parenting children following cochlear implantation, including parents' emotional and cognitive internal process, parents' actions as part of their coping process and their involvement in the habilitation process, and parents' meaning making – the ways parents understand their role,

their own actions, needs, and resources. Furthermore, parenting children with CIs does not occur in vacuum; it is important to acknowledge and understand the context and the reality of parents' and children's daily life, all of which are embedded within and influence parents' experiences.

Overall, parenting children with CIs can present challenges some unique and others consistent with the experience of parenting deaf children without CIs. At the same time, parents bring many strengths and internal resources to the experience, and these strengths have been found to be valuable supports for both themselves and for other parents on the same journey.

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**Appendix A:**

**UBC Research Ethics Review Board's Certificates of**

**Approval**



**Appendix B:**  
**Measures - Chapter 2**

**Appendix B1: Demographic background.**

ID number: \_\_\_\_\_

**Survey of Parents of Children with Cochlear Implants**

Information that would permit identification of any individual will be held strictly

**CONFIDENTIAL**

Date (MM/DD/YY): \_\_\_\_\_

Person completing the survey: ☐ child's mother ☐ child's father ☐ other: \_\_\_\_\_**A. YOUR CHILD'S AND FAMILY'S BACKGROUND INFORMATION****Your Deaf Child**

1. Date of child's birth: (Month/ Day/Year) \_\_\_\_\_

2. Child's gender: ☐ Male ☐ Female

3. Number of siblings \_\_\_\_\_

4. Birth order of deaf or hard of hearing child \_\_\_\_\_

5. Number of deaf or hard of hearing siblings \_\_\_\_\_

6. Are there any other people in the family with a hearing loss? \_\_\_\_\_

7. Does the child have any additional special needs? ☐ yes ☐ no

If yes, please

describe \_\_\_\_\_

8. Indicate the spoken language(s) most commonly used at your child's home:

9. Place of living: ☐ urban area ☐ rural area**Mother:**

1. Please check one:

☐ Married ☐ Common-Law ☐ Single ☐ Widowed ☐

Divorced

2. Education level: ☐ Less than high school ☐ High school only☐ 1 or 2 years of university or college ☐ Bachelor's degree (typically a 4-year university degree).

3. Country of birth: \_\_\_\_\_ (if other than Canada please answer 3.a)

(a) Number of years in Canada: \_\_\_\_\_

**Father:**

1. Please check one:

- ☐ Married                      ☐ Common-Law                      ☐ Single                      ☐ Widowed                      ☐  
 Divorced

2. Education level:    ☐ Less than high school                      ☐ High school only

☐ 1 or 2 years of university or college                      ☐ Bachelor's degree (typically a 4-year university degree).

3. Country of birth: \_\_\_\_\_ (if other than Canada please answer a)

(a) Number of years in Canada: \_\_\_\_\_

**B. PRE-IMPLANT INFORMATION**

1. How old was your child when her/his deafness was first identified?

☐ at birth                      \_\_\_\_\_ (#) months old (if under 36 months)                      **or**                      \_\_\_\_\_ (#) years old (if 3 years or older)

2. To the best of your knowledge, when did your child's deafness occur?

☐ before birth                      ☐ at birth                      ☐ younger than 6 months                      ☐ between 6 and 12 months  
☐ between 13 and 18 months                      \_\_\_\_\_ (#) years old                      ☐ unknown

3. Reported cause of deafness: \_\_\_\_\_

**Hearing aids (HAs)**4. How old was your child when (s)he began using **hearing aids (HAs)**?

☐ child did not ever use HAs                      \_\_\_\_\_ (#) months (if under 36 months)                      **or**                      \_\_\_\_\_ (#) years old (if 3 years or older)

5. **Before getting a cochlear implant** how long did your child use **HAs**?  
\_\_\_\_\_6. **Before getting the cochlear implant**, how regularly did your child use HAs? (Mark only **ONE**.)

☐ nearly all waking hours, everyday                      ☐ about ½ day, virtually daily                      ☐ 3 hours or less everyday  
☐ nearly all waking hours, few days/wk                      ☐ about ½ day, some days/wk                      ☐ 3 hours or less, some days/wk  
☐ very rarely and/or sporadically                      ☐ other (*specify*) \_\_\_\_\_

### **Pre-Implant Communication**

7. **Just before** receiving the cochlear implant, my child was communicating at home by using... (Mark only ONE.)

- |  |   |
|--|---|
| <input type="checkbox"/> only speech (i.e. spoken language)          | <input type="checkbox"/> only signing             |
| <input type="checkbox"/> roughly equal amounts of signing and speech | <input type="checkbox"/> more signing than speech |
| <input type="checkbox"/> more speech than signing                    | <input type="checkbox"/> cued speech              |
| <input type="checkbox"/> minimal (if any) spoken words or signs      | <input type="checkbox"/> other                    |

(specify) \_\_\_\_\_

8. Which of the following best represents the communication mode used by others in home when communication with your child **just before** (s)he received the cochlear implant? (Mark only ONE.)

- |  |   |
|--|---|
| <input type="checkbox"/> only speech (i.e. spoken language)          | <input type="checkbox"/> only signing             |
| <input type="checkbox"/> roughly equal amounts of signing and speech | <input type="checkbox"/> more signing than speech |
| <input type="checkbox"/> more speech than signing                    | <input type="checkbox"/> cued speech              |
| <input type="checkbox"/> minimal (if any) spoken words or signs      | <input type="checkbox"/> other                    |

(specify) \_\_\_\_\_

9. Who was the **first** to suggest the cochlear implant as an option for your child?

\_\_\_\_\_

10. a. Which of the following information *sources* did you use **in making the implant decision?** (Mark ALL that apply.)

- |  |   |                                      |
|--|---|--------------------------------------|
| <input type="checkbox"/> adults/children with cochlear implant (hearing clinicians)  | <input type="checkbox"/> pediatricians      | <input type="checkbox"/> audiologist |
| <input type="checkbox"/> teacher for children with hearing loss otolaryngologist/ENT | <input type="checkbox"/> speech clinician   | <input type="checkbox"/>             |
| <input type="checkbox"/> parents of children with cochlear implant                   | <input type="checkbox"/> printed literature | <input type="checkbox"/> Internet    |
| <input type="checkbox"/> other (specify) _____                                       |   |                                      |

b. Please list the source of information you think were **most important and helpful** \_\_\_\_\_

\_\_\_\_\_

c. Do you feel that this information source provided accurate information (both the advantages and disadvantages) of getting a cochlear implant? ☐ Yes ☐ No

If No Please

explains: \_\_\_\_\_

11. How long did you have to wait for surgery since your child was accepted as a candidate?

- ☐ less than 3 months      ☐ 3 – 6 months      ☐ 7 – 11 months  
       \_\_\_\_\_ (#) years

12. When the implant surgery was performed, were you familiar with the risks associated with the surgery?

- ☐ rather unfamiliar      ☐ somewhat familiar      ☐ very familiar

### **C. IMPLANTATION and EQUIPMENT**

1. When was your child's cochlear implant surgery performed? (MM/DD/YY):  
 \_\_\_\_\_

2. When was your child's cochlear implant first stimulated (i.e., date of "hook up")?  
 (MM/DD/YY): \_\_\_\_\_

3. What type of cochlear implant did your child receive when (initially) implanted?

- ☐ NU-22   ☐ NU-24   ☐ Clarion   ☐ Med-El Combi40 (+)   ☐ other

(specify) \_\_\_\_\_

4. During the implant surgery, were the cochlear implant electrodes successfully inserted? ☐  
 Yes   ☐ No

If NO, were you informed, before the surgery, of the possibility of a partial insertion? ☐  
 Yes   ☐ No

### **F. AFTER RECEIVING the COCHLEAR IMPLANT**

1. Was sign communication used with your child before getting the cochlear implant? ☐  
 Yes   ☐ No

IF YES, which of the following statements best characterize your pattern of sign communication exchange during the first year or two after the CI was received: (mark only one)

- ☐ sign communication exchanges were discontinued immediately following cochlear implant "hook up"
- ☐ signing was phased out on a regulated or prepared schedule
- ☐ your child's use of signing disappeared gradually as spoken communication improved

- ☐ sign communication continued as a support to spoken communication with the cochlear implant
- ☐ sign communication continued as an occasional alternative to spoken communication with the cochlear implant
- ☐ other

(indicate) \_\_\_\_\_

2. How would you describe the influence that speech therapy has had on your child's spoken communication abilities?

- ☐ negative    ☐ not helpful    ☐ slightly helpful    ☐ very helpful    ☐ indispensably helpful

### **G. OTHER COMMUNICATION ISSUES**

1. How does **your child** communicate with you **now** at home? (*Mark only one*)

- |  |   |
|--|---|
| <input type="checkbox"/> only speech                                 | <input type="checkbox"/> only signing             |
| <input type="checkbox"/> roughly equal amounts of signing and speech | <input type="checkbox"/> more signing than speech |
| <input type="checkbox"/> more speech than signing                    | <input type="checkbox"/> cued speech              |
| <input type="checkbox"/> minimal (if any) spoken words or signs      | <input type="checkbox"/> other                    |

(specify) \_\_\_\_\_

2. How do **you** communicate with your child **now** at home? (*Mark only one*)

- |  |   |
|--|---|
| <input type="checkbox"/> only speech                                 | <input type="checkbox"/> only signing             |
| <input type="checkbox"/> roughly equal amounts of signing and speech | <input type="checkbox"/> more signing than speech |
| <input type="checkbox"/> more speech than signing                    | <input type="checkbox"/> cued speech              |
| <input type="checkbox"/> minimal (if any) spoken words or signs      | <input type="checkbox"/> other                    |

(specify) \_\_\_\_\_

**Provide the most appropriate ending to the sentences in items 5 and 6.**

4. **"I understand my child's when he or she speaks...."**(*Mark only ONE*)

- ☐ all the time    ☐ most of the time    ☐ about half of the time    ☐ some of the time    ☐ hardly at all

5. **"When using his/her CI, my child seems to understand me when I speak....."**(*Mark only ONE*)

- ☐ all the time    ☐ most of the time    ☐ about half of the time    ☐ some of the time    ☐ hardly at all

## F. EDUCATIONAL ISSUES

1. List your child's complete educational placement history. Please indicate the school name, whether the school is public or private, the hearing status of child's classmates, the instructional communication mode used with your child, and the grade levels of your child's attendance. **(For each school entry, mark ONE box in each section)**

School (including preschool)	Year/ period	Child's classmates			School communication approach			Grade levels
		deaf	hearing	both	speech	sign	both	
1.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

2. Which of the following best describes your child's current educational environment? (Mark only one)

- ☐ **Fully mainstreamed** with hearing children for all activities in **regular school or preschool**
- ☐ **Partially mainstreamed** with hearing children (only certain class/activities/ times) in **regular school or preschool**
- ☐ **Self contained classroom** of deaf/hard of hearing children in **regular school**
- ☐ **School** for deaf/hard of hearing children
- ☐ Other (describe) \_\_\_\_\_

3. What accommodations and/or special supports related to deafness or the CI does your child **now** receive in his/her educational setting? (Mark all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> resource room help               | <input type="checkbox"/> note taker/assigned "buddy"                           |
| <input type="checkbox"/> remedial work/tutoring           | <input type="checkbox"/> media captioning (closed or real time)                |
| <input type="checkbox"/> sign language interpreting       | <input type="checkbox"/> classroom amplification system (e.g., loop, infrared) |
| <input type="checkbox"/> itinerant teacher support        | <input type="checkbox"/> personal assistive device (e.g., FM system)           |
| <input type="checkbox"/> classroom teacher aide/assistant | <input type="checkbox"/> other (specify) _____                                 |





2. With whom do you work (collaborate) to solve the above problems (challenges, hassles obstacles, conflicts and demands) you have with regard to your deaf child? (Mark ALL that apply.)

☐ spouse

☐ family member

☐ other parent of deaf child

☐ professionals

☐ friend

☐ other \_\_\_\_\_

3. From the above choices, who do you like to work with the most when solving everyday problems that you have with regard to your deaf child? **Please explain.**

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**Appendix C:**  
**Measures - Chapter 3**

## Appendix C1: Background questionnaire

### "Cochlear Implants in Deaf Children:

### Parental Experiences and Implications for Early Intervention Programs"

#### Background Information on Children and Families

Thank you agreeing to be part of this study. The information will be kept strictly confidential.

#### A. Mother

1. Age: \_\_\_\_\_

2. Please check one:

☐ Married    ☐ Common Law    ☐ Single    ☐ Widowed    ☐ Divorced

3. Ethnic background: \_\_\_\_\_

4. Country of birth: \_\_\_\_\_ (if other than Canada please answer a)

(a) Number of years in Canada: \_\_\_\_\_

5. Level of education (CHECK ONE)

☐ Less than high school

☐ High school only

☐ 1 or 2 years of university or college

☐ Bachelor's degree (typically a 4 year university degree)

☐ Master's (M.A.), doctoral Ph.D. or professional degree (e.g. doctor)

6. Current occupation? (Please describe the kind of work you do - e.g., manager, salesperson) \_\_\_\_\_

7. Is there anything you want to add about yourself?

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B.

**Father**

1. Age: \_\_\_\_\_

2. Please check one:

☐ Married    ☐ common Law    ☐ Single    ☐ Widowed    ☐ Divorced

3. Ethnic background: \_\_\_\_\_

4. Country of birth: \_\_\_\_\_ (if other than Canada please answer a)

(a) Number of years in Canada: \_\_\_\_\_

5. Level of education (CHECK ONE)

☐ Less than high school

☐ High school only

☐ 1 or 2 years of university or college

☐ Bachelor's degree (typically a 4 year university degree)

☐ Master's (M.A.), doctoral Ph.D. or professional degree (e.g. doctor)

6. Current occupation? (Please describe the kind of work you do - e.g., manager, salesperson) \_\_\_\_\_

7. Is there anything you want to add about yourself?

---

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*C. Your Deaf or Hard of Hearing Child*

**General information**

1. Date of birth: (Month/ Day/ Year) \_\_\_\_\_
  2. Male ☐ Female ☐ (Please check one)
  3. Number of siblings \_\_\_\_\_
  4. Birth order of deaf or hard of hearing child \_\_\_\_\_
  5. Number of deaf or hard of hearing siblings \_\_\_\_\_
  6. Are there any other people in the family with hearing loss ? \_\_\_\_\_
- 

**Information about the hearing loss**

7. Was your child born with hearing loss? ☐ Yes ☐ No ☐ Unknown
  8. Cause of hearing loss: \_\_\_\_\_
  9. Age of diagnosis: \_\_\_\_\_
  10. Current degree of hearing loss (in the better ear):  
  
☐ Mild ☐ Moderate ☐ Severe ☐ Severe to profound ☐ Profound
  11. Age at entry to intervention program: \_\_\_\_\_
-

12. How do you communicate with your child at home?

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13. Does your child have any disabling conditions in addition to the hearing loss?

☐ No ☐ Unknown ☐ Yes if yes, please describe:

---

**Information about the cochlear implant**

14. Date on implementation: (Month/ Day/ Year) \_\_\_\_\_

15. How did you learn about the cochlear implant option?

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16. Were there any complications either during or following the surgery?

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17. Is there anything you would like to add about your deaf child?

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**Thank you for your co-operation.**







**Appendix D:**  
**Measures - Chapter 4**

**Appendix D1: Background Information on Children and Families**

Thank you agreeing to be part of this study. The information will be kept strictly confidential.

**A. Mother**

Age: \_\_\_\_\_

Please check one:

☐ Married      ☐ Common Law ☐ Single      ☐ Widowed      ☐ Divorced

Ethnic background: \_\_\_\_\_

Country of birth: \_\_\_\_\_ (if other than Canada please answer a)

(a) Number of years in Canada: \_\_\_\_\_

Level of education (CHECK ONE)

☐ Less than high school

☐ High school only

☐ 1 or 2 years of university or college

☐ Bachelor's degree (typically a 4 year university degree)

☐ Master's (M.A.), doctoral Ph.D. or professional degree (e.g. doctor)

Current occupation? (Please describe the kind of work you do - e.g., manager, salesperson)

\_\_\_\_\_

Is there anything you want to add about yourself?

\_\_\_\_\_  
\_\_\_\_\_

**B. Father**

Age: \_\_\_\_\_

Please check one:

☐ Married      ☐ common Law ☐ Single      ☐ Widowed      ☐ Divorced

Ethnic background: \_\_\_\_\_

Country of birth: \_\_\_\_\_ (if other than Canada please answer a)

(a) Number of years in Canada: \_\_\_\_\_

Level of education (CHECK ONE)

☐ Less than high school

☐ High school only

☐ 1 or 2 years of university or college

☐ Bachelor's degree (typically a 4 year university degree)

☐ Master's (M.A.), doctoral Ph.D. or professional degree (e.g. doctor)

Current occupation? (Please describe the kind of work you do - e.g., manager, salesperson)

Is there anything you want to add about yourself?

### **C. Your Deaf or Hard of Hearing Child**

General information

Date of birth: (Month/ Day/ Year) \_\_\_\_\_

Male ☐ Female ☐ (Please check one)

Number of siblings \_\_\_\_\_

Birth order of deaf or hard of hearing child \_\_\_\_\_

Number of deaf or hard of hearing siblings \_\_\_\_\_

Are there any other people in the family with hearing loss? \_\_\_\_\_

Information about the hearing loss

Was your child born with hearing loss? ☐ Yes ☐ No ☐ Unknown

Cause of hearing loss: \_\_\_\_\_

Age of diagnosis: \_\_\_\_\_

Current degree of hearing loss (in the better ear):

☐ Mild ☐ Moderate

☐ Severe ☐ Severe to profound ☐ Profound

Age at entry to intervention program: \_\_\_\_\_

How do you communicate with your child at home?

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---

Does your child have any disabling conditions in addition to the hearing loss?

☐ No ☐

Unknown ☐ Yes if yes, please describe:

---

Information about the cochlear implant

Date on implementation: (Month/ Day/ Year) \_\_\_\_\_

How did you learn about the cochlear implant option?

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Were there any complications either during or following the surgery?

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---

Is there anything you would like to add about your deaf child?

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**Thank you for your co-operation.**

## Appendix D2: Mother Interview Protocol

### Orientation:

Thank you again for agreeing to participate in this research project.

The aim of this research is to learn about the process in which parents support their children following a cochlear implantation and help them adjust and gain benefits from the cochlear implant. That is, how parents work together with their children in response to changes and possibilities brought about to their deaf child by the cochlear implant. In addition, we would like to understand how parents feel and think regarding their role of parenting a child who receives a cochlear implant. For example, what concerns parents have regarding parenting their child and their child and the ways they address these concerns in their daily life with their child and family.

\*\*\*As we mentioned in the consent forms, we will be video- and audio-taping everything, to make sure we have accurate records of what is going on. I'll just turn on the equipment now.

### Interview's Questions:

1. The topic of our study is "**Promoting children's outcomes following a cochlear implantation as a parenting project,**" how do you see your role in that process? How do you see your role in the adjustment of your child?
2. What are the daily activities that you are doing with your child in order to support this progress?
3. What goals do you have for your child in the near future and in the long term future?
4. What kind of things/activities you are doing by yourself and/or jointly with your child in order to promote your goals?
5. What goals do you have regarding your parenting?
6. What concerns are you currently experiencing related to your deaf child and/or parenting a deaf child? How do you feel about these concerns? What are your thoughts you have regarding those concerns?
7. How do you address those concerns? What are the things that you are doing in order to deal with the above concerns?
8. What is a source of satisfaction to you regarding your deaf child and/or parenting a deaf child?

9. What was a source of frustration to you regarding your deaf child and/or parenting a deaf child?
10. What kinds of things do you think still need to happen? How these things might be accomplished in your family?
11. What does parenting a deaf child mean to you? What is involved in parenting a deaf child? In your opinion, is it different to parent a hearing child versus a deaf child?

## **Part II: Mother-child Interaction**

Next, I would like to invite you to engage in two short activities with your child. First, I would like you to suggest an activity that represent what you are usually doing together with your child in your home (for example, playing a specific game, a language or listening activity you doing with your child, looking at a picture book. Please engage in the activity for about 5 - 7 minutes. The moment you finish this activity, I will bring into the room a series of toys and ask you to play with it together with your child. The activity will last around 7-10 minutes.

Do you have any questions?

I will leave the room now. Take the next minutes or so to participate in the first activity with your son/daughter. next, I will come in the room to bring you the toys.

## **Part III: Self-confrontation**

Now we are going to view together the videotape of the activities that you just had with your child. Whenever you want to say something regarding what was going on for you, you may stop the tape, and tell me about it.

What were your goals in these activities? What you were thinking and feeling in each segment of the activities.

Do you understand what we will be doing? Are you ready to begin?

(minute by minute, playing tape and pausing it) What were you thinking, what were you feeling, what was your goal for that part of the activity?

**Follow-up questions at end of minute by minute:**

So overall, what were your thoughts about your activities with your child?

- Typical vs. not typical
- Feeling
- Thoughts

1. If you had to sum up what you were trying to do in that these activities what would you say was your overall purposes? goals?
2. Did you have a chance in the past to view yourself, on a videotape, interacting with your child?
3. How do you feel about the way you work with your child on his/her speech, language and listening? What are the difficulties that you have experienced when working with your child on his/her speech, language and listening?
4. In your opinion, what is the way children learn best? What is the best way in supporting their learning?