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FACULTY OF GRADUATE AND
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The Ecological Transition to Auditory-Verbal Therapy : Mother's and Father's Experiences with
Children Who Wear Cochlear Implants

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The Ecological Transition to Auditory-Verbal Therapy: Mothers' and Fathers'
Experiences with Children Who Wear Cochlear Implants

by
Deirdre Neuss

Dissertation submitted to the School of Graduate Studies
of the
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The Ecological Transition to Auditory-Verbal Therapy: Mothers' and Fathers' Experiences with Children Who Wear Cochlear Implants

Abstract

The research reported in this study centred around the experience of adopting auditory-verbal therapy from the perspective of parents whose children wear cochlear implants. Although it has been asserted that family involvement is pivotal to the communication attainment of children with hearing loss, and despite the significant parental commitment required to implement auditory-verbal therapy, there have been no studies thus far that have examined the auditory-verbal process from the parents' perspective. Therefore, the major research question was: What are parents' experiences in making the transition to auditory-verbal therapy with their children who wear cochlear implants?

A qualitative case study methodology, framed in Bronfenbrenner's ecological theory of human development and family systems theory guided this exploratory study. Bronfenbrenner indicates that an ecological transition occurs "whenever during the life course, a person undergoes a change in role either within the same or a different setting" (Bronfenbrenner & Crouter, 1983, p. 381). Parents whose children are diagnosed with a hearing loss and who adopt auditory-verbal therapy experience such a transition. Participants were 9 parents and 2 auditory-verbal therapists. Data collection procedures included individual interviews, observation sessions, a group discussion and a family information questionnaire.

The major themes were: personal characteristics and family interactions (microsystem level of Bronfenbrenner's model); choice, compliance and support (mesosystem); support

(exosystem); and accessibility and inclusion (macrosystem).

This is the first time that Bronfenbrenner's model has been used as a theoretical framework for examining auditory-verbal therapy. The study revealed the importance of parent and child personality traits and their compatibility. It underlined that support from the cochlear implant team, as well as funding from the provincial Ministries assist the parents' transition. It emphasized that ease of access to technology, therapy and speaking role models, as well as inclusion in mainstream education also facilitate this transition.

Acknowledgements

The journey to the completion of this dissertation represents my own ecological transition. As so aptly described in Bronfenbrenner's model, elements at the four nested levels facilitated this transition.

At the macrosystem level is a society that encourages adults who have been in the work force to return to university to realize their academic goals.

At the exosystem level are policies that support the pursuit of research. In this case, the Children's Hospital of Eastern Ontario (CHEO) has made research one of its priorities.

There are several microsystems with which I have been involved and which comprise the mesosystem level. I want to thank the families who agreed to participate in this study. I have learned a lot from them about resiliency, persistence and dedication.

The Operations Director of the Rehabilitation PSU (Patient Service Unit), Lloyd Cowin, translated CHEO's research initiative into funding. He and the members of the Rehabilitation PSU Research committee, comprised of David Collins, Robin Gaines, Sarah Miles and Dominique Surprenant, granted me paid leave which enabled me to complete this study.

My colleagues/friends at CHEO read several drafts of this manuscript and contributed their insightful comments. Thank you to: (in alphabetical order) Rosemary McCrae, Linda Moran, Kelley Rabjohn and Pamela Steacie! My university colleagues/friends have been a great source of inspiration and guidance.

My committee members have each contributed immeasurably to the completion of this work. My advisor, Dr. Cheryll Duquette, has always been available to answer questions, discuss ideas and offer wise counsel and positive comments. Her calm, nurturing manner reduced my

stress level on more than one occasion! Dr. Andrée Durieux-Smith gave me my first job in this field and has been my mentor and friend for many years. She provided me with a “room of my own” without which this dissertation could not have been completed. As a teacher and committee member, Dr. Raymond LeBlanc has challenged me intellectually. He has demonstrated an excitement about research that I aspire to emulate. Dr. Richard Maclure taught the first course in which I enrolled as a doctoral student. His integrity and discipline as a teacher and researcher have been an inspiration to me during this journey.

I am fortunate in having a large network of friends who have cheered me on through this endeavour. Amongst them are Anne Makhoul and Denise Bellfo, to whom I am very grateful for their editing expertise and computer wizardry.

At the microsystem level, my family members have offered me encouragement and support. I could not have realized this dream without three special people: David, Kyla and Zachary. Thank you for the time and for your love. I love you!

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"Holland?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

"But there's been a change in the flight plan. They've landed in Holland and there you must stay."

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy and they're bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special, very lovely things that Holland has to offer.

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CHAPTER 1

INTRODUCTION

*“What an amazing piece of technology (cochlear implant). I think it’s a medical miracle”
Zach, parent participant*

[this way of speaking] “comes now instinctively. It’s like eating our food” - Kyla, parent participant

Auditory-verbal therapy is a method of intervention used in many centres around the world. In Ontario, this approach is one of the options available at the three pediatric cochlear implant centres located around the province. This method of habilitation purports to develop the child’s spoken language following normal developmental patterns, using the access to hearing provided by a hearing aid or cochlear implant (Dornan, 1999). This method requires a significant commitment on the part of the parents and has been described as a “way of life” (Goldberg & Flexer, 1993; Simser, 1997). Parents who choose to adopt auditory-verbal therapy with their children presumably must embrace this “way of life”. They learn to stimulate their children’s audition, speech and language development within the context of everyday activities and routines. It has been documented that early identification, paired with active family involvement results in higher linguistic attainment (Moeller, 2000). It has also been stated that the meaning attributed to a situation by its participants will determine their response to it (Seligman & Darling, 1997). However, the literature indicates little about how parents perceive the transition in their lives brought about by their adoption of auditory-verbal therapy.

The cochlear implant is considered by some to be the most important technological advancement of the twentieth century for people with severe to profound hearing loss

(Estabrooks, 1998). It is widely recognized that those who receive cochlear implants require intensive therapy in order to attain maximum benefit from their device (Estabrooks, 2000; Simser, 1997). In the case of auditory-verbal therapy, parents are expected to partner therapists in developing their child's speech and language using various techniques to develop listening skills. Although it is acknowledged that parental support is a critical factor in determining outcomes with cochlear implants (Cohen & Waltzman, 1996), there have been only a few studies that have examined parents' views of implants. Previous research has consisted mainly of questionnaires that survey parents regarding the benefits attained by their children with the implant (Cunningham, 1990; Kelsay & Tyler, 1996). In view of the commitment required of parents who adopt auditory-verbal therapy with their children who wear cochlear implants, it is crucial to understand their lived experiences.

For the last 20 years, there has been an increasing number of studies that have examined the role of families in the development of children with disabilities (Sontag, 1996). A family systems perspective views the family as a whole unit and considers that the unit is affected by any change occurring in any one of its members (Minuchin, 1985). Given the upheaval in the families of children who are diagnosed with hearing loss and the importance of active family involvement in successful intervention (Moeller, 2000), an examination of this transition from a family systems perspective seems warranted.

Bronfenbrenner's (1979, 1995) theory of the ecology of human development provides a contextual perspective in examining development. He postulates that when a person experiences a change in role within his/her existing context or in a different one, this change is an ecological transition. The aim of this thesis is to describe one such ecological transition, that which occurs

in parents who discover that their child has a hearing loss and that technology and intervention are required. Their thoughts about this transition to “being a parent of a deaf child” (Bodner-Johnson, 2001, p. 266) will be affected by their perceptions of the relationships at four nested levels: the microsystem, that consists of direct interactions (parent-child, parent-parent); the mesosystem, that consists of direct or indirect relationships (partnerships with the intervention centre); the exosystem, that consists of relationships in which they are not directly involved, but which impact on them (public policies); and the macrosystem (belief systems and culture).

As an auditory-verbal therapist, who has worked with many families of children with hearing loss, I have often marvelled at the resiliency of the parents and wondered how they experienced auditory-verbal therapy in their daily lives and what effects this intervention method had on the family. Guided by a contextual theory and a case study research design, I investigated these issues.

Purpose of the Study

The purpose of the study was to explore the experiences of parents regarding this fundamental change in their lives, in order to extend theory and also to raise awareness and enhance practice. The major research question was: What are parents’ experiences in making the transition to auditory-verbal therapy with their children who wear cochlear implants? The secondary questions were:

- (1) What are the parents’ daily activities, roles and interpersonal relations and how are these changed by the transition to auditory-verbal therapy?
- (2) What personal and family characteristics impede and/or facilitate this transition at the level of the microsystem?

- (3) What elements of the auditory-verbal therapy model and work place impede and/or facilitate this transition at the level of the mesosystem?
- (4) What elements of the public policies impede and/or facilitate this transition at the level of the exosystem?
- (5) What elements of the culture and belief system about hearing loss impede and/or facilitate this transition at the level of the macrosystem?

This thesis has been organized into chapters that discuss various aspects of this topic. Chapter 1 provides an introduction and overview of the problem. Chapter 2 furnishes a review of the literature including references related to cochlear implants; auditory-verbal therapy; parents of children with disabilities and specifically with hearing loss; family systems theory and the theory of the ecology of human development. It concludes by describing the conceptual framework and model that guided this study. Chapter 3 discusses the methodology that was implemented, including a description of the constructivist paradigm on which it is based, and the data collection and analysis procedures. Chapter 4 recounts the participants' stories and chapter 5 provides a discussion of these stories as they relate to the literature. Chapter 6 includes limitations of the study, suggestions for future research and recommendations for practice, as well as an epilogue which provides the participants' closing words.

CHAPTER 2

REVIEW OF THE LITERATURE AND CONCEPTUAL FRAMEWORK

Review of the Literature

Approximately three children in 1000 are born with some degree of hearing loss and in 20% of these children, this hearing loss will be profound (Allen et al., 1999). Hearing impairment (see Appendix A for the definitions of terms) in early childhood may have debilitating effects on the child in the form of delayed speech and language development, cognitive, psychosocial skills, and academic achievement (Durieux-Smith, Seewald & Hyde, 2000). Robinshaw and Evans (2001) found that hearing impairment has an impact not only on the child but also on her parents and the whole family network. Bronfenbrenner's ecological theory of human development (Bronfenbrenner, 1979), renamed the bioecological systems theory (Bronfenbrenner, 1995) recognizes that children's development occurs in relation to the family, environment and services surrounding them (Dym, 1988). Family systems theory views the family as a whole unit and considers that the unit is affected by any change occurring in any one of its members (Minuchin, 1985).

After the diagnosis of hearing loss in their child, parents might experience what Bronfenbrenner refers to as an ecological transition, which "takes place whenever during the life course, a person undergoes a change in role either within the same or in a different setting" (Bronfenbrenner & Crouter, 1983, p. 381). When parents are involved in such a transition, they must adopt new roles, new activities and new relationships (McMillan, 1990). At this point, we know very little about parents' perceptions regarding the transition to auditory-verbal therapy.

With the evidence that intervention by six months of age is a significant factor in

the ultimate development of language (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998), there has been growing support for early diagnosis and intervention. In the United States, a position paper published by the Joint Committee on Infant Hearing (JCIH, 2000) endorsed early detection and intervention for children with hearing loss through a system of universal newborn hearing screening and family-centred intervention. Thus, they recommended that audiological evaluation should be performed before three months of age and intervention for children with confirmed hearing loss should begin before six months of age. This position was supported by the Canadian Association of Speech-Language Pathologists and Audiologists and the Canadian Academy of Audiology (Durieux-Smith, Seewald, et al., 2000).

The Ontario government has recently begun to provide funding for universal newborn hearing screening, with the intention of promoting earlier detection of hearing loss, as well as early intervention and management. Parents will receive the diagnosis of hearing loss when their children are infants or toddlers and will be required to make decisions regarding technology and language intervention methods at earlier points in their children's lives. Such decisions will have repercussions on their own lives and indeed on the lives of each of the family members.

The majority of children with hearing loss can benefit from some form of amplification (JICH, 2000). For those who show minimal improvement with amplification, cochlear implants, which are now being implanted in children as early as 12 months of age, are an option. The use of implants has increased significantly as the criteria for degree of hearing loss have broadened and as the age at implantation has dropped (Most & Zaidman-Zait, 2003). Parents' involvement in cochlear implantation is very challenging, as they must first make the decision to proceed with the surgery and then embark on the lengthy intervention process (Most & Zaidman-Zait, 2003).

The history of education of the deaf is fraught with controversy regarding the optimal method of intervention for children with hearing loss (Easterbrooks, O'Rourke & Todd, 2000). Some believe in a multimodal approach, which includes the use of sign language, finger spelling, speechreading and speech, a method called total communication. Others espouse the use of speech and lipreading only, the oral approach. Still others believe that children born deaf are part of a separate culture and should be taught their "native" language, sign language.

Another approach, auditory-verbal therapy, is practised in several centres around the world and throughout Ontario. Proponents of this approach believe that, given the advanced technology available today, the majority of children with hearing loss have access to hearing, which should enable them to develop spoken language following normal developmental patterns (Dornan, 1999). Although this approach requires a significant commitment on the part of the parents and has been described as a "way of life" (Goldberg & Flexer, 1993; Simser, 1997), little is known about parents' views regarding this commitment.

Educators of children with hearing loss have provided preschool programmes for over 100 years (Moore, 1996). Yet it is only since the 1970's that the role of parents in early intervention has been recognized (Harrison, Dannhardt, & Roush, 1996). Since that time, there has been an evolution from a child-centred philosophy, where the child is treated as an entity separate from her family, to a family-centred focus where the contribution of parents, and indeed of the family, is sought.

For the last 20 years, there has been an increasing number of studies which have examined the role of families in the development of children with disabilities (Sontag, 1996). The goal of family-centred intervention is to provide parents with information and support and

thereby empower them to become collaborators and partners with the professionals who work with their family (Most & Zaidman-Zait, 2003). The Joint Committee on Infant Hearing (JCIH, 2000) indicates that one of the essential principles of early intervention is environmental support and family involvement (Meadow-Orlans, Mertens, Sass-Lehrer & Scott-Olson, 1997). In fact, Moeller (2000) found that family involvement was the factor most predictive of positive outcome in intervention with children with hearing loss. Bronfenbrenner's theory (1979, 1995), which provides a contextual perspective in examining development, considers the family and the environment in which it is embedded.

Given the upheaval in the families of children who are diagnosed with a hearing loss and the importance of active family involvement in successful intervention, an examination of this transition from the parents' perspective seems warranted. This exploratory study was guided by family systems theory and the theory of the ecology of human development. Included in this chapter will be the literature review, which will discuss cochlear implants, auditory-verbal therapy and the role of the parent. Family systems theory, the theory of the ecology of human development, as well as the conceptual framework, which will apply these two theories to the domain of auditory-verbal therapy, will also be addressed.

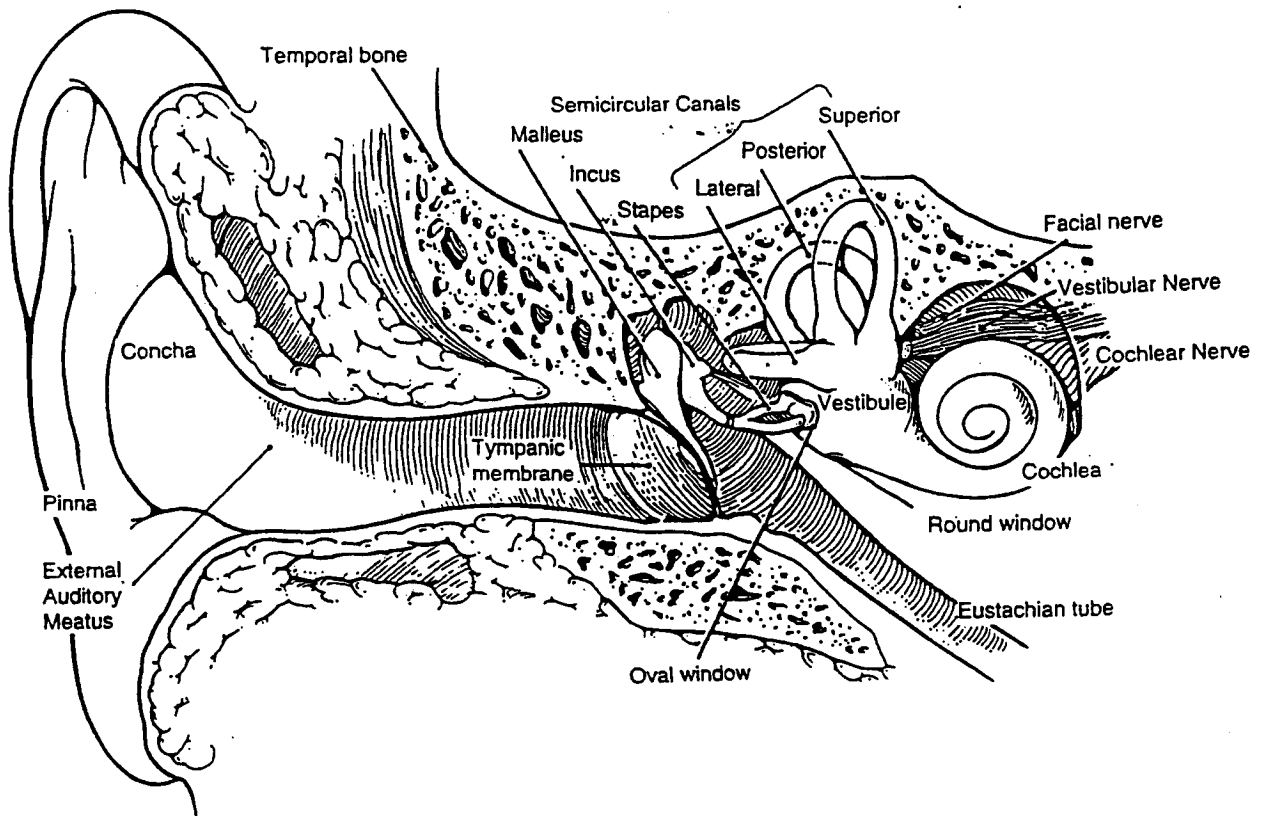
Cochlear Implants

The cochlear implant is considered by some to be one of the most important technological advancements of the twentieth century for people with severe to profound hearing loss (Estabrooks, 1998). In this section, I will trace some of the events that led to the development of this device, describe how it operates, provide a summary of some of the recent research on outcomes and review the few studies that have examined parents' perspectives. Before beginning

this discussion, it is important to have a basic understanding of the anatomy and physiology of the human ear in order to appreciate the significance of this technological advancement (see Figure 1).

The ear is divided into three parts: the external ear, the middle ear and the inner ear. Sound enters the ear canal of the external ear and then causes the ear drum to vibrate. This vibration is transmitted by the three ossicular bones (the malleus, incus and stapes) from the ear drum to the cochlea in the inner ear. This vibration creates movement of the fluid in the cochlea and the motion stimulates the hair cells. When these move, they generate an electric current in the nerve endings which form part of the auditory nerve. This current is transmitted via the brain stem to the brain where it is interpreted as sound. Disease or blockage in the external or middle ear may result in a conductive hearing loss, which is medically or surgically treatable. A problem in the inner ear is most likely due to damage to the hair cells and a sensorineural hearing loss results. The degree of the loss can be mild, moderate, severe or profound and depends on the number of hair cells damaged. Despite the fact that 10% to 90% of the nerve fibres may be intact (Niparko, 2000), they are not able to transmit electrical energy to the brain because of an absence of stimulation by the damaged hair cells. A cochlear implant circumvents the hair cells and provides electrical stimulation directly to the auditory nerve.

Figure 1- Anatomy of the Ear



A cross-section of the peripheral portion of the auditory system revealing some of the anatomic details of the outer, middle, and inner ear. (Adapted from Kessel RG, Kardon RH: *Tissues and Organs: A Text-Atlas of Scanning Electron Microscopy*. San Francisco, W. H. Freeman, 1979.)

From: Audiology - The Fundamentals (2nd ed.) 1995
Fred H. Bess & L. E. Hume Chap. 3, p. 58
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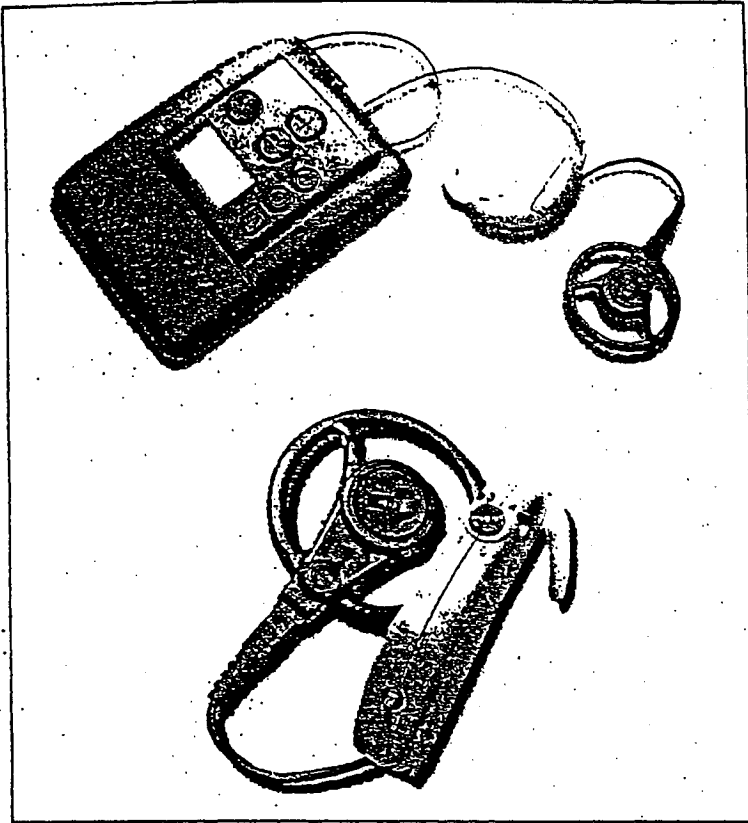
In 1800, Count Alessandro Volta of Italy stimulated his own ears electrically, and thus began a long interest in electrical stimulation of the cochlea. Following Weaver's and Bray's discovery in 1930 that the cochlea transforms acoustical energy into electrical energy, further interest was aroused in obtaining artificial hearing via direct electrical stimulation. In the 1960's, after much research, the first clinical cochlear implant was developed by Dr. William House in collaboration with Jack Urban, an engineer (Sheppard, 1994). This implant, known as the House Implant and later the 3M/House Implant, is no longer available, but over several years this single-channel cochlear implant did provide some benefit to its recipients. At the same time, research into multichannel cochlear implants was conducted in the United States, France, Austria and Australia (Sheppard, 1994). The research of Dr. Graeme Clark, in Australia, led to the development of the Nucleus Melbourne Cochlear Implant. This instrument, with its emphasis on speech-processing strategies, was the precursor of the Nucleus implants, produced by Cochlear Corporation, which are the most frequently implanted devices in children today. Other cochlear implant systems available today are manufactured by Advanced Bionics and Med-El. Once positive data from adults with acquired hearing losses had been obtained, cochlear implants were made available to children. The first child was implanted with a single-channel cochlear implant by Dr. William House in 1980. Later, multi-channel implants began to be used with children (Sheppard, 1994). Cochlear implants were approved for implantation in children by the Federal Ministry of Health in Canada in 1990.

There has been great resistance to cochlear implants from the Deaf community because they felt that hearing people were trying to "cure" their deafness and thereby eliminate their culture (Lane & Bahan, 1998). Many researchers, on the other hand, believe that the cochlear

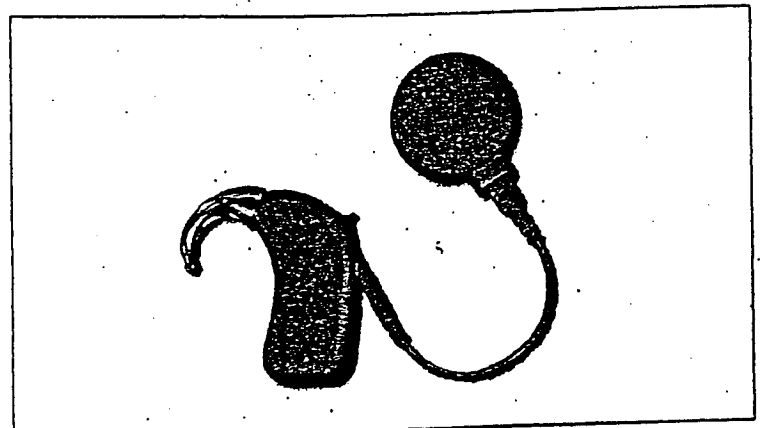
implant is a device that can help improve the communication skills of those with very profound hearing loss (Sheppard, 1994). This debate continues although there are some members of the Deaf community who are recognizing the advantages for communication that a cochlear implant can provide (Christiansen & Leigh, 2002). The most recent position paper by the National Association of the Deaf (as cited in Chute & Nevins, 2002) indicated more acceptance of the cochlear implant. This is thought by some to herald a new era with a “cochlear implant world view” which will bridge the current gap that exists between the Deaf and hearing worlds (Chute & Nevins, 2002).

Each cochlear implant consists of both internal and external components (see Figure 2). The internal parts, which are surgically placed in the head behind the ear, consist of electrodes, that are arranged in an array and are responsible for sending the electrical pulses to the auditory nerve endings; a receiver-stimulator, that receives and transmits the signal; and a magnet, that holds the transmitting coil securely in place. The external parts consist of a microphone, that captures the sound; a speech processor, which is computerized and decodes speech; and rechargeable batteries to provide power to the system. These external components are carried in a pouch that is worn on the body and can also be housed in an ear-level device which looks like a hearing aid (Niparko, 2000). The microphone picks up the sound and sends it via a cable to the speech processor, which analyzes the sound into coded signals. These signals are sent to a coil which transmits them as FM signals to the implanted receiver. The electrical energy is then sent to the electrode array which is in the cochlea and the electrodes provide

Figure 2- Photographs of Cochlear Implants



External components of the Nucleus 24 cochlear implant system. Top: Bodyworn processor showing the speech processor, which also houses batteries, ear-level microphone, and circular headworn external transmitter with magnet. Bottom: Ear-level processor, which houses batteries, microphones, and speech processor, attached to circular headworn external transmitter with magnet. Copyright 2001 Cochlear Corporation. Reprinted with permission.



Ear-level processor of the Clarion cochlear implant system. A bodyworn speech processor would be connected by wire to a headpiece looking the same as the circular headpiece shown attached to the ear-level processor. Copyright 2001 Advanced Bionics Corporation. Reprinted with permission.

stimulation to the nerve endings. This electrical sound is transmitted to the auditory cortex of the brain via the auditory pathways which consist of the cochlear nuclei, the pons, the midbrain and the thalamus (Chute & Nevins, 2002).

During a surgical procedure, an incision is made behind the ear and a flap of skin covering part of the mastoid bone is raised. The surgeon then drills a space in the bone where the receiver/stimulator is placed (Staller, 1996). A tiny hole is made near the round window of the cochlea and the electrode array is threaded through the hole into the snail-shaped organ, so that the contacts follow its spiral shape and are in close contact with the nerve endings. After a four to six week period of healing, the implant is “switched on” by the audiologist, who programs the implant’s computer to send information to each of the electrodes on the electrode array, which will then send the information to the auditory nerve (Niparko, 2000). In the case of children whose profound hearing loss is due to meningitis, ossification (bone growth) may occur. Children whose cochleae have some ossification may still benefit from an implant. However, if the degree of ossification impedes the signal from reaching the auditory nerve, then the benefit may be limited (Chute & Nevins, 2002). It is common practice to expedite the provision of a cochlear implant to children who are candidates due to meningitis.

It is widely recognized that those who receive cochlear implants require intensive intervention in order to attain the maximum benefit from their device (Estabrooks, 2000; Simser, 1997). It is also acknowledged that implantation earlier in life results in better speech production (Cheng, Grant & Niparko, 1999; Fryauf-Bertschy, Tyler, Kelsay, Gantz & Woodworth, 1997; Lesinski, Battmer, Bertram & Lenarz, 1997; Waltzman & Cohen, 1998).

There are numerous studies that describe the outcomes obtained with a cochlear implant

in the areas of speech perception, the awareness of sounds and the recognition of sounds in the context of syllables and words (Spencer, 2002); speech production, the ability to formulate intelligible speech; and language, the ability to string words together in meaningful sentences (Hodges, Ash, Balkany, Butts & Schloffman, 2000; Meyer, Svirsky, Kirk & Miyamoto, 1998; Molina, Huarte, Manrique, Cervera-Paz & Garcia-Tapia, 2000; Waltzman, Cohen, Gomolin, Green, et al., 1997; Waltzman, Cohen, Gomolin, Shapiro et al., 1994).

There are far fewer studies that have examined the psychological and social aspects of cochlear implantation (Beadle, Shores & Wood, 2000; Chmiel, Sutton & Jenkins, 2000). When a child receives a cochlear implant, he/she is not the only one affected by it and there are consequences for the quality of life of the whole family (Beadle et al, 2000). In the following paragraphs, I will briefly review some recent studies in the areas of speech perception, speech production and language, as well as those that examine psychological and social aspects, and quality of life issues for the family.

In the study by Meyer et al. (1998), speech perception testing was performed over time on two groups of children, one which was comprised of cochlear implant users and the other which consisted of conventional hearing aid users. Linear regressions of speech perception scores as a function of age were calculated to determine how much improvement in speech perception might occur due to maturation. The regression lines that indicated the estimated rate of growth in speech perception with hearing aids was compared with the actual performance gains obtained by the children who wore cochlear implants. These results were compared within communication mode: total communication versus oral. It was concluded that generally speech perception scores for children who wore cochlear implants were higher than scores for children with 101 - 110 dB

hearing loss using hearing aids and neared the scores for those with 90 - 100 dB hearing loss with hearing aids. The effect of communication mode was not assessed specifically, however it was found that generally, children enrolled in oral programmes attained higher speech perception scores than those enrolled in total communication programmes. The authors stated that one cannot generalize from these findings about the superiority of one communication mode over another because there were several variables that were not controlled, such as socioeconomic status and cognitive skills. Thus the results of this study are inconclusive.

Hodges et al. (2000) assessed the speech perception skills of 40 children who wore cochlear implants, attended their centre and received a variety of intervention methods. They administered a battery of four speech perception tests to each child. They too found that those enrolled in oral programs obtained significantly higher scores than those in total communication programmes. Although factors such as surgery, implant programming, parental counselling and school inservicing were controlled by the single centre, other variables such as socioeconomic status, bilingualism, parental motivation, cognitive ability and educational setting were not controlled. These authors also advised against drawing definitive conclusions about the differences in results, thus this study too is inconclusive.

In a landmark study by Geers, Brenner and Davidson (2003), 181 American and Canadian children, aged eight and nine years, who had received their cochlear implants before the age of five years were administered a battery of tests that evaluated speech perception, production, and language. There was no comparison group, however results of speech perception testing with this cohort indicated that approximately 64% of the children understood 50% of the information presented through listening alone, in an open-set situation (that is, the examiner asks the child to

answer a question or imitate a word, phrase or sentence without pictures) and almost 80% through lipreading and listening.

Waltzman, Cohen, Gomolin, Green et al. (1997) assessed the open-set speech perception of 38 children who had received their cochlear implant before the age of five and had worn it for at least one year. There was no control group in this study, however results obtained from this group revealed that of the 38 children, 37 used oral language to communicate and one used total communication. Thirty-seven children attended regular school; one child attended an oral school for the deaf and used oral language to communicate; and one child used total communication and attended a regular school with access to a manual interpreter. All the children demonstrated significant improvement in their ability to repeat words and sentences using their implant only. In addition, the language and speech development of 33 of these children was assessed over a three year post-operative period. The Peabody Picture Vocabulary Test and the Expressive One-Word Picture Vocabulary Test were administered and mean increases of 33 months and 48 months respectively were noted with a 53-month increase in expressive vocabulary for children who received their cochlear implant before the age of two years. In addition, production of suprasegmentals (including duration, pitch, intensity and rhythm) was assessed using the CID Phonetic Inventory Samples. While the mean score obtained preoperatively was 32%, after three years of implant use, a mean score of 90% was obtained. The authors attributed this successful performance to several factors: age at implantation, length of usage, programming expertise and frequency, communication mode and educational setting.

Tobey, Geers, Brenner, Altuna and Gabbert (2003) reported on the speech production results of the 181 American and Canadian children who were described earlier. They found an

average score of 63.5% speech intelligibility on key words. Geers, Nicholas and Sedey (2003) also found that 30% of the same group of children had age-appropriate language comprehension and 47% had age-appropriate expressive language. The extent of integration into general education classrooms and emphasis on speech and listening seemed to be the major rehabilitative factors associated with all the findings of this study.

In their study, Purdy, Chard, Moran and Hodgson (1995) administered the Parenting Stress Index to the parents of six children who had received cochlear implants in New Zealand. While the mean scores fell in the average range, there were some families who exhibited extremely high stress levels. Stress levels, particularly on the subscale, Sense of Competence, seemed to increase with time. The authors posited that this could be due to poorer outcomes with the implant than anticipated or to the requirement for extensive parental involvement in the habilitation process.

These findings are similar to those of Quittner, Steck and Rouiller (1991), who administered a series of questionnaires related to daily parenting tasks, time demands and childhood deafness to 24 Canadian mothers of children who had received cochlear implants within the previous three years. They found that these mothers experienced higher stress levels than mothers of normally hearing children. In contrast to these findings, Nicholas and Geers (2003) administered three measures to assess the psycho-social adjustment of the 181 children previously assessed on speech perception, speech production and language measures. They concluded that generally, the children perceived themselves as well-adjusted and the parents concurred with this assessment. In addition, the parents were satisfied for the most part with the cochlear implant and were positive about its effects on family life.

The aim of the study by Beadle et al. (2000) was to gain knowledge about stressors in families of children with cochlear implants and to determine what factors help families cope. The authors developed a rating scale which examined four areas: parents' expectations before implantation, their views on factors that contribute to stress, their outlook on social support and items that related to quality of life. Of the 22 sets of questionnaires sent to parents, 17 were returned. The authors reported that quality of life seemed better when the parents perceived high social support, particularly from formal sources, such as educators and the cochlear implant team and that a high level of perceived social support was linked to lower ratings of parental stress. They advised that attention to siblings' needs is warranted.

Although it is acknowledged that parental support is a critical factor in determining outcomes with cochlear implants (Calien, 2002; Cohen & Waltzman, 1996), only a few studies, such as those just described, have addressed psychosocial issues of cochlear implantation from the parents' perspective. Most studies involving parents have consisted of questionnaires that poll them regarding the benefits attained by their children with the implant (Chmiel et al., 2000; Christiansen & Leigh, 2002; Cunningham, 1990; Kelsay & Tyler, 1996; Most & Zaidman-Zait, 2003; Nikolopoulos, Lloyd, Archbold & O'Donoghue, 2001; O'Neill, Lutman, Archbold, Gregory & Nikolopoulos, 2004). In the following paragraphs, the recent research by Archbold, Lutman, Gregory, O'Neill and Nikolopoulos (2002), Christiansen and Leigh (2002), Most and Zaidman-Zait (2003) and O'Neill et al. (2004) will be described. In addition, Perold's (2001) qualitative study on the experiences of mothers of children with cochlear implants will be reviewed.

The study by Archbold et al. (2002) analysed the free text responses of parents of children

who had worn cochlear implants for three years. The most common issues raised by these parents included: their increased confidence related to their children's developing communication skills; the importance of the link between the cochlear implant centre and the local educational services; and the desire for continued support from the implant centre, especially in the management of technical difficulties. .

The book written by Christiansen and Leigh (2002), *Cochlear implants in children*, is a compilation of the data obtained from the parents of 439 children who responded to a 12-page questionnaire entitled "Survey of Parents of Pediatric Implantees". The book also contains qualitative data from 56 interviews with 82 parents, conducted by the two authors. After the questionnaires were completed, the authors selected participants for their interviews. They attempted to obtain representation from a variety of regions throughout the United States and succeeded in talking with parents from 15 states. Christiansen and Leigh reported that almost all the parents they interviewed used some form of speech and "auditory therapy" with their child. In addition, many of the parents used some form of signing in their daily routines. They concluded that the ultimate usefulness of cochlear implants for the pediatric population is still being determined and depends on several factors including: the child's intellectual functioning, age at implantation, educational placement and consistent exposure to language. The authors indicated that most parents in their study felt that professionals provided them with complete information on which to make decisions. Christiansen and Leigh opined that the conflict between proponents of cochlear implants and opponents of the device is becoming less intense. They advocated for objective measures for determining success and failure with the implant, particularly in the area of psychosocial wellness. They lamented the unequal distribution of cochlear implants amongst

children in the United States as well as in Third World countries and described obstacles such as lack of access to technology, personnel and insurance coverage which will likely result in fewer children receiving implants than are eligible.

Most and Zaidman-Zait (2003) suggested that parents should be considered not only as collaborators in the intervention required for cochlear implants, but also as direct clients due to the stressful impact of this process. The purpose of their study was to determine what information parents sought concerning cochlear implants, how and when they would like to receive it, and the team member who should deliver it. They administered a questionnaire to 35 mothers of children who were cochlear implant candidates or who were currently cochlear implant users. They found that these mothers considered the ideal intervention team to be one comprised of a multidisciplinary group of professionals, including a surgeon, a psychologist, an audiologist, a social worker, a speech clinician and a teacher. They requested emotional support, and they wanted to meet parents of other children who had received cochlear implants. They also wanted to be provided with information and support throughout the first year post implantation.

O'Neill et al. (2004) tested the reliability of a validated closed-format questionnaire that assessed parents' experiences with cochlear implants and the effects on their children. This survey was based on issues that had been found to be important to parents in an earlier study (Archbold, Lutman, Gregory, O'Neill & Nikolopoulos, 2002). The questionnaire was found to have high test-retest reliability, however as with other tools of this genre there is very little scope for parents to comment on their individual perceptions.

Perold (2001) conducted semi-structured in-depth interviews with eight mothers of pre-school children who had received cochlear implants within the previous two years. All children

attended an oral pre-school programme in South Africa and received parental guidance on a regular basis. The purpose of the study was to examine mothers' expectations and the influence of satisfaction with outcomes on these expectations over time. Expectations were found to be dynamic and hope and/or knowledge were moving forces. Perold described four periods: the switch-on, the honeymoon period, the despondency period and the breakthrough phase. The switch-on was characterized by increased levels of anxiety, less reliance on knowledge and increased reliance on hope-based expectations. The honeymoon period was marked by decreased anxiety as the child's auditory responsiveness improved. This period was followed by a despondency phase when mothers' anxiety increased because of the lack of meaningful speech development. This period was accompanied by unrealistically high expectation levels. The breakthrough phase was associated with the emergence of intelligible, meaningful speech. This led to a decrease in anxiety, high levels of satisfaction and knowledge-based expectations. This study supports the conclusion of Purdy et al (1995) who surmised that parents' expectations were linked to their stress levels. Similarly, Spahn, Richter, Burger, Lohle and Wirsching (2003) found heightened expectations and stress levels in parents of children with cochlear implants. Although Perold's study (2001) has excellent clinical value in terms of counselling parents of young children with cochlear implants, it does not examine fathers' views, nor does it provide insight from any source other than individual interviews.

Cunningham (1990) indicated that parents are valuable resources, as they are in a position to report on their children's real-life performance with cochlear implants. Perold (2001) added that parental commitment, attitudes and involvement are vital factors in long-term success, but lamented the fact that there is a paucity of research that examines the degree of

satisfaction. Although the aforementioned studies have acknowledged the valuable role that parents play in a variety of intervention methods, none of them has considered parents who have selected auditory-verbal therapy for their children. As it is an approach that demands a high level of parental commitment, a study that explores their experiences with this change in their lives is warranted. Finally, in a discipline that has been dominated by quantitative methodology, there is a need to examine parents' perspectives of this transition in a way that allows them to describe their lived experiences.

Ferguson (2002) conducted a historical review of the literature on parental reactions to having a child with a disability and concluded that "the need continues for more extended narrative accounts from parents and other family members that capture the full range of details of daily life and family routine" (p. 129). Moreover, Moores (2001) stated, "Few researchers have attempted to observe systematically the impact of deafness on a child and his or her family" (p. 157). Qualitative methodology provides a vehicle for such an endeavour. Perold (2001) stated that qualitative research methodology permits the researcher to examine selected issues in depth and increases comprehension of the cases studied. Morgan-Redshaw, Wilgosh and Bibby (1990) added that open-ended interviews allow parents, who become "co-researchers", to share their experiences without the constraint of questionnaires. In the next section, the principles and practice of auditory-verbal therapy will be described and available research will be examined.

Auditory-Verbal Therapy

The pioneer work of Helen Hulick Beebe (1976), Daniel Ling (1976, 1978, 1989) and Doreen Pollack (1985, 1997) provides a foundation for the tenets which guide auditory-verbal therapy today. Each of these pioneers believes strongly that most children with hearing loss have

some residual hearing which can be utilized to develop speech and language, following normal developmental patterns (Pollack, Goldberg & Caleffe-Schenck, 1997). The goal of auditory-verbal therapy is to enable children with hearing loss to grow up within their family unit, to attend their neighbourhood schools and community centres and to become productive citizens in mainstream society (Simser, 1993).

The principles of auditory-verbal therapy include: early identification of hearing loss, prompt medical and audiological management, guidance for parents (who are the primary models for spoken language), the integration of listening into the development of children's communication and social skills, the development of skills through one-on-one teaching, the improvement of speech intelligibility through self-monitoring, the use of normal developmental patterns to promote natural communication, ongoing assessment of the above areas with modifications when required, and provision of support services to facilitate inclusion in regular classes.

Several studies provide documentation which supports the tenets of auditory-verbal therapy (Dorman, 1999). It has long been known that the majority of children with hearing loss have residual hearing that can be accessed through appropriate technology. When suitable amplification is used, these children can hear most, if not all, of the speech spectrum (Ling, 1989). Once access to the speech spectrum is provided, these children can then develop spoken language using audition. It is now accepted that there is a critical period for neurological and linguistic development (Robertson & Irvine, 1989). If the child does not receive input during the optimal language-learning years, then his/her ability to access acoustic information will decrease because of physiological and psychological factors. The first three to five years of life

are widely considered to be the crucial time during which it is important that the child receive intensive language stimulation (O'Donoghue, 1996; Spencer, 2002), but there may be variation in each child. It is therefore essential that appropriate amplification be provided to the child as early as possible.

Auditory-verbal therapy follows the sequence of normal language development. Studies have shown that infants require consistent interaction with a nurturing caregiver in a supportive environment in order to learn language most effectively (Leonard, 1991; Ross, 1990). Proponents of auditory-verbal therapy state that the advantage of this approach is that parents do not have to learn another language, such as sign language or cued speech to teach their children (Dornan, 1999). They claim that what parents must do is to “interact with a child through spoken language and create a listening environment that helps a child to learn” (Dornan, 1999, p.17). Given the emphasis on the parents' commitment in auditory-verbal therapy, it is surprising that there have been no systematic studies that examine parents' perceptions of their new roles, once they have adopted this therapy for their child.

According to the model of service provided at one Canadian hospital (Fitzpatrick, 1997), after a hearing loss is detected, the child is fitted with hearing aids and parents attend weekly therapy sessions, which usually last one to one and a half hours. During these sessions, the therapist demonstrates techniques for achieving targets in the areas of speech, language and audition. During therapy sessions, parents are encouraged to participate in the activities as the therapist models appropriate language and speech input. The parents are taught techniques for stimulating language and speech at home, and they learn to use strategies for integrating listening, speech and language into the daily home routines (Simser & Steacie, 1993). The

parents are responsible for informing the therapist of the child's current interests, for interpreting the child's early communication attempts and for being partners in the therapy process. Together, the therapist and parents discuss the child's progress and develop long and short-term goals. Throughout the years of therapy which continue for the duration of the child's preschool and school years, the parents become very knowledgeable about the management of the child's hearing loss, learn to make informed decisions and to advocate on their child's behalf (Estabrooks, 2000).

At the aforementioned hospital, when a profound hearing loss is detected in a child he/she is considered a candidate for a cochlear implant. The child is fitted with hearing aids and the parents are informed about the cochlear implant. If the parents want to pursue this option, a pre-implant assessment is carried out, during which the parents and child meet with the members of the cochlear implant team, including the surgeon, audiologist, auditory-verbal therapist and psychologist (Durieux-Smith, Angus, Fitzpatrick, Olds, Schramm, & Whittingham, 2000).

There has been a small number of studies that have documented outcomes with auditory-verbal therapy (Biro, Cumbaa, Ficker, Kelly, Olmstead, & Pugh, 1986; Durieux-Smith, Eriks-Brophy, Olds, Fitzpatrick, Duquette, & Whittingham, 2001; Easterbrooks et al., 2000; Easterbrooks & O'Rourke, 2001; Goldberg & Flexer, 1993; Lewis, 1996; Okun, 1995; Rhoades, 2001; Rhoades & Chisolm, 2000; Roberts & Rickards, 1994; Robertson & Flexer, 1993; Tyler, 1990; Wray, Flexer, & Vaccaro, 1997). One of these (Durieux-Smith et al., 2001), is a Canadian retrospective study that used quantitative and qualitative methodologies to investigate outcomes of auditory-verbal therapy in adolescents and young adults who had received preschool service at one Canadian centre in the late 1970's and 1980's. As this was a Canadian study, part of which

employed qualitative measures and family systems theory to examine parents' recollections of their experiences, it will be described in more detail below.

Of 65 young adults successfully contacted, 43 young people and their parents participated in the study. Assessment of 24 of the young adults revealed scores within the average range on measures of academic achievement, communication and self perception. These findings are in stark contrast to those reported by Carver (as cited in a status report by the Canadian Hearing Society, 2004) wherein he states that 65% of Deaf Canadians may be functionally illiterate; only 5% of Deaf students graduate from Grade 10; and 60% of this group complete their education having achieved an academic level of Grade 5 or less and an average reading level equivalent to Grade 4.

A portion of this comprehensive study (Durieux-Smith et al., 2001) involved the parents of the participating young adults who were asked to recollect their roles in the academic and social inclusion of their children (Duquette, Durieux-Smith, Olds, Fitzpatrick, Eriks-Brophy, & Whittingham, 2002). This descriptive study was guided by Turnbull and Turnbull's (1997) model of family systems theory, which states that when parents collaborate with schools they take on many roles in the education of their children with disabilities. In the first stage of the study, all the participants completed questionnaires that included items related to the family's resources, the child's school history, auditory-verbal therapy, and the child's academic and social activities. In the second phase, 24 parents and 16 young adults participated in focus groups. Each of the groups discussed the barriers and facilitators to integration provided by the school, peers and the family.

The findings indicated that parents felt they had four major roles to play in the integration

of their children: as teachers, as advocates, as members of a support group and as facilitators of social integration for their children. For the most part, these parents had experienced success in teaching their children to listen and speak during their preschool years, and therefore they felt empowered to continue to participate in their children's education. They had also acquired knowledge about the services required for their children's successful inclusion and were able to take on the role of advocate in the schools. Generally, these parents felt that the hard work involved in teaching their children and advocating for them academically and socially had been worth the effort. While this study has provided us with retrospective views of parents and we do have some testimonials and anecdotal evidence about parents' experiences (Estabrooks, 1998, 2000), we have no systematic documentation of the experiences with auditory-verbal therapy of parents whose children have been recently diagnosed with hearing loss.

Role of Parents

This section will begin with a brief description of the role of parents of typical children, followed by a discussion of the role of parents of children with disabilities. It will conclude with a review of studies related to the parenting of children with hearing loss. According to Barbara Coloroso (1994), the role of the parent is to provide encouragement and discipline to the child and to empower and influence him/her so that he/she develops to his/her potential as a responsible and productive adult. Crnic and Greenberg (1987) found that the perceptions of mothers of premature infants about their support from intimate relationships, friendships and community affected their overall life satisfaction. The authors suggested that perception of satisfaction must be investigated in relation to individual differences and personality variables. In addition, the various types of support: emotional, informational/advice and instrumental/material

may vary in different ecological contexts and the interactions between these contexts.

The parent of a child with disabilities pursues the roles to which Coloroso referred but must assume other roles as well. Parents were regarded as the source of their children's disability and were blamed for it in the early 1900's (Ferguson, 2002). Until the 1970's, intervention with children having disabilities was primarily child-centred and little consideration was given to the parents and families of these children. The 1980's brought family-centred intervention and with that, greater inclusion of parents in a variety of roles: as organization members, as service developers, as receivers of professionals' decisions, as teachers, as political advocates and as educational decision makers (Turnbull & Turnbull, 1996). A more recent role of parents is that of collaborator. In this role, parents are viewed as partners with professionals in decisions regarding their children's education. The toll that such collaboration with professionals takes on the family can be quite high, as parents feel they are being asked to become well-versed about a new system and often their role of case manager supercedes their parental role (Knoll, 1992). In the case of hearing loss, its detection in a child followed by the introduction of technology and intervention is all foreign territory for parents. The experience has been likened to "plunging parents into a totally new profession without any training" (Simser, 2001, p.47).

Parents of Children with Disabilities

It has been recognized that the family is a unit and that any change in one family member has consequences for the other members of the family (Minuchin, 1974). In the past, most studies tended to encourage the investigation of the family as the smallest unit of analysis and to discourage the examination of the experiences of each of the members independently (Traustadottir, 1991). However some authors have advocated for the examination of the family

systemically, that is, investigation of the disability's effect on parents and siblings and the response of these family members on the person with the disability (Patterson, 1991).

In many studies, the term "parent" is used but for the most part, it is the mother who is the participant (Crnic, Friedrich & Greenberg, 1983). The few studies that have examined fathers of children with disabilities have been characterized by nonrepresentative samples and weak methodology, according to Hornby (1994) who critiqued 13 studies and nine reviews of the literature on this topic. He cautioned professionals, who deal with families, that the existing literature offers a negative and erroneous view of fathers. He suggested that future research should examine comparison groups of fathers and study fathers of children with various disabilities separately.

When addressing the issue of parents and their needs, most studies tend to group parents of children with a variety of disabilities rather than focussing on one. The studies that have examined the needs of mothers and fathers separately, have found that there is a difference. While fathers want more information about the child's disability, mothers seek more emotional support and respite (Beckman, 1991; Cooper & Allred, 1992; Hadadian & Merbler, 1995; Krauss, 1993). Other studies have focused on mothers' needs for more information, respite, reading material, support groups and more personal time (Brotherson & Goldstein, 1992; Garshelis & McConnell, 1993; Gowen, Christy & Sparling, 1993; Krauss, Upshur, Shonkoff & Hauser-Cram, 1993; McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993). It has been found that the mother in particular, often takes on the role of maintaining the family's well-being, as well as the additional demands made on her by the needs of the child with a disability (DeVault, 1999; Traustadottir, 1995). Indeed, Koester and Meadow-Orlans (1990) found that

mothers of children with hearing loss often feel pressure to stay home and become their child's full-time teacher.

In their oft-cited study of fathers and mothers of young developmentally disabled and nondisabled boys, Bristol, Gallagher and Schopler (1988) found that fathers of disabled children assumed less responsibility for their care and that the amount of involvement was even more reduced in children with more severe disabilities. An interesting finding of this study was that greater harmony between spouses occurred when the amount of support expected was the same as the amount offered by the other spouse.

Willoughby and Glidden (1995) also found that when fathers of developmentally disabled children participated more in the care of their children, there was greater marital satisfaction for both mothers and fathers. Similarly, Vadasy, Fewell, Greenberg, Desmond and Myer (1986) reported that fathers' participation in a Fathers Program, consisting of support and information, resulted in reduced stress levels, greater social support and more information for both mothers and fathers. Despite the great differences that were observed in the dynamics of family functioning between families of children with disabilities and those whose children were not disabled, there did not appear to be a direct relationship between the severity of the disabilities and the measures of adaptation (Bristol et al., 1988). Thus the authors concluded that the effect of having a child with disabilities must be considered within the context of family relationships.

Parents of Children with Hearing Loss

Studies of parents of children with hearing loss tend to include children who have experienced a variety of interventions, instead of focusing on one method (Morgan-Redshaw et al., 1990) or they neglect to mention the type of intervention (Quittner, 1991; Meadow-Orlans &

Steinberg, 1993). Although auditory-verbal therapy requires an enormous commitment on the part of parents, there are few studies that report on the needs or perceptions of parents who have chosen this intervention option.

Crnic et al. (1983) bemoaned the unidimensionality and unimodality of research with families having a child with developmental delay. To a great extent this is the case in research with parents of hearing impaired children. Most studies focus on one family member, usually the mother, and use questionnaires or rating scales to obtain information (Cunningham, 1990), although more recently there has been a call for investigations that address members of the extended family and individual family differences, as well as other ecological factors (Calderon, Bargones & Sidman, 1998; Fisiloglu & Fisiloglu, 1996). Calderon and Greenberg (2003) state, “there is a need to conceptualize the multiple reciprocal interactions among persons and environment that determine healthy, competent behaviour” (p.187).

Research related to the parents of children with hearing loss generally falls into the following main categories, according to Meadow-Orlans (1990): the effects of the hearing impaired child on the parents in terms of their grief, their coping and their stress levels; the communicative interactions between the child and his/her parents; the relationships of parents with professionals who provide service to their child; parent satisfaction with their child's performance; and the relationship between the child and other members of his/her environment including siblings and grandparents. In the following paragraphs, these topics will be discussed.

Parents' Stress, Support and Coping.

Stress can be defined as physiological, cognitive or emotional strain or tension. One type of stress is that experienced in the role of parent (Crnic & Booth, 1991; Pipp-Siegel, Sedey, &

Yoshinaga-Itano, 2002). It is widely believed that the presence of stress is dependent on the person's perception of a situation, that is the meaning attached to it, as well as the individual's estimate of his/her ability to cope with this stress (Meadow-Orlans, 1990; Quittner et al., 1991; Seligman & Darling, 1997).

The literature seems ambiguous about the effects of stress on the family (Feher-Prout, 1996). Some studies have indicated that the mother's adjustment may influence the adaptation of the whole family, as may coping resources such as problem-solving skills and social support networks (Calderon & Greenberg, 1999; Feher-Prout, 1996). Meadow-Orlans (1995) reported that both mothers and fathers of nine month-old babies with hearing loss obtained similar overall scores on the Parent Stress Index but that there were differences on the subtest scores. Fathers reported more stress on the subtests related to appearance and interaction and difficulty in caring for and comforting the child and worry about the future. Mothers' scores reflected greater depression, greater restriction of role and more concern regarding their spousal relationships. In general, mothers indicated that they felt greater life stress. Similar to the findings of Crnic and Greenberg (1987), analyses of these mothers' interactions with their babies at 18 months of age revealed a relationship between family support and positive maternal behaviours.

Some authors have reported that while there is stress in families that have children with disabilities, this does not necessarily render these families dysfunctional (Ferguson, 2002; Fisiloglu & Fisiloglu, 1996; Seligman & Darling, 1997) and in fact may present an opportunity for personal growth (Fisiloglu & Fisiloglu, 1996). While some investigators have observed more stress in parents of children with hearing loss (Quittner, Gluekauf & Jackson, 1990), others have reported no difference in the levels of stress between mothers of hearing preschoolers and

mothers of preschoolers with hearing impairment (Lederberg & Golbach, 2002). Some have found that stress has a negative effect on families of children who wear cochlear implants (Olds, Fitzpatrick, Durieux-Smith & Schramm, 2004; Quittner et al., 1991), while other investigators have not noted this tendency (Horsch, Weber, Bertram & Detrois, 1997). It is unclear whether it is the nature of parents' expectations and therapy demands related to the cochlear implant that create more stress in parents whose children wear these devices or the number of pre- and post-operative visits, the surgery and hospital stay and the financial costs (Most & Zaidman-Zait, 2003; Quittner et al., 1991). The three studies that examined stress in parents of children who wore cochlear implants will be described below.

Quittner et al. (1991) conducted a study with the parents of 24 children, each of whom had worn their implants for an average of two years. Thirteen children had received 3M/House single-channel devices and eleven wore Nucleus 22-channel implants. Approximately half (54.2%) of the children used total communication and 45.8% used oral communication or cued speech. The investigators defined stress as difficulties in completing daily routines and parenting tasks, time demands related to caretaking and stress involved in communicating with a child who has a hearing impairment. Three measures of parenting stressors, the Time Demands Scale from the Questionnaire on Resources and Stress (QRS), the Stress and Communication subscales from the Impact of Childhood Hearing Loss Questionnaire and the Family Stress Scale were administered. In addition, two measures of psychological distress, the Center for Epidemiological Studies-Depression Scale (CES-D) and selected subscales from the Symptom Checklist-90 Revised (SCL-90-R) were employed. The Meaningful Auditory Integration Scale (MAIS) which assesses the child's daily use of the implant was also used.

Although the children with single-channel devices had worn their implants more than twice as long as those with multi-channel implants, the authors found no relationship between time of use and parental stress and adjustment. Activities involving communication issues, behaviour and differential treatment of the child with hearing loss were rated as the highest disability-specific stressors. The authors suggested that the greater stress levels measured with the multi-channel implant may be related to the greater time commitment involved in programming and therapy, as well as to the higher expectations for the multi-channel implant. As the children had worn their multi-channel implants only just over one year, performance would likely continue to improve and therefore stress levels might decrease with time.

The investigators advised that their results should be viewed with caution because of the small sample size and the difficulty of separating the effects of the variables, length of use and type of device. They recommended that social workers and psychologists affiliated with cochlear implant teams should aid families in developing coping strategies and that follow-up within the first year or two post implant may be warranted.

Olds et al. (2004) reported preliminary findings of a prospective study being conducted in Ontario, Canada. The subjects recruited to date include: 48 children with normal hearing, 15 children with hearing aids and 13 children with cochlear implants. Outcome assessments in the following areas will be completed at 12, 18, 24, 36, 48 and 60 months: speech perception, language, cognition and social-emotional and behavioural functioning. The Parent Stress Index was included as a measure of social-emotional and behavioural functioning and preliminary findings on a subset of these participants indicate higher stress in parents of children with cochlear implants than in the parents of children in the other two groups.

Horsch et al. (1997) administered the Parent Stress Index (PSI) and also conducted qualitative problem-oriented interviews with the parents of children who wore cochlear implants ($n = 81$). The PSI was also administered to parents of deaf children ($n = 33$) and hearing children ($n = 27$). The authors did not state whether the deaf children wore some other amplification device, nor did they indicate what type of communication mode was used with the children. They also did not describe the interview protocol used. Their results indicated that parents of children with cochlear implants seemed to have developed strategies for reducing stress and even reported rich positive experiences. The investigators noted that in the interviews, mothers described a positive relationship with their partners. The authors remarked that these parents were amongst the first in Germany to have selected cochlear implants for their children, as the study took place in 1994 - 1995. As they were pioneers in this medical and educational realm, the authors caution that they may not be typical of parents of children with cochlear implants.

Communicative Interactions.

The literature on communicative interaction tends to examine outcomes based on parent-child interaction rather than parents' perceptions of their interactions. Meadow-Orlans and Steinberg (1993) noted positive effects of social support on mother-child interactions. They concluded that such a finding supports an ecological schema that stresses the importance of the extended family, professionals and the community in supporting the development of the child with hearing loss.

Calderon and Low (1998) examined the social-emotional, language and academic outcomes of children with hearing loss, some of whose fathers were present at the time of early intervention and some of whose fathers were not present. Their sample of 22 children with

moderately severe to profound hearing loss all were enrolled in a program that offered total communication as the intervention approach. In contrast to the study by Meadow-Orlans (1995), the investigators found that the fathers' presence or absence had no effect on the mothers' behaviour or perceptions about their children. However, it was noted that children with a father present demonstrated better language skills at the time of discharge from the early intervention programme (at 3 years of age) than their peers without a father present. In addition, those strengths endured over time (9 to 47 months post early intervention).

Parent-Professional Relationships.

Professionals support parents in a variety of ways: at the time of diagnosis; in procuring appropriate services, equipment and programs; in planning for the future as well as the present; and in dealing with financial and childcare issues (Meadow-Orlans & Sass-Lehrer, 1995). It has been suggested that professionals who work with parents of hearing impaired children have a history of directing families regarding appropriate service and of teaching the child rather than providing emotional and informational support that considers the following elements: an understanding of the variety of cultural and linguistic backgrounds and a sensitivity and respect for individual responses to the diagnosis of hearing loss (Meadow-Orlans & Sass-Lehrer, 1995). Harrison et al. (1996) concurred with this view and indicated that the change from child-centred to family-centred service delivery represents a change in philosophy for many professionals for which their training has not prepared them. Winton and DiVenere (1995) indicated that professionals are now being required to exercise less power and foster the empowerment of families by recognizing and supporting their expertise. These authors advocated an ecological approach in which strong parent-professional collaboration would encourage the participation of

the child's family, extended family and network of caregivers.

There are several variables that affect the relationship between the professional and the parent: gender, that is, fathers attend parent meetings less than mothers because these often do not address their needs, which differ from those of mothers (Meadow-Orlans, 1990); the hearing status of parents, whether deaf or hearing; and parental language and cultural background (Steinberg, Davila, Collazo, Loew & Fischgrund, 1997). Professionals must be aware that socioeconomic status including parents' age, education and marital status will also affect their ability to benefit from services (Meadow-Orlans & Sass-Lehrer, 1995).

Meadow-Orlans and Sass-Lehrer (1995) advised that professionals must maintain a delicate balance between encouraging parents to make decisions regarding their children and advocating for what they feel would be the best choice for the child. The results of a survey study by Roush, Harrison and Palsha (1991) supported this finding and indicated that when there is a conflict between parent and professional preferences, professionals are often reluctant to defer to parents' priorities. Similarly, the results of the qualitative investigation by Minke and Scott (1995) indicated that both parents and staff rated the importance of personal relationships highly, however staff found it difficult to support parental decisions in all cases and felt a loss of control when their advice was not followed on some issues. In a questionnaire distributed by Meadow-Orlans (1990) both mothers and fathers of younger children rated their relationships with professionals better than the parents of older children. It was suggested that this may indicate that services had improved since the parents of older children received information about diagnosis and remediation. Alternatively, it may represent progressive dissatisfaction on the part of parents as their children grew older. In a survey study conducted by Sjoblad, Harrison, Roush

and McWilliam (2001), in which they examined the ages of identification of hearing loss, they also found that the relationship between the family and the audiologist plays an important role in the families' ultimate management of their child's hearing loss. They advocated an ecological approach to the process of intervention.

While most of the studies cited above do not separate the views of mothers and fathers, one recent study by Dromi and Ingber (1999) involved interviews with 50 Israeli mothers. They found that these mothers sought professionals who have excellent interpersonal skills and provide information, support and guidance. They preferred to have one professional, either the speech pathologist or deaf educator, as case manager. They also indicated that it was important to them to be able to rely on the professional who teaches their child and that that person should have good counselling skills, including empathy, openness and thoughtfulness. In view of the many variables affecting parent-professional relationships, it appears that an ecological approach is warranted. Such an approach would consider not only the dyadic parent-professional relationship but also the extended family, the support network, the workplace and policy issues that may interact with the parent-professional relationship and have effects on the parents and the child.

Parents' Satisfaction with Outcomes.

Most studies that investigate parents' satisfaction use questionnaires to obtain their information. Cunningham (1990) administered a questionnaire to the parents of 132 children aged 3 to 17 years, 69% of whom used total communication. All the children had been implanted with the 3M/House cochlear implant. He found that the parents reported significant effects of the implant on the perception of environmental sound and speech production.

Approximately half the parents expressed concern about the size and the cords of the external processor. He concluded that “parents are uniquely situated to comment knowledgeably about their children’s real-world performance. As such, they are a valuable resource that can be used to improve our understanding of cochlear implants in children” (p. 380).

Similarly, Vidas, Hassan, and Parnes (1992) found that parents influence the attitudes of children as well as those of their teachers and clinicians. They distributed questionnaires to the parents and therapists of four children living in Ontario, Canada in order to determine their real-life performance with their Nucleus 22-channel cochlear implant. All the children were receiving auditory-verbal therapy. All respondents reported that the children performed better in structured than in unstructured settings. The therapists’ responses most closely corresponded to the results of speech perception testing, as did the responses of the two parents who were most involved with their child’s therapy. The authors recommended that all individuals involved with the child should meet regularly in order to obtain a realistic impression of the child’s performance with the implant. Although this study examined parents’ views using questionnaires instead of more naturalistic means, it is interesting that the investigators consulted with therapists as well, thus providing information from a source other than the immediate family.

Kelsay and Tyler (1996) examined parents’ perceptions of their child’s performance with a multi-channel cochlear implant (the Nucleus 22-electrode cochlear implant). Over a four year time period, 50 parents were given an open-ended questionnaire in which they were asked to list the benefits and disadvantages of the cochlear implant. All of the children, with the exception of three, used total communication. The three remaining children communicated orally. Similar to the findings of Cunningham (1990), their results indicated that parents expected and reported

improvements in the following areas of performance: environmental sound perception, speech perception and speech production. The only disadvantages reported were in the areas of the size and maintenance of the equipment.

Robinshaw and Evans (2001) set out to determine the kinds of service considered desirable by parents in England. Their study consisted of two phases: first, the distribution of surveys to professionals who described existing models of service delivery to preschoolers; and secondly, semistructured interviews with the heads of the schools selected for study, in addition to focus groups with the parents whose children attended these facilities. This comprehensive study is one of the few that used naturalistic methodology to obtain parents' perceptions. The focus groups examined the following areas: the nature of the service being provided; their experience of it in terms of logistics, comprehensiveness and accessibility; their perceptions of the benefits they obtained in support of their child; the areas where they perceived gaps in service and support; their perceptions of their own role in stimulating their child's linguistic development; and their perceptions of the role of other agencies in supporting them and their families.

Their findings indicated that these parents wanted to receive information at an early stage from a team of professionals who were sensitive to their needs. They also wanted to participate in support groups with other parents who have children with hearing loss. Finally, they recommended family-centred programming which is convenient and considers the needs of the family as a whole. Of the nine centres that participated in this study, three provided exemplary service, incorporating the features which the authors deemed to comprise best practice: a) referral and early identification, b) family focus and parent-professional partnership, c) multi-agency

participation, d) monitoring and assessment of provision, e) assessment and statementing of the child's needs and f) funding and management. Two of these three exemplary centres offered auditory-verbal therapy services. Unfortunately, the findings obtained from the auditory-verbal therapy centres were not analysed separately from the others.

Interaction with Siblings and Grandparents.

Quittner (1991) indicated that there was no difference in the stress levels of mothers of preschool hearing children and mothers of preschool hearing impaired children in the domains of toilet training and sibling interaction. The fact that mothers of normally hearing children rated sibling interaction second in difficulty after behaviour management indicates that with this age group, sibling interaction tends to be a stressful issue. Morgan-Redshaw et al. (1990) reported that the siblings in their qualitative study were generally protective. However, similarly to Quittner (1991), they found that there was some tension between siblings when the child with hearing loss was younger because he/she received a lot of their mother's time and the sibling was asked to assume additional responsibilities. They noted that by adolescence, when the child with hearing loss had become more independent, the tension between them seemed to decline.

Citing family systems theory as a rationale for investigating environmental rather than individual explanations of behaviour, Bat-Chava and Martin (2002) proposed to study the relationships of siblings with their brothers and sisters who have hearing impairment. They conducted 29 in-depth interviews with the parents of 37 children who wore cochlear implants or hearing aids. They found that family context is important in understanding the relationships of children with hearing loss and their siblings, as did Israelite (1985). They observed that children who wore cochlear implants appeared to enjoy better relationships than those who wore hearing

aids and found that if parents compared the hearing sibling negatively with the hearing impaired child, this differential treatment affected the relationship negatively. While the authors noted generally satisfactory relationships between siblings, similarly to Quittner (1991) and Morgan-Redshaw et al. (1990) they observed friction when the younger sibling was the one with hearing loss. They attributed this finding to the differential treatment the younger sibling may continue to receive from parents, the conception of the younger child as “different” and the lack of effective communication strategies employed by the older sibling. They added that family size and parents’ anxiety about deafness were also crucial elements in sibling relationships.

Kizielewicz (1999) provided an anecdotal account of her family’s and several other families’ experiences dealing with the relationships between their child with a cochlear implant and his/her siblings. In one case, where the child suffered a hearing loss as a result of meningitis, the older sister experienced a sense of loss of a companion as she had known her. In another family, the older sister became quite overprotective and the family encouraged separate activities for the girls in order to foster their independence. The author cited the views of Dr. David Luterman, Professor of Communication Disorders at Emerson College, who indicated that there is an effect on the normally hearing sibling that varies according to birth order and gender. The oldest male tends to be least affected and the oldest female child most affected. Some of the negative consequences he mentioned are: the adoption of a caregiving role at a young age, anger about the attention provided to the child with the hearing loss, fear of losing their own hearing and guilt about not having a hearing loss. He added that there are some positive aspects for siblings including: being more responsible, capable and compassionate towards others. He recommended that time be set aside for each of the hearing children. He also suggested that the

health of siblings is dependent on the parents' adjustment to the hearing loss.

Nybo, Scherman and Freeman (1998) completed a qualitative study that was comprised of interviews with one member of each of three generations of the participating families. It was found that the grandparents proved to be helpful in the families' adjustment to the hearing loss. It appeared that the overriding role of the grandparent was to assist in stressful times. Other factors that tempered that role included geographic location, the parent-grandparent relationship and the financial resources of the grandparent. The authors suggested that grandparents faced difficulties due to their lack of access to medical information, the sacrifice of their own need for adjustment in order to help their grandchild and their lack of a peer group with whom to share these issues. The researchers concluded that professionals should be aware of the importance of grandparents in helping families adjust in times of crisis.

Family Systems Theory

In the area of education of children with hearing loss, service delivery models have evolved since the 1970's from child-centred to mother-centred to parent-centred to the more recent family-centred approach. Three developments contributed to the current emphasis on a family-centred approach. First, research indicated that parents are important language models for their children. Second, in the United States, the passage of Public Law 94-142 in 1975 mandated the involvement of parents in the planning of their child's education. Last, there was a growing realization that early intervention in the first two years of a child's life can have significant benefits (Fitzgerald & Fischer, 1987). These findings of the 1970's resulted in greater parent participation in the education of children with hearing loss and paved the way for the inclusion of the family as a whole. The Education for Handicapped Children Act of 1986 (Public Law 99-

457) in the United States broadened the scope of Public Law 94 - 142 and legislated a role for families in the education of young children with hearing loss (Harrison et al., 1996).

In Canada, although the Hope Commission had advocated for special education programs in 1950, it was not until the 1960's that the sporadic service for children with exceptionalities developed into a movement to educate these children according to their needs. The medical model which emphasized students' inadequacies, was replaced by a move to normalization, led by Wolf Wolfensberger of the National Institute on Mental Retardation. While the provinces of Nova Scotia and Saskatchewan had legislated special education services in the early 1970's, it was not until 1982 that Ontario enacted Bill 82 which mandated provision for students with special needs.

The implementation of Bill 82 was established with alacrity and ensured that every school board in the province offered a special education programme or paid another board to do so. Identification, Placement and Review Committees (IPRCs) identified children who were exceptional and parents of the identified student were included in the process. Each school board established a Special Education Advisory Committee (SEAC), whose role was to make recommendations regarding service for children with special needs. It was mandated that a special education plan be administered by each board and that procedures which ensure early and ongoing identification of children with special needs be implemented (Weber & Bennett, 2004).

As developments over the last two decades have led to more involvement of families in intervention with hearing impaired children, there has been a call for an ecological perspective. Such a viewpoint regards the child as a member of a family system and requires that intervention target the range of relationships in the child's environment and help develop social networks that

encourage families to gain confidence in their ability to manage their child with hearing loss (Fitzgerald & Fischer, 1987). It is now realized that hearing impairment has an impact on the entire family and therefore the family requires resources, counselling and support (Koester & Meadow-Orlans, 1990). There is an interplay between the child, family and environmental characteristics that affect and are affected by the intervention process, therefore it is imperative to investigate these dynamic processes (Calderon & Greenberg, 1997). Both family systems and ecological theorists offer frameworks that allow the child to be viewed within a broader cultural and social context. These models allow the components of the child's family system and environment to be understood (Hammer, 1998).

While intervention programmes in the field of education were evolving from child-centred to family-centred, so too was the field of mental health counselling embracing models that encourage intervention with families rather than with individuals. One of these models is a systems approach to family therapy, which recognizes the interaction between family members as well as their effect on each other. The family systems model acknowledges that the behaviour of one member influences all members of the family (Morton, 2000).

The framework for discussing family systems theory that is used in this thesis is described by Turnbull and Turnbull (1990, 1997). According to these authors, family systems theory comprises three assumptions. The first is that the family system responds and interacts with inputs and in so doing carries out family functions which create outputs. The second assumption is that the family must be considered as a whole entity which consists of subsystems (marital, parental, sibling and extended). The last assumption is that family subsystems have boundaries between them that affect their interaction with each other and with those outside the

subsystems. The family's characteristics will affect the nature of these boundaries. Family interactions are characterized by varying degrees of cohesion, that is the emotional attachment and level of independence each family member feels towards the others, and by adaptability, the ability to respond to change and stress.

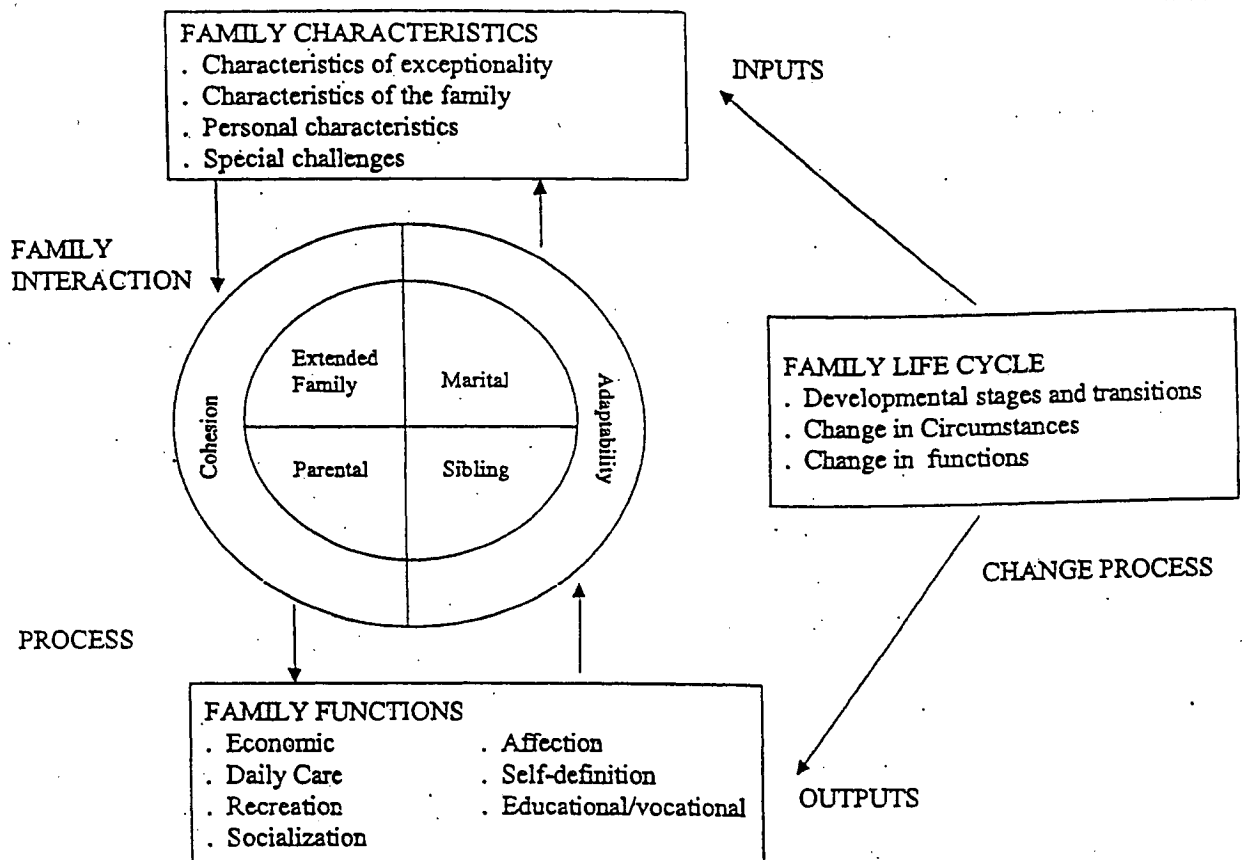
In their model (see Figure 3), the Turnbulls describe four major domains: family characteristics, family interaction, family functions and family life cycle. Family characteristics are referred to as the input to the system and include all those ways in which families may differ: characteristics of the disability, characteristics of the family, personal characteristics, and special challenges. Family size, form and socioeconomic background are all part of family characteristics. Physical and mental health and individual coping styles comprise personal characteristics. Special challenges may include poverty, parental disability and/or substance abuse (Turnbull & Turnbull, 1997).

Family interaction is regarded as the process component of the system. Herein are included roles, relationships and communication that take place among family members on a regular basis. The four subsystems of family interaction are the marital, parental, sibling and extended family subsystems.

Family functions are the output of the system, which are the many responsibilities families must fulfill in order to meet the needs of each of its members. These include economic, recreational, social, physical and health, educational and emotional needs.

Family life cycle refers to the changes and transitions, both developmental and nondevelopmental, that confront families over time. The diagnosis of hearing loss in a young child is one such transition. This change process has a profound effect on family characteristics,

Figure 3- Model of Family Systems Theory



From: Families, professionals, and exceptionality: A special partnership. (3rd ed.) 1997
 A. Turnbull.& H. R. Turnbull. Chap. 7, p. 116
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interactions and functions.

Dunst, Trivette and Deal (1988) devised an assessment procedure based on a family systems model to be used in intervening with families of children with special needs. Their aims were to enable families, by encouraging them to become more independent in mobilizing their social networks to get their needs met; to empower them by helping them increase their sense of control over their lives; to strengthen them by supporting those skills they already performed well; and to increase their competencies in meeting their needs through their social networks. The authors posited seven social units which they organized into four major categories represented by concentric circles with the immediate family being at the innermost circle and kinship network, informal network, professionals and organizations and influences of the larger society representing the more distal circles. While these authors referred to their model as a family systems approach, their framework borrows significantly from that of Bronfenbrenner (1979, 1995).

Turnbull, Turbiville and Turnbull (2000) described four types of parent-professional partnerships: parent counselling/psychotherapy; family involvement; family-centred; and collective empowerment. The parent counselling/psychotherapy model deems the professional the “expert” who must “fix” the mother-child relationship (referred to as the mother-child microsystem by the authors). The family involvement model treats the parent, usually the mother, as in need of training to develop her child. The professionals’ role in this model is to train the parent to provide the intervention. The family-centred model acknowledges the relationship between immediate family members, extended family and community and aims to improve the family’s well-being. The collective empowerment model encourages collaboration between

parents and professionals which results in a synergy of power that radiates out to the community. This model assumes access to resources, participation and changing community ecology. In keeping with these assumptions, the authors proposed a model that incorporates the four levels of Bronfenbrenner's (1979) framework. Inherent in this model is the need for parents to be aware of community resources and to be partners in decision-making.

Garbarino (1982) stated, "Families are the central microsystem, the 'headquarters' for human development. Therefore we must know the kinds of experiences a family offers parents and children if we are to understand the ecology of human development" (p.62). He then described family characteristics, developmental stages and functions, similar to those outlined by family systems theorists and embedded his discussion of family as a microsystem within the ecological framework set out by Bronfenbrenner (1979). Thus, the aforementioned researchers, while advocating a family systems approach, see the virtue of incorporating this approach into a more ecologically expansive framework. In the next section, Bronfenbrenner's model, which provides a taxonomy with which to discuss various ecological levels, will be introduced and described.

The Theory of the Ecology of Human Development

While consideration of the family as a changing interdependent unit represents major progress in its conceptualization, there still remains the fact that the family functions within a broader societal context which must be addressed (Seligman, 1991).

Similar to what occurs within the family (and as delineated by the family systems model), the basic tenet of the ecological model is that a change in any part of the ecological system affects subparts of the system, creating the need for system adaptation, that is, for

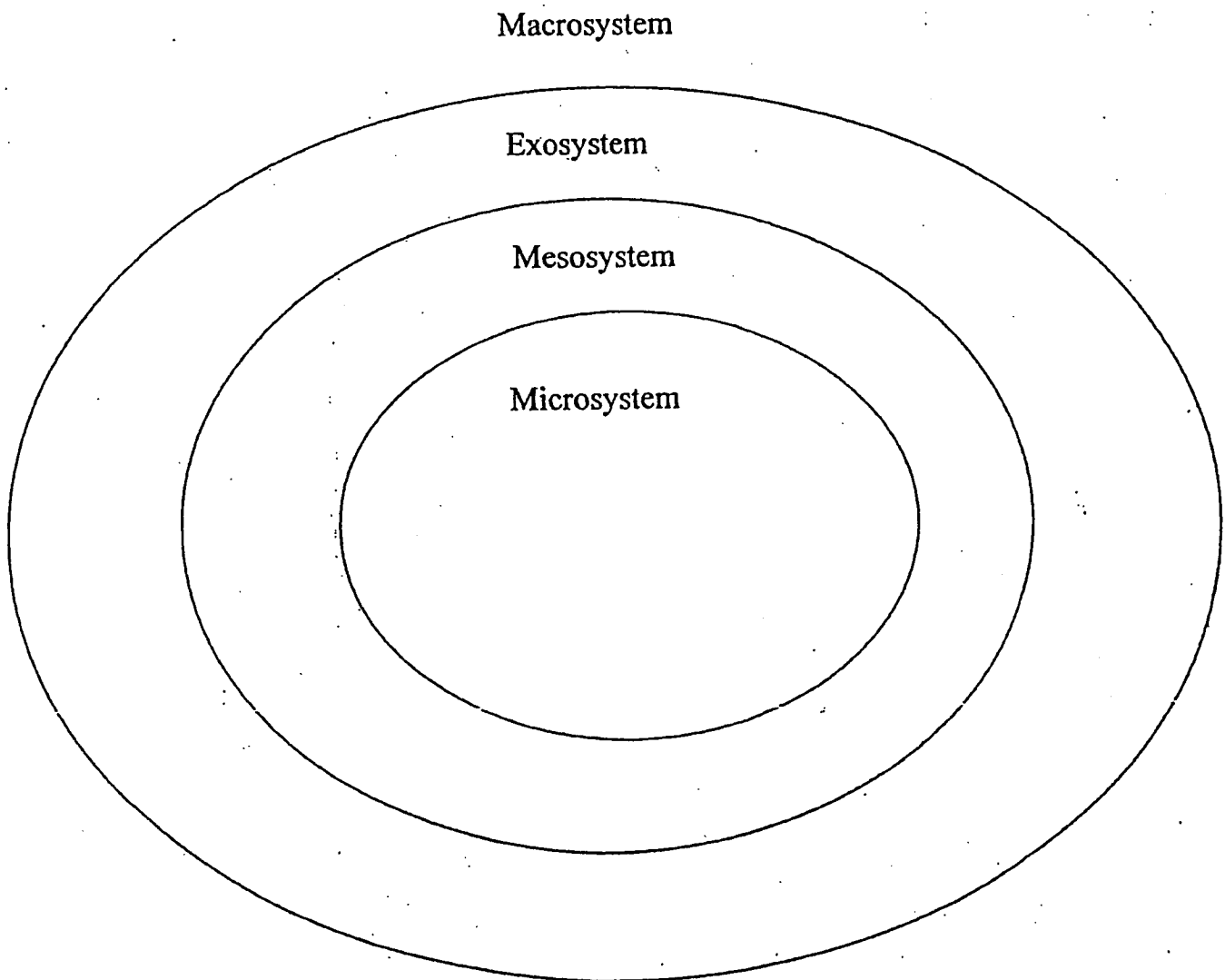
equilibrium (Seligman, 1991, p.36).

Seligman (1991) posited further that in helping families who have children with disabilities, it is not sufficient to address only the child, nor even the relationships within the family, but in addition, it is crucial to examine the family within the social, political and economic circumstances with which it is faced. Bronfenbrenner's (1979) theory of the ecology of human development provides a taxonomy for consideration of the developing child as well as for the examination of nondevelopmental changes, such as transitions that are not related to age and stage.

This theory has been applied to adolescents with exceptionalities who are making a transition from high school to the work force (Petruka, 2001), as well as to children with other disabilities (Bubolz & Whiren, 1984; Champion, 1983; Mitchell, 1983) and to children with hearing loss who use a variety of communication approaches (Cebe, 1996; Konstantareas & Lampropoulou, 1995; Lampropoulou & Konstantareas, 1998). It has not to date been applied in naturalistic settings to children whose families have selected auditory-verbal therapy as a means of intervention.

Bronfenbrenner originally proposed the theory of the ecology of human development in 1979 and then subsequently renamed it the bioecological systems theory in 1995 (see Figure 4). Seligman (1991) suggested that it may have been Kurt Lewin in the 1930's and 1940's who laid

Figure 4- Model - Conceptualization of Bronfenbrenner's Theory of the Ecology of Human Development (1979)



the groundwork for the social ecological viewpoint when he posited Field theory, which viewed the adaptation of an object as dependent on the field in which it exists. Bronfenbrenner's theory, to which I will refer as the theory of the ecology of human development, proposes a hierarchical system of four nested levels: the microsystem, the mesosystem, the exosystem and the macrosystem, each of which impact on the development of the individual.

The theory suggests that child development is influenced not only by the most immediate environments in which the individual is situated, but that change is mediated also by the more distal settings in which these environments are embedded (Anderson, 1983). Some of these environments work simultaneously to mediate change and the influence of some may precede or follow the change. The term, development, is commonly used to refer to the set of changes that occur in physical, social, intellectual and personal characteristics as a person grows older (McMillan, 1990). Bronfenbrenner expands on this definition by examining the meaning of this change for the person who is experiencing it.

He uses the term ecological transition to refer to that which "takes place whenever during the life course, a person undergoes a change in role either within the same or in a different setting" (Bronfenbrenner & Crouter, 1983, p. 381). When the individual is involved in such a transition, he/she must adopt new roles, new activities and new relationships (McMillan, 1990). Such transitions actually represent "experiments of nature", as examination of them can provide before/after information about an intervention (McMillan, 1990). In the case of parents who discover that their child has a hearing loss, their role of parent is altered and they undergo an ecological transition.

Microsystem

The microsystem is the immediate setting in which the individual participates. This setting is characterized by roles, activities and interpersonal relationships. Crucial to Bronfenbrenner's model is the individual's perception of each of these. A role is defined at the level of the culture or subculture, that is at the level of the macrosystem. Activities are ongoing behaviours that are perceived as having meaning or intent by the participants in the setting. An interpersonal relation exists whenever one person in a setting participates in activities with another, thus establishing a dyad. Within the microsystem, there may be a variety of primary dyads, which are comprised of two people who have emotional significance for each other. Bronfenbrenner (1979) hypothesizes that when one member of a dyad undergoes a developmental change or transition, so too will the other member.

Mesosystem

Most individuals are involved in more than one microsystem and move from one setting to the next. A mesosystem consists of the relationship between two or more microsystems, as perceived by the person in transition. The links between these settings may be direct or indirect. When one person participates in two or more settings, this is considered a direct link or first-order network. When the individual is connected to a setting only by an intermediary, then this is an indirect link, or second-order social network.

Exosystem

This level consists of one or more settings that do not involve the person in transition directly, but nevertheless impact on that person, for example the relationship of parents to the Ministries of Health and Education.

Macrosystem

This level includes the belief systems, and ideology that characterize a culture and subculture and the consistency of the content of the micro-, meso- and exosystems of which it is comprised. In his 1995 version of the ecological model, Bronfenbrenner suggested that the individual's own developmental life course is shaped by the events and conditions that exist during the historical period through which the person lives.

While this model has been lauded for its emphasis on multilevel analysis of the interaction between the child and his/her environment, some feel that it does not go far enough and that the focus on child outcomes and traditional measures remains (Minuchin, 1985). As well, the requirement for multiple settings has been described by some as a formidable task for investigators trained to study the individual (Sameroff, Seifer, Baldwin & Baldwin, 1993). Moreover, there is no discussion in the theory regarding the methods by which ecologically valid data may be obtained (McMillan, 1990). Bronfenbrenner (1995) states that his theory has been accused of emphasizing laboratory settings at the expense of more naturalistic settings.

More recently, it has been suggested that Bronfenbrenner's ecological framework can provide a useful tool for examining the reciprocal influence of families and the environment on children with special needs (Sontag, 1996). The oft-cited studies by Cochran and Brassard (1979), Crnic and Greenberg (1987) and Crnic et al. (1983) applied adaptations of Bronfenbrenner's model to explore the concept of social support. While the former two studies employed the model with groups of normally developing children, the latter study examined children with developmental disability.

Cochran and Brassard (1979) adapted the ecological model to discuss the effects of parents' personal social networks on their attitudes and the direct and indirect influences of these networks on the normally developing child. Similarly, Crnic and Greenberg (1987) examined spousal support and satisfaction with that support in the postpartum adaptation of mothers of premature and full-term babies. They concluded that the need for different levels of support may vary with individual parents at particular times.

The ecological theory has also been cited in studies that have investigated children with special needs. Crnic et al. (1983) examined families' adaptation to a child with developmental disability. They examined the features that differentiated families who coped well with the stress of having a child with developmental delay from those who did not. Similarly to Quittner et al. (1991) and Seligman and Darling (1997), they found that a family's perceived stress is a function of the coping resources available to the family and that these resources are influenced by the ecological systems in which the family is involved. Bubolz and Whiren (1984) proposed a holistic framework for delivering service to the family of a disabled individual based on an ecological systems model. More recently, Duckworth et al. (2001) have used an ecological model, which they refer to as a wraparound system, in managing children with emotional and behavioural disorders.

Mitchell (1983) applied Bronfenbrenner's model to children with developmental delay in New Zealand. He likened the microsystem to the immediate family described in family systems theory, and included the following dyads: mother/father, mother/disabled child, mother/nondisabled child, father/disabled child, father/nondisabled child, disabled child/nondisabled child. At the mesosystem level, he included medical and health workers as well as extended

family. At the level of the exosystem, he discussed health and education policies and at the macrosystem level he referred to the belief systems represented by social institutions. A particularly valuable feature of Mitchell's discussion is his reference to the developmental tasks that parents must accomplish at each of four stages in the developmentally disabled person's life: initial diagnosis; infancy and toddlerhood; childhood and early adolescence; and late adolescence and adulthood. The author posited that the manner in which these tasks are resolved will have implications for the future adaptations of parents to their child with developmental delay.

P.R. Champion (1983) employed Bronfenbrenner's model in a doctoral dissertation that studied early intervention with children who had Down syndrome. The ecological model was selected to guide this study as the author felt that if early intervention was to be effective, it would have to create changes in the "context" in which these children lived. These changes would then enable the parents, siblings, extended family and community to carry out activities that would encourage development in the child with Down syndrome.

This study took place in New Zealand over a two year period. Eleven infants and their caregivers attended weekly sessions where procedures for stimulating language, physical, cognitive and social growth were demonstrated. The emphasis was on a parent-professional partnership and weekly contact provided opportunities for the parents to interact with each other and gain social support, as well as to learn about child development and its application to children with Down syndrome. The evaluation involved ongoing assessment of infant progress and various instruments were used to obtain a representative sample of both child and caregiver behaviours. This intervention group was compared with a group of four infants, who received no intervention. The comparison group was born in a similar time frame at Queen Mary Hospital,

Dunedin.

The author found that the intervention programme introduced a new microsystem that consisted of new activities, roles and interpersonal relations. Prior to the intervention, the infants experienced one microsystem, that of the home. By introducing a new microsystem in which the child and parent participated, other microsystems were affected and a mesosystem was formed. The new microsystem altered the home microsystem in several ways: household routines and equipment were adapted to teach skills and the family's activities with the infant were modified. The extent to which the intervention system altered the existing system depended on several factors: the mother's personal style of interaction, the role of the father, the role of siblings, socioeconomic status and the belief systems of the home. The roles of caregivers changed as they took on the role of the child's teacher. Families experienced changes in the children and individual families became involved in a variety of settings, for example picnics and other visits. It was also noted that mothers often engaged in more community-based activities. The author concluded by observing that the introduction of the new microsystem created a mesosystem that would not have existed at the infancy stage.

This study provides a valuable addition to those that have applied Bronfenbrenner's model to the study of children with special needs. Although Champion (1983) indicated that a critical element in describing the microsystem is an understanding of how it is experienced by those who participate in it, the reader does not glean from this study the experiences and perspectives of the families, as objective measures were the primary tools employed to collect data. In addition, information about family characteristics and interactions were not provided in this study.

Only three studies that have employed Bronfenbrenner's model with children who have hearing loss have been located. Cebe's (1996) doctoral dissertation included children with a variety of special needs including hearing impairment. The studies by Konstantareas and Lampropoulou (1995) and Lampropoulou and Konstantareas (1998) examined stress in mothers of children with hearing loss who used total communication. Although they did not use Bronfenbrenner's model to guide their study, Calderon and Naidu (2000) cited his theory as support for their contention that deafness does not necessarily lead to poor academic and social outcomes but that these are rather the result of the interaction between the child with hearing loss and his/her family and educational climate. Their study used this rationale to support early identification of hearing loss, followed by early intervention. The first three studies cited above will now be described in more detail.

In her doctoral dissertation, Cebe (1996) examined parents' satisfaction with preschool services for their children with a variety of special needs. Her study was guided by family systems theory and Bronfenbrenner's ecological model (1979). Her stated purpose was to determine the extent to which parents were satisfied with special education services provided to the child and family, to measure the influence of child-related, parent/family and program-related variables on their level of satisfaction and to obtain parents' recommendations for improving services. The sample population was drawn from those parents whose children (3 to 5 years old) were enrolled in a preschool special education programme in a large suburban school district in the Washington, D.C. metropolitan area prior to April, 1995 and continued to receive services during the 1995 - 1996 school year. Sixteen hundred (1600) preschool children received services in three settings: 110 preschool classes in 23 elementary schools, three centres for deaf and hard

of hearing students (where cued speech, total communication and oral methods were used) and two home resource centres. A validated instrument, the Parent Satisfaction Survey: Parts A and B and Importance Rating, was used to collect data. Part A was a researcher-developed survey aimed at obtaining data on child and parent/family-related variables. Part B assessed parent satisfaction related to program variables and section 3 consisted of an Importance Rating that was used to measure parents' ideals or expectations. The results of section 3 were compared with the parent satisfaction survey results. Fifty-seven percent of the surveys were returned. Her findings indicated that parents were not satisfied with certain elements of the service: the information provided on normal development and behaviour, the utilization of community resources and the development of a support system. She concluded that those who didn't pay for additional services, those who had a positive first experience with the school system staff and those whose child's disability was mild or moderate not severe or profound, were more satisfied with services.

Cebe's study adds to our knowledge base regarding services for children with disabilities, however she relied only on quantitative measures to do so. Her findings for children with hearing loss were not separated from those obtained for children with other disabilities, and there may be differences between these populations. In addition, she did not distinguish between mothers and fathers in considering the responses and as has been discussed, their concerns may be different (Calderon & Low, 1998).

In their 1995 study, Konstantareas and Lampropoulou examined the effect of having a child with hearing impairment on the stress levels of 42 hearing mothers living in Greece. The authors employed Hill's (1949) ABCX model of stress (A is the stressor, in this case the child with hearing impairment; B refers to the family's resources; C is the cognitive component or

meaning attached to the stressor, and X refers to the interactions of these variables and to the family's adaptation) and Bronfenbrenner's ecological model to examine deafness and also to furnish information about cross-cultural research on stress. The mothers' names were randomly drawn from lists obtained from three of the main educational programmes for deaf children, all of which provided total communication programmes. The students enrolled in these schools comprised 38% of the total population of students enrolled in special schools or units in Greece. The investigators reported that maternal stress was higher if the child's hearing loss was detected before the age of 18 months. They concluded that degree of hearing loss, family size and socioeconomic status appeared to be unrelated to stress, while self-esteem did seem to be related. The authors stated that a number of cultural issues seemed to affect their results. There are few government programmes available to parents (exosystem) and the macrosystem level leaves the microsystem and mesosystem levels to manage stressors. Consequently, the mothers might feel helpless in changing their child's outcome. In addition, the traditional family roles present in Greek society may place added pressure on mothers and the proximity of extended family may be a source of stress as the deaf child is compared to his/her typical cousins.

The 1998 study of Lampropoulou and Konstantareas investigated the same cohort of Greek mothers of children with hearing loss and aimed to consider the following variables: degree of maternal involvement; the distribution of this involvement as a function of age; and the affective tone related to this involvement. Greek mothers who reported higher stress levels were involved for longer periods of time with their children and indicated that they did not enjoy these activities. The authors added that these mothers knew very little sign language and the limited communication with their children may have exacerbated their stress levels. In addition, they

received very little support from extended families and only limited support from neighbours. They compared this group with four groups of Canadian mothers who had participated in an earlier study. These included: children without disabilities, with autism, with developmental delay, and with learning disability. Despite the fact that the Greek mothers reported lower stress levels than all the Canadian mothers of children with disabilities, they expressed a more negative affective tone than the other mothers. This finding was attributed to the cultural practice of openly expressing feelings or to lower levels of defensiveness in the Greek women or possibly to greater defensiveness on the part of Canadian women.

While this study contributes to our knowledge of cross-cultural differences at the microsystem, mesosystem, exosystem and macrosystem levels with regard to children with hearing loss, its applicability is limited to children who use total communication. It considered only one variable, that of stress. It did not address children with cochlear implants, nor did its quantitative methodology consider the complexity of the interaction amongst other variables and the meaning attached to them by the participating parents.

Thus Bronfenbrenner's model has been useful for understanding intervention with children having a variety of special needs. Given the ecological transition lived by the parents of children who choose auditory-verbal therapy, it is surprising that this model has not been employed as a guide for examining their experiences with this transition. There is a need for research that investigates the transition parents incur as they meet the challenge of providing auditory-verbal therapy to their very young children with cochlear implants. Currently, there is a gap in our knowledge about how parents experience the changes they must make in their daily lives and in their community affiliations when they discover that their child has a significant

hearing loss and requires a cochlear implant, as well as a special type of intervention in order to learn to speak. The present study addresses the elements in the immediate family (microsystem), the intervention setting (mesosystem), the public policies (exosystem) and the belief system (macrosystem) that impede this transition, as well as those elements that facilitate it.

Beadle et al. (2000) stated,

As an increasing number of children receive cochlear implants, it is important to find out not only how successful cochlear implantation is in providing profoundly deaf children with sound perception, but also how the process of cochlear implantation and the long training period that follows it affect the lives of child implant recipients and their families (p. 114).

In the following section, the conceptual framework that has guided this study, will be described. While it is primarily based on Bronfenbrenner's theory of the ecology of human development, it also draws from family systems theory.

Conceptual Framework

The literature indicates that family involvement is an important factor in the development of children with hearing loss (Moeller, 2000) and that the meaning ascribed to the experience of having a child with a disability is fundamental in the parent's adaptation (Seligman & Darling, 1997). The implementation of a system of universal neonatal hearing screening in Ontario and the availability of cochlear implants for babies as young as 12 months has led to earlier therapeutic intervention. In view of the fact that this approach is offered throughout the province, and in light of the intense parental commitment it requires, it is crucial that an understanding of parents' experiences with this approach be obtained. Konstantareas and Lampropoulou (1995)

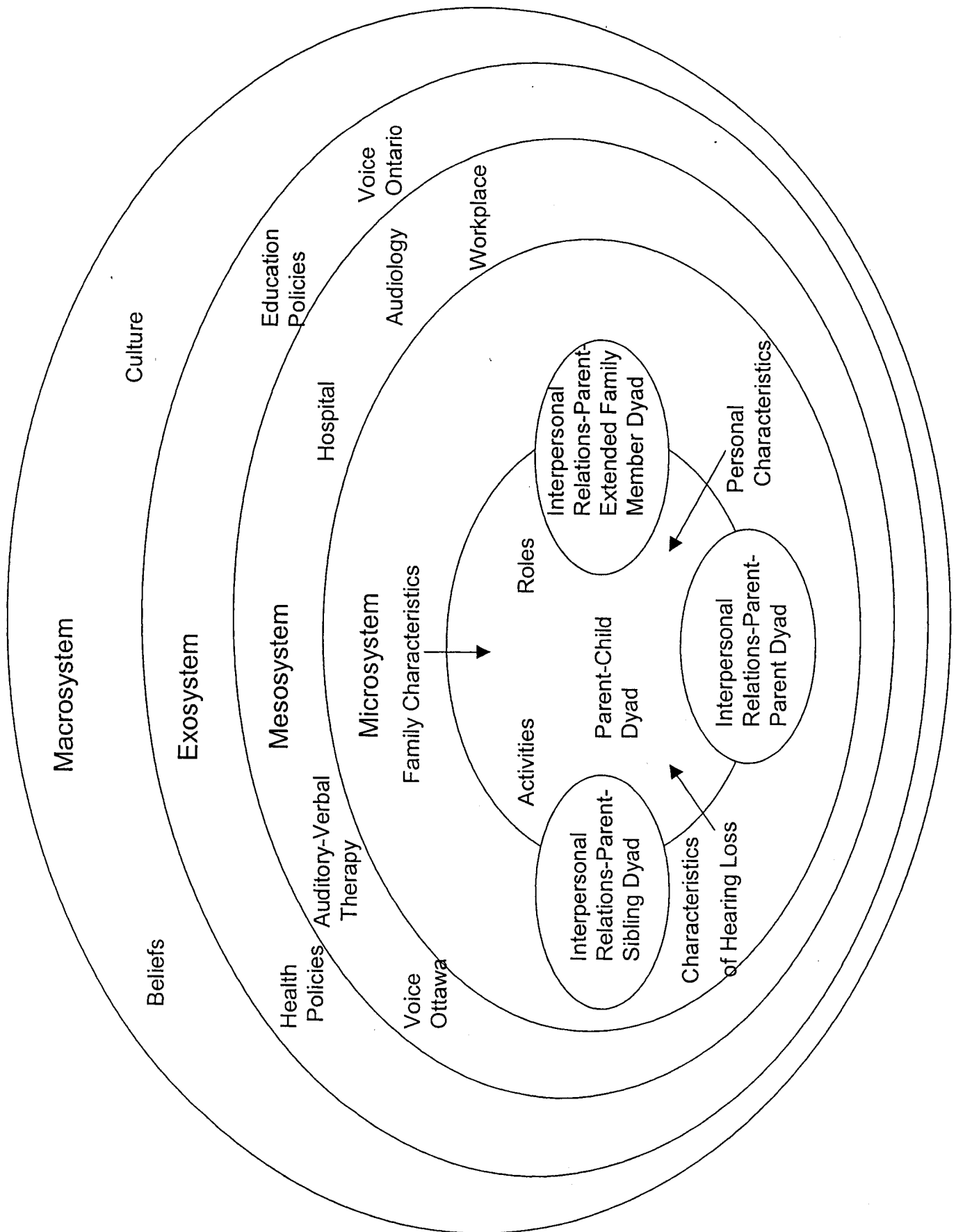
stated, "It is quite evident that we cannot understand a family's adaptation to a child who is deaf unless these broader social structures and institutions are taken into account as well" (p. 265).

When parents learn that their child has a hearing loss, it is suggested that they undergo an ecological transition, which incorporates the period of time from detection of the hearing loss to fitting of amplification to adopting a therapeutic intervention. They must abandon one vision of their child and accommodate to a new reality that includes professionals, equipment and a "way of life" that may be quite foreign to them. While Bronfenbrenner's model captures the essence of the environmental impact on the parents as they undergo this transition, it does not specifically address the family characteristics that have an impact. The proposed model melds the features of the family and those of the environment that influence the parents' perceptions of this transition.

Similar to Bronfenbrenner's model, the proposed framework (see Figure 5) consists of four concentric circles, with the largest being the macrosystem and the smallest being the microsystem. Each of these levels influences the others, and the experiences of parents as they make this transition to auditory-verbal therapy will be influenced by each of these levels.

The macrosystem is described by Bronfenbrenner as the belief systems, ideology and policies that characterize a culture, and that are in place prior to the detection of a particular child's hearing loss. It corresponds to the beliefs about the potential of children with hearing loss and to the ideology which provides access to health and education in Ontario. Auditory-verbal therapy is a method of intervention used in Ontario. There are, in addition, proponents of Deaf culture, whose members support sign language as the first option for hearing impaired children. The availability of auditory-verbal therapy and of the technology appropriate for its

Figure 5- Model of Conceptual Framework



implementation will have a major influence on events at the other three levels of the model. In turn, each of these levels will influence the macrosystem.

The exosystem consists of one or more settings that do not involve the person in transition directly, and which may have been in place prior to the detection of a particular child's hearing loss. Voice Ontario, which is a group of parents and professionals who deal with children having hearing loss, has played a significant advocacy role in the Ottawa-Carleton area and, in fact, throughout the province of Ontario (Fitzpatrick, 1997). With its representatives sitting on committees at the level of boards of education, as well as at the level of the provincial Ministry of Education, it has been instrumental in establishing audiological and therapy services for children with hearing loss. At the exosystem level is included legislation such as universal newborn hearing screening, which has been mandated in this province and will likely result in earlier detection of hearing loss and earlier therapeutic intervention.

The mesosystem consists of the relationship that exists between two or more microsystems. In the case of the proposed model, the parent is a member of the parent-child dyad, the parent-parent dyad, the parent-sibling dyad, the parent-grandparent dyad and then also becomes a member of the parent-therapist dyad. The parent provides a link between the child and therapist as well as between the child and other members of the Audiology Service. The parent may be directly involved in these two microsystems, home and hospital, or indirectly involved, as when the therapist and audiologist confer about the child or when another member of the extended family, such as the grandparent, attends therapy sessions with the child. During the auditory-verbal therapy process, the therapist attempts to familiarize himself/herself with the family's routines, in order to incorporate these into the goals, which are agreed upon by the

parents. He/she attempts to create activities that are similar to those in which the parent-child dyad might engage at home, and he/she coaches the parent in his/her role as parent/teacher. The local chapter of Voice is also included at the mesosystem level, as the interaction between Voice and the therapist and/or audiologist may not involve the parent directly, but may nevertheless have an impact on the parent. The parent's workplace also forms part of the mesosystem.

The innermost circle of the model is the microsystem, which consists of the interpersonal relations, activities and roles that take place between the parent and the child. Bronfenbrenner (1979) indicates that the microsystem may be comprised of a variety of primary dyads, which consist of two people who have emotional significance for each other. In the proposed model, the parent-parent dyad, the parent-sibling dyad and the parent-member-of-the-extended family dyad are included at the microsystem level. Each of these relationships represents the element of family interaction, referred to in family systems theory and the interpersonal relations which Bronfenbrenner describes. These relationships comprise the home setting that surrounds the parent-child dyad. The activities are the nonverbal and verbal play activities in which the parent-child dyad engages with the goal of accessing listening in order to develop speech and language. The roles taken on by the parents as they adopt auditory-verbal therapy are addressed at this level as well.

This model depicts the influence of the family and personal characteristics on the parent-child dyad by arrows. With reference to Turnbull and Turnbull's (1997) framework of family systems theory, the family characteristics and family interactions are at the microsystem level of this model, while family functions are found throughout the mesosystem and exosystem levels. As the different stages of the family life cycle influence each of the other components of family

systems theory and also comprise a time element, this is considered to be at the macrosystem level, in which the three other concentric circles are nested.

Research Questions

The purpose of the study, therefore, was to examine the changes incurred by the family when it adopts auditory-verbal therapy. The major research question was: What are parents' experiences in making the transition to auditory-verbal therapy with their children who wear cochlear implants? The secondary questions were:

- (1) What are the parents' daily activities, roles, and interpersonal relations and how are these changed by the transition to auditory-verbal therapy?
- (2) What personal and family characteristics impede and/or facilitate this transition at the level of the microsystem?
- (3) What elements of the auditory-verbal therapy model and workplace impede and/or facilitate this transition at the level of the mesosystem?
- (4) What elements of the public policies impede and/or facilitate this transition at the level of the exosystem?
- (5) What elements of the culture and belief system about hearing loss impede and/or facilitate this transition at the level of the macrosystem?

Summary

This chapter has provided an overview of relevant research in the areas of cochlear implants, auditory-verbal therapy, the role of the parent of typical children, as well as children with disabilities and specifically, those with hearing loss. It has also described the conceptual framework that guided this study. Following is an account of how parents experience the changes they must make in their daily lives and in their community affiliations when they discover that their child has a significant hearing loss and requires a cochlear implant, as well as a special type of intervention in order to learn to speak. It addresses the elements in the immediate family (microsystem), the intervention setting (mesosystem), the public policies (exosystem) and the belief system (macrosystem) that may facilitate and may provide challenges to this transition. In exploring this research area, this study will extend the theory of the ecology of human development. It will not only increase awareness of the experiences of parents, but also contribute to the practice of auditory-verbal therapy.

CHAPTER 3

METHODOLOGY

To understand the experiences of families who adopt auditory-verbal therapy for their children with severe to profound hearing loss, it was necessary to enter their homes and gain their trust. In this way they could share their feelings and perceptions with me regarding their transition to the world of hearing impairment, including its technology and remediation.

It appeared, therefore, that a qualitative methodology would best guide this study. An important purpose of qualitative research is to describe the perceptions of a group of people about specific issues (Hogan, 1997), as it aims to depict the subject of interest from the perspective of the participants (Merriam, 1998) and focuses on the meaning people make of their lives in a cooperative and interactive fashion (Barnes, 1992; Carpender, 2000). Marshall and Rossman (1999) state that “Qualitative research is pragmatic, interpretive and grounded in the lived experiences of people” (p. 2). It is naturalistic, employs multiple methods to obtain information, and constructs knowledge from the data collected (Stake, 1995).

Qualitative research has been used more frequently in recent years to investigate the delivery of services for children with disabilities (Katz & Scarpati, 1995). In addition, some researchers are advocating its use in the field of human communication disorders. “The goal of qualitative research, as applied to communication disorders, is to describe and explain human communication in terms of its meaning in the lives of people living in their specific social contexts” (DiLollo & Wolter, 2004, p. 5). At this point, there are no studies that have examined parents’ experiences of the transition to auditory-verbal therapy with young children who have severe to profound hearing loss. Therefore, qualitative research methods were selected to obtain

data that would lead to an understanding of the experiences and perspectives of these parents.

This study was guided by a case study research design. Creswell (1998) states that “a case study is the exploration of a ‘bounded system’ or a case (or multiple cases) over time through detailed, in-depth data collection, involving multiple sources of information, rich in context” (p. 61). This method is particularistic in that it focuses on a specific phenomenon, which is bounded by time and place (Merriam, 1998). It delimits the object of study, that is, there is a limit to the number of participants who could be interviewed and a finite amount of time for observations (Merriam, 1998). Guided by a constructivist paradigm, which will be described in the next section, the data for this research were collected using an exploratory multiple case study approach within a single site.

Constructivist Paradigm

Denzin and Lincoln (2000) indicate that paradigms “represent belief systems that attach users to particular world views” (p. 6). The qualitative researcher is guided by a set of beliefs that determine how she understands the world, how she formulates questions and how she interprets findings. Therefore it is important to examine the belief system espoused by the researcher. Each paradigm is defined by its views on the following premises: ontology (“What is the nature of reality?”); and epistemology (“What is the relationship between the inquirer and the known?”); (Denzin & Lincoln, 2000, p.19) as well as axiology (What are the values of the researcher?). Methodology is considered an umbrella term encompassing the other three and related to the logic behind the method used (R. LeBlanc, personal communication, March, 2004). In my own case, I am an auditory-verbal therapist who believes that most children with severe to profound hearing loss can develop spoken language, following the principles of auditory-verbal therapy,

when they are provided with cochlear implants. I believe that effective parent guidance and inclusion or mainstreaming facilitate this process.

According to the constructivist paradigm, humans don't find knowledge; rather, they create it. We invent concepts to make sense of our experiences, and we constantly alter these constructs based on new experiences (Denzin & Lincoln, 2000). From an ontological perspective, the constructivist paradigm assumes that there are multiple realities. The epistemological basis of constructivism is that these realities are created by the researcher and participants. The researcher is viewed as a "passionate participant" who facilitates the reconstructions of many voices (Lincoln & Guba, 2000). The methodological procedures are naturalistic (Denzin & Lincoln, 2000).

Thus, in order to understand the multiple realities perceived by families who experience auditory-verbal therapy, a case study approach driven by a constructivist paradigm seemed appropriate. Such an approach gives voice to participants in a variety of naturalistic contexts.

Participants

The participants in this study included: (a) parents, (b) children, (c) siblings, and (d) therapists. The selection criteria included: (a) parenting a child who had been diagnosed with severe to profound hearing loss and received auditory-verbal therapy in English, (b) enrollment in the auditory-verbal therapy programme at an Ontario pediatric hospital for at least one year (c) the presence of at least one older sibling with normal hearing and development, so that the parents had experienced child-rearing before the diagnosis of hearing loss, and (d) being a practitioner of auditory-verbal therapy for at least one of the participating families. It was understood that as the youngest child in each family was the one with hearing loss, this meant

that the whole family had to make a transition to auditory-verbal therapy. It was decided not to invite the nanny or the parent tutors who worked with some of the families, in order to keep the information equitable amongst all the participants. Due to the low incidence of hearing loss in the population, there were only six families that met the selection criteria. This number excludes the two families for whom I provide auditory-verbal therapy, as I felt it would be difficult to interview and observe these parents in an unbiased fashion. The therapists who work with the eligible families were provided with a letter outlining the purpose of the study (see Appendix B). They were asked to give this letter to those families who met the eligibility criteria, and interested parents were told that I would contact them. In all, five families agreed to participate in the study. They included: Nancy Wood and her daughter, Diane; Margaret Briggs and Jean Dupuis and their daughter, Melanie; Susan and Zach Owen and their son, Peter; Evelyn and Dave Wright and their daughter, Allison; and Kyla and Jared Jones and their daughter, Shelley. The two auditory-verbal therapists who agreed to participate were Sarah Randall and Simone Serr.

Nancy Wood was a single mother who had two daughters, Linda and Diane. Linda, who was 19 years old at the time of this study, worked part-time and Diane who was 3 years old received her cochlear implant at 2 years of age. Nancy emigrated from Jamaica in 1991 and worked full-time at a centre for seniors. Diane attended a home daycare which was managed by Janet, one of Nancy's neighbours. This home daycare was located in the same apartment building, where the family lived. Most of the five children who were cared for by Janet spoke Arabic as their first language, however Janet spoke English to Diane. Nancy received the services of a parent tutor, Frances, who had a 10-year old daughter with a cochlear implant. Frances provided therapy to Diane for four hours each week under the supervision of her

auditory-verbal therapist, Simone Serr. In addition, Frances took Diane to a play group for two hours each week.

Margaret Briggs and Jean Dupuis were the parents of Mark, aged 8 and Melanie, aged 6. Melanie had been wearing her cochlear implant for 18 months at the time of this study. Margaret worked as an accountant at an engineering firm, and Jean worked in automotive sales. While both parents had agreed to participate at the time of our first contact, they later contemplated withdrawing from the study as they had recently separated. After discussing it further, they decided to continue their involvement in the research. The family had lived in western Quebec at the time of the detection of Melanie's hearing loss, but had recently moved to Ontario. Melanie had just turned 6 at the time of my observations and was attending Senior Kindergarten at her local school. She was receiving the service of an itinerant teacher of the hearing impaired, employed by the local school board. Her visits to the hospital for auditory-verbal therapy with Sarah Randall had terminated four months earlier. Jean had moved back to western Quebec when I first encountered the family, while Margaret and the children were living in a townhouse in Ontario. While Jean's native language was French and Margaret's was English, they have spoken English to the children since birth. They had planned to educate the children at a French school but had abandoned that idea when Melanie's hearing loss was detected and when Mark began experiencing difficulty at school. Jean was the only participant who preferred that his interview not be audiotaped. Although he did not offer a reason for this, it is possibly due to the fact that his speech is mildly dysfluent and that English is his second language. His responses to questions were therefore recorded by hand.

Susan and Zach Owen had three children, Sean, aged 9, Kate, aged 7 and Peter, aged 4,

who received a cochlear implant at the age of 15 months. Zach was a partner in his own management consulting company and Susan had worked as a systems analyst, but had recently decided to stay at home with the children. Peter was receiving weekly auditory-verbal therapy sessions with Sarah Randall at the hospital. He was enrolled in Junior Kindergarten at his local school, where he also received the service of an itinerant teacher of the hearing impaired, who visited him three times each week. The family spoke English as their native language.

Evelyn and Dave had three children at the time of the study, Mitchell, aged 6 and twin girls, Allison and Melissa, aged 5. Allison had been wearing her cochlear implant for approximately three years at the time of the study. Dave worked as a financial analyst in a government agency and Evelyn worked at two part-time jobs, one as a florist and the other as a clerk in a retail store. Allison had recently completed her auditory-verbal therapy programme at the hospital, where she had received service from Sarah Randall. She was enrolled in Senior Kindergarten at her local school and was receiving service from an itinerant teacher of the hearing impaired, who visited her four times each week. Although Evelyn's first language had been French, she spoke English fluently and both parents spoke only English to the children.

Kyla and Jared Jones had two daughters, Sally, aged 9 and Shelley, aged 4. Shelley had been wearing her cochlear implant for about 2 ½ years at the time of the study. Jared worked as a computer professional and Kyla stayed at home to take care of the children. Shelley had been receiving auditory-verbal therapy from Sarah Randall since the fitting of her hearing aids at 11 months of age. Shelley attended Montessori school, but the family was planning to enrol her in the public school system when she turned six years old. Both parents had emigrated from India and their first language is Tamil, however they had chosen to speak English in the home soon

after Shelley's hearing loss was detected. When they first heard about the study, they said they would participate if I needed more people. As I did need more participants, I telephoned the mother and she was happy to meet with me, indicating that her initial hesitation stemmed from the fact that the family was building a home and she thought she wouldn't have the time to participate. This was the last family with whom I met, and by that time they were fully moved into their new home.

Two of the families were Caucasian, English-speaking and had two parents living with the child. Two of the families were led by single parents. Three of the families had at least one parent for whom English was not the native language. Two of the families were composed of members of a racial group other than Caucasian, one of Jamaican descent and the other of Indian descent. A description of the participants and their pseudonyms can be found in Table 1.

I provided letters describing the study to the two therapists who worked with the families and both agreed to participate. One therapist worked with four of the families and the second worked with the other one. All the children were cochlear implant users. Thus, there were five children, nine parents and two auditory-verbal therapists who participated in the study.

Access and Consent

The Research and Ethics Committee at the hospital reviewed my proposal. I was then asked to meet the Committee members as a group, give a brief presentation about the study, and answer the Committee members' questions. I was given permission to proceed with the study once I made some minor revisions to the proposal.

Table 1

Participants

Participant Type	Pseudonyms	Gender M/F	Age in years	Relationship
Child	Diane	F	3	N/A
Child	Melanie	F	6	N/A
Child	Peter	M	4	N/A
Child	Allison	F	5	N/A
Child	Shelley	F	4	N/A
Parent	Nancy Wood	F	N/A	Mother of Diane
Parent	Margaret Briggs	F	N/A	Mother of Melanie
Parent	Jean Dupuis	M	N/A	Father of Melanie
Parent	Susan Owen	F	N/A	Mother of Peter
Parent	Zach Owen	M	N/A	Father of Peter
Parent	Evelyn Wright	F	N/A	Mother of Allison
Parent	Dave Wright	M	N/A	Father of Allison
Parent	Kyla Jones	F	N/A	Mother of Shelley
Parent	Jared Jones	M	N/A	Father of Shelley
Auditory-Verbal Therapist	Sarah Randall	F	N/A	Auditory-Verbal Therapist for Allison, Peter, Melanie and Shelley
Auditory-Verbal Therapist	Simone Serr	F	N/A	Auditory-Verbal Therapist for Diane

After obtaining approval from the hospital, I distributed letters describing the study to the therapists (see Appendix B). I also contacted the family whom I intended to ask to participate in the pilot study.

At my first visit with the families, I informed them of their rights and responsibilities as participants, including the ability to withdraw from the study at any time. The participants were also guaranteed confidentiality and have been assigned pseudonyms in this thesis. A signed copy of the participants' consent forms were retained (see Appendix B for a copy of the consent form).

Pilot Study

As the number of children who might potentially meet the selection criteria was small, it was decided to invite the parents of a very young school-aged child to participate in a pilot study. The child was male, 7 years of age, and had one older sibling with normal hearing and development. He and his family had been enrolled in the preschool auditory-verbal therapy programme at the hospital during his preschool years. I conducted two observations with the family, and then had semi-structured interviews with each of the parents. I later made a final visit to the family to conduct a third observation. This small pilot study allowed me to hone my observation and interviewing skills. In addition, I was able to ensure that the proposed data collection methods were feasible (Seidman, 1991), that the interview questions could be understood, and that it was possible to glean data from them. The use of a pilot study in which both parents are interviewed separately, was suggested by Cooper and Allred (1992). They posited that mothers and fathers view their disabled children differently and that having both perspectives enriches the data. After interviewing these parents, minor changes to the interview protocol were made.

Main Study Research Design

There were four data collection methods employed: (a) observation sessions, (b) interviews, (c) a discussion group, and (d) a questionnaire regarding the demographics of the participating families. A summary of these can be found in Table 2. The primary modes of data collection were interviews and observations. Triangulation involves the use of a variety of methods for data collection. Maxwell (1996) indicates that employing such a technique reduces the risk of bias of a specific method. Each of these modes of data collection are described more fully in the following sections.

Observation Sessions

“Observation entails the systematic noting and recording of events, behaviours and artifacts (objects) in the social setting chosen for study” (Marshall and Rossman, 1999, p. 107). In order to obtain in-depth and detailed data about the experience of auditory-verbal therapy and how the daily activities of a family are changed by its introduction, observations were conducted with each family. Such observations provided information about the microsystem level of the model. Three observation sessions were accomplished with each family during the 10-month period in which data were collected. Each session was approximately 60 minutes to 90 minutes in duration. These observations were held at times that were convenient to the families during the morning, afternoon and evening. It was felt that by scheduling the

Table 2

Methodology

	DEMOGRAPHIC QUESTIONNAIRE	OBSERVATIONS	INTERVIEWS	DISCUSSION GROUP
PURPOSE	-to obtain demographic information regarding family, workplace	-to become familiar with the setting and the participants -to note interaction between children and parents, activities in which they engage	-to obtain information regarding transition to auditory-verbal therapy at the levels of the microsystem, mesosystem, exosystem and macrosystem	-to gain additional insights regarding the transition to auditory-verbal therapy at the levels of the microsystem, mesosystem, exosystem and macrosystem
PARTICIPANTS	-parents of 5 children with severe to profound hearing loss (9 parents)	-5 families having children with severe to profound hearing loss	-9 parents -2 auditory-verbal therapists	-2 parents
DATA COLLECTION PROCEDURE	-written questionnaire	-participant observations during informal play between parents and child	-semi-structured interviews	-group discussion
DATA COLLECTION ACTION	-complete questionnaire with parents in interview format	-observe, record, audiotape and transcribe	-semi-structured interviews, audiotape and transcribe	-audiotape and transcribe
FREQUENCY	-once with all participant families	-3 times with each family at varying times during the day	-once with each participant	-once with the group
RESEARCH QUESTION	#2	#1	#1,2,3,4,5	#1,2,3,4,5

observations at varying times throughout the day I could secure an understanding of the range of activities in which the families engaged. Hasselkus (2000) suggested that this type of scheduling contributes to the depth and breadth of the data record. These observations focused on the activities engaged in by the child and parent, both incidental and planned, the setting, the parent's roles and the verbal and nonverbal interaction between the parent and child (see Appendix C for a sample of the observation focus form). Copious notes were taken during the observation sessions. In addition, the observations were audiotaped and transcriptions of each observation were completed.

At the initial visit, I spent some time getting to know the participants and putting them at ease. During subsequent visits, I attempted to be as unobtrusive as possible. My role was one of "observer as participant", in which the researcher's participation is secondary to her role as collector of data (Merriam, 1998, p.101). I found that after the first meeting, the family members became more comfortable with my presence. The parents tended to include me in activities and wanted to chat with me and I became more of a participant with each successive visit. Several of the siblings of the children with hearing loss were also interested in interacting with me. For the most part, the families carried on with their routine activities. I found this was generally easier for them to do if my visit coincided with a time when the family was engaged in a prescribed activity, such as breakfast in the morning or bedtime routines at night. At other times, I had the impression that some families attempted to do activities which they thought would please me. After my third and final visit with the families, I gave each one a gift certificate to Chapters, a retail bookstore, to thank them in a small way for their valuable participation.

Interviews

Merriam (1998) indicated that the researcher can effectively obtain information through interviewing when conducting case studies of a few individuals. Meadow-Orlans (1990), in her discussion of the impact of childhood hearing loss on the family, stated that “distinct differences exist between the richness of experience conveyed through a narrative and the quantitative response provided to a written question” (p. 322). She further stated that an interview is the preferred way of collecting information, but that time constraints often oblige the researcher to use questionnaires. In their study of family support resources and needs, Able-Boone, Sandall, Stevens and Fredrick (1992) found that parents enjoyed participating in interviews and the opportunities these provided for sharing their stories and talking about their child. The semi-structured interview is comprised of open-ended questions that allow flexibility for the interviewer and interviewee to clarify meaning and to explore issues which arise during the interview process (Barnes, 1992). The main aim of the interviewer is to invite the participant to reconstruct her experiences within the topic under study (Seidman, 1991). Merriam (1998) stated that the semi-structured interview format enables the researcher to respond to the emerging world view of the participant. This meshes well with the constructivist paradigm adopted in this study. Therefore, a semi-structured interview was held with each of the parents participating in the study, as well as with the auditory-verbal therapist, who worked with each family. I followed the prescribed set of open-ended questions fairly closely and conducted the interview much like a guided conversation. As research indicates that fathers and mothers may perceive the process differently (Cooper & Allred, 1992), parents were interviewed separately. Auditory-verbal therapists were included in the semi-structured interviews only, because it was felt that this

format would yield the most information about the mesosystem level of the model. Questions for the parent interviews were developed in collaboration with the auditory-verbal therapists and examined issues at each of the four levels of Bronfenbrenner's ecological model. The barriers and facilitators provided by the immediate family, the hospital staff, the workplace, the community and the society were investigated. The goal of these interviews was to obtain from the participants their perceptions of the transition which occurred in the family since the auditory-verbal therapy process was adopted and their views on the barriers and facilitators to this adoption. As expected, these interviews supported information about the microsystem level, obtained from observations and provided information about the mesosystem level of the model. The interviews took place after the second observation session, thus affording me and the families time to get better acquainted. The interviews were guided by the questions in Appendix D.

All but one of the participants agreed to having the interview audiotaped. In this one case, copious field notes were written instead. Transcripts of the interviews were provided to the participants for their review. This served as a form of member checking (Merriam, 1998). No changes were made by the participants. All interviews took place at the participants' homes at times that were convenient to them. The duration of each of the interviews was generally 60 minutes to 2 hours.

Discussion Group

A focus group consists of a group discussion wherein a moderator uses open-ended questions to encourage participants to share their insights regarding key topics (Brotherson & Goldstein, 1992). While it is customary to have several focus groups in which

similar topics are discussed, it is also possible in an exploratory study to use only one or two focus groups (Vaughan, Schumm, & Sinagub, 1996). The hallmark of the focus group is to use group interaction to produce insights that would not be accessible if the group did not interact (Morgan, 1997). The advantages of focus group interviews are that they afford a more relaxed and natural atmosphere than the individual interview and they are more socially oriented (Marshall & Rossman, 1999). Thus focus groups are more controlled than observation and less controlled than individual interviews. The groups usually consist of a minimum of seven to ten people, who have in common certain characteristics which relate to the topic of inquiry (Krueger, 1994). All the parents of the participating children were invited to attend a focus group on June 20, 2003 after the completion of the observations and individual interviews and preliminary analysis of the data. Morgan (1997) indicated that focus group interviews can provide a basis for asking questions that enable participants to share a full range of their experiences, that is they can promote "collective memory" (R. LeBlanc, personal communication, June, 2003). The meeting was held at the hospital where the families had attended auditory-verbal therapy sessions, as this is fairly centrally located and is familiar to all the participants. The goal of the group was to elaborate on themes that emerged during the individual interviews and observations. It was guided by the topics which appear in Appendix E. Unfortunately, only two of the expected participants attended the meeting. A third had indicated that she would attend, but she did not. Despite the few participants, it was decided to proceed and conduct a discussion rather than a focus group. Vaughan, Schumm and Sinagub (1996) indicated that focus groups offer support to individual participants and encourage openness in their responses. During the discussion, the participants seemed to enjoy the time they spent and contributed some interesting insights. The

discussion was audiotaped and a colleague, who is familiar with qualitative research but does not know the participants, attended the group and served as the recorder.

Demographic Questionnaire

A questionnaire was completed at the first visit with each of the families. It consisted of some questions about home, family composition and workplace (Durieux-Smith et al., 2001). I administered the questionnaire in an interview format to all but one of the families, who completed it on their own. I felt that an oral administration of the form served as an “icebreaker” and put the parents at ease. A copy of the questionnaire may be found in Appendix F.

Role and Perspective of the Researcher

I am an auditory-verbal therapist who has worked with families of children with hearing loss for more than twenty years. While my initial training involved a total communication approach, I currently practice auditory-verbal therapy exclusively. My aim for a child who wears a cochlear implant and is following an auditory-verbal approach is that he/she be integrated into his/her daily environment so that he/she can achieve his/her maximum potential. I feel that this perspective enabled me to establish trust and rapport with the participants, however it may also have introduced a Hawthorne effect, whereby the participants attempt to please me by providing the “right” responses. Maxwell (1996) referred to the effect of the researcher on the setting or individuals studied as reactivity. In order to reduce the perceived bias, I included in the study only families who were seen by the other therapists in the department.

I began with the observations and thus was for the most part a complete observer at the initial meetings. I found, as mentioned previously, that as I became more familiar with the families I was included more in their activities and I was consulted occasionally about services

for their children. I answered any questions that I was able and referred them to their respective therapists regarding issues which I felt were more appropriately answered by them.

While I found all the participants very honest and forthright in their comments during the individual interviews and group discussion, I think in some instances the Hawthorne effect did influence the participants' behaviour during observations, as discussed previously. I did encourage all participants to carry on the normal activities they would be doing at the time of my visit, however this seemed to be easier to accomplish if my visit coincided with a meal time or homework time. Despite this drawback, I do feel that I obtained an accurate impression of the verbal interactions between all the parents and their children.

Data Analysis

Embarking on the task of data analysis enabled me to read and re-read the transcripts and to thereby render the words and voices of the participants even more familiar to me, thus facilitating the process of interpretation. "Data analysis is the process of making sense out of the data. And making sense out of data involves consolidating, reducing and interpreting what people have said and what the researcher has seen and read - it is the process of making meaning" (Merriam, 1998, p. 178). The present study involved an accumulation of approximately 1000 pages of data from interviews (eleven individual and one discussion group), 15 observation sessions, and five family information questionnaires. Each of the interviews and observations was transcribed and then page numbers and line numbers were assigned to each document in order to facilitate later reference. Words that were emphasized in the oral version were italicized in the transcribed text. Notation was also made of any nonverbal interjections such as laughter, sighs and tears.

Each interview was read and re-read and then codes were assigned to “chunks” of various sizes that represented meaningful units of data (Miles & Huberman, 1994). These preliminary codes were descriptive in nature and those obtained from the first interview were compared with those of the second interview and a master list of pattern codes was created (Merriam, 1998). This master list representing recurring regularities and patterns was more inferential and explanatory in nature and was the classification system used to code the remaining interviews. As Merriam (1998) indicates, “Data analysis is a complex process that involves moving back and forth between concrete bits of data and abstract concepts, between inductive and deductive reasoning, between description and interpretation” (p. 178). During the re-reading of transcripts, memos were written on post-it notes as insights occurred. Once the pattern codes were delineated, each interview was photocopied and the pattern codes were cut up and labelled with the name of the participant, the page and line number. These bits of raw data were placed in file folders, each of which was labelled with the name of a theme. Each of the coded pieces of paper was placed on a sheet representing a sub-theme and was placed in the appropriate file folder. As this study is guided by the theory of the ecology of human development, the themes were examined in relation to this theory.

While approximately 46 descriptive codes were initially identified, they were grouped into seven pattern codes or themes and these were then grouped into the four nested levels of Bronfenbrenner’s theory of the ecology of human development. The seven pattern codes or themes are: personal characteristics, family interactions, choice, compliance, support, inclusion and accessibility. Personal characteristics and family interactions relate to the microsystem of the conceptual framework (see Figure 5). Under the pattern code, personal characteristics, are the

following sub-themes: mother's personality, father's personality, child's personality, mother's role, father's role and personal growth. Under the pattern code, family interactions, are the sub-themes: parent-hearing impaired child relationship, relationship with spouse, relationship with siblings, behaviour management, and support of extended family.

Choice, compliance and support relate to the mesosystem of the conceptual framework. Under the pattern code, choice are the sub-themes of trust in professionals and desire for the child to speak. Under the theme of compliance are the sub-themes: compliance with hearing aids and cochlear implants and compliance with auditory-verbal therapy including changes with auditory-verbal therapy, ways of doing auditory-verbal therapy, and progress with auditory-verbal therapy.

The theme of support relates to both the mesosystem and exosystem levels of the conceptual framework. At the mesosystem level, support was noted in the following areas: health-local, education-local, Voice-Ottawa, community and workplace. At the exosystem level, support was documented at the provincial level in the domains of health, education, community and social services and Voice Ontario.

Accessibility and inclusion relate to the macrosystem of the conceptual framework. Under the theme, accessibility, are the sub-themes: availability of cochlear implants, auditory-verbal role models and Deaf culture and under the theme inclusion are the two sub-themes: desire to maintain normalcy and stigma. In addition, a file of miscellaneous codes was kept. These were added to pattern codes or noted as negative instances to be discussed later.

The observations were numbered from one to three for each family. They were read and coded for the themes that had been derived from the interviews. This same procedure

was applied to the discussion group. The aforementioned themes and sub-themes were compiled into tabular form (see Table 3).

Table 3

Themes and Sub-themes Corresponding to Bronfenbrenner's Four Nested Levels

<u>Microsystem</u>		
<u>Personal Characteristics</u>	<u>Family Interactions</u>	
Mother's/Father's role	Parent-child relationship	
Mother's/Father's/Child's Temperaments	Spousal/sibling/grand-parent relationships	
Personal growth	Behaviour management	
<u>Mesosystem</u>		
<u>Choice</u>	<u>Compliance</u>	<u>Support</u>
Trust in professionals	Compliance with hearing aids, cochlear implants, A-V therapy	Health, Education, community-local
Desire for child to speak		Voice-Ottawa, workplace
<u>Exosystem</u>		
<u>Support</u>		
Health, Education, Voice, Community-provincial		
<u>Macrosystem</u>		
<u>Accessibility</u>	<u>Inclusion</u>	
Availability of implant, A-V role models	Desire to maintain normalcy, stigma	
Deaf Culture		

Research Trustworthiness

Merriam (1998) indicated that research findings are trustworthy to the extent that attention has been paid to the issues of validity and reliability. Trustworthiness was strengthened in a number of ways. First, in order to avoid inaccuracy and incompleteness of data, I tape-recorded and transcribed all interviews and observations and kept detailed notes of all observations. I asked the participants to read transcripts of the interviews and to make modifications as necessary. They also read the “stories” that I wove from the transcriptions and were asked to alter these as they felt appropriate. This member check served to avoid inaccurate description as well as to avoid the imposition of my own meaning on the data, rather than the meaning of the participants. Second, I used a variety of methods to collect data, which also reduced the possibility of bias (Maxwell, 1996). Third, I solicited feedback from my colleagues, my advisor and committee members. Fourth, the detailed notes of my observations served as an audit trail, which records my rationale for decisions made during the course of the study.

Merriam (1998) defined reliability as the extent to which the research findings can be replicated, and added that it is important to refine the research instrument in any research in order to ensure reliability. In the case of qualitative research, the instrument of data collection is the researcher. The pilot study enabled me to develop my skills in interviewing and observation. In addition, I used triangulation, member checks and provided an audit trail.

Generalizability involves the extent to which findings of one study can be applied to another situation (Merriam, 1998). Stake (1995) suggested that in qualitative research it is the user of the information who determines its generalizability. Therefore, I have provided rich, thick description in order to enable the reader to determine how closely his/her situation resembles that of the researcher and therefore how transferable the findings are.

Summary

In summary, five families participated in this study and four methods of data collection were employed: (a) observations, (b) individual interviews, (c) a discussion group, and (d) a family information questionnaire. All interviews and observations were transcribed and transcripts were reviewed by the participants. Data were read and coded and emerging themes were used to further categorize the data. Triangulation, member checks and an audit trail were employed to ensure validity and reliability. It is my hope that in giving voice to the families who participated in this study, I will shed light on the process of auditory-verbal therapy as it is lived by them.

CHAPTER 4 - THE STORIES

In this chapter, each family's story will be presented using an identical format. First, the observations of the parent-child interactions will be reported. Then, the parents' perceptions as they relate to the four nested levels of the conceptual framework will be discussed by theme and sub-theme. Each of these sections will conclude with a summary citing the elements which were viewed as barriers and facilitators by the parents. The word barrier in this context is defined as a challenge that confronted the parents. At the microsystem level which describes personality traits and family interactions, the word barrier is used to refer to personal challenges as perceived by the parents. Therapists' remarks are not included, as they did not live the experiences described by the parents. Last, the parents' current feelings about the transition will be presented. The themes and sub-themes that emerged during the analysis are documented by the voices of the participants in the form of quotations from interviews and the discussion group (DG). Following each of these is a page and line number in brackets for interviews. References to observations are used to illustrate verbal interactions between parents and children and are indicated by a bracketed number from 1 to 3. The tables summarizing these data can be found in Appendix G.

Before telling the stories of the participants, it is important to review the definitions of each of Bronfenbrenner's (1979) four nested levels and their relationship to the components of family systems theory. The microsystem refers to the immediate setting in which an individual participates. This setting is comprised of activities, roles and interpersonal relationships, and the individual's perceptions of each of these is crucial to Bronfenbrenner's model. Activities are behaviours that are perceived as meaningful by the participants in the setting. A role is defined at the level of the culture or subculture, that is at the level of the macrosystem. Interpersonal

relationships are characterized by dyads which are established when one person in a setting participates in activities with another. There may be several primary dyads within the microsystem, each comprised of two people who are emotionally significant to each other. Bronfenbrenner hypothesizes that when one member of a dyad undergoes a developmental change or transition, so too will the other member of the dyad. Family systems theory, as described by Turnbull and Turnbull (1990, 1997), is comprised of an input portion, a process portion and an output segment. Family characteristics, the input component, includes all those ways families may differ: personal characteristics, characteristics of the family, characteristics of the disability, family size, form and socioeconomic background. Family interactions include the process portion and comprise: parental, sibling, marital and extended family interactions. The input and process segments of the family systems model correspond with and enrich the microsystem level of Bronfenbrenner's theory. In this study, the categories, personal characteristics and family interactions correspond to the microsystem of the conceptual framework.

The mesosystem consists of the relationship between two or more microsystems, as perceived by the person in transition. Most individuals are involved in more than one microsystem and move from one setting to the next. The output component of family systems theory, family functions, includes the many responsibilities families must fulfill in order to meet the needs of each of its members. These include educational, economic, recreational, social, physical, health and emotional, each of which may represent an interaction at the mesosystem level of Bronfenbrenner's model. In this study, the interaction with the Audiology service was one of the functions at the mesosystem level of the conceptual framework, as was the link with Voice Ottawa, the local chapter of Voice.

The exosystem level consists of one or more settings that do not involve the person in transition directly, but nevertheless impact on that person. Some family functions, such as education and health may be affected by activities at the exosystem level. In this study, the indirect link between the parents and the provincial Ministries of Health, Education and Community and Social Services, as well as that with Voice Ontario, constitute family functions at the exosystem level of the conceptual framework.

The macrosystem level of the model includes the belief systems and ideology that characterize a culture. In the 1995 version of the model, Bronfenbrenner added that the events and conditions prevailing in the historical period during which an individual lives influence that person's life. Family life cycle, the fourth component of family systems theory, refers to the changes that may confront a family over time. This component of family systems theory corresponds to the macrosystem level, in that each phase of the life cycle has repercussions on family characteristics, interactions and functions, just as events at the level of the macrosystem impact on all the levels nested within it. In this study, the availability of cochlear implants and auditory-verbal therapy, as well as the philosophy of inclusion, impact the participants at the level of the macrosystem. This study examines the experiences of parents whose children are at the preschool to beginning school age phase of the life cycle.

Nancy Wood and Family

When I arrived at Nancy Wood's apartment, I was greeted at the door by her and 3-year old Diane, who had a twinkle in her eye and a smile on her face. Nancy explained that the television, which was showing a Kirk Douglas movie, had been turned on by Diane. It was turned off upon my arrival. In one corner of the living room was a stack of toys, books and puzzles which were used during my three observations. After the Family Information

Questionnaire was completed, Nancy attempted to read a book with Diane, however Diane was reluctant to join her. Nancy succeeded in motivating her to come over by using objects that matched the pictures in the book. She used some auditory-verbal techniques, such as sound-word associations (eg: oink, oink for the pig) and repetition, "Where's the carrot ? Carrot. O.K. Let's go and get the carrot" (obs. 1). Nancy indicated that Diane does not always like to sit with her. Nancy attempted to cover her lips, so that Diane would have to use her hearing to understand, an auditory-verbal technique. She did not quite cover her mouth, however, and so permitted Diane to lipread. Soon after, Nancy referred to a helicopter and varied her intonation pattern as she said, "round and round and round and round", thereby using another auditory-verbal technique. Later, when Nancy was repeating, "woof woof woof woof. Yeah (laughs)" (obs. 1), her laughter seemed to indicate that she was somewhat embarrassed at speaking this way but she also seemed to enjoy her daughter's response.

At my second visit, most of our time was again spent with the toys in the corner of the living room. Nancy's primary method of verbal interaction with Diane was asking questions. Sometimes she would provide the answer herself and would expect Diane to repeat it. At those times, when Diane answered appropriately, Nancy seemed very pleased and proud, (eg: N: Where's the *cat*? The *cat*? [italics added] D: cat"). At one point she commented, "We have to get some *new* [italics added] stuff, Diane. You know this too much" (obs. 2). When Diane experienced difficulty placing letter puzzle pieces, Nancy repeated "no" several times before Diane accomplished the task. In fact, she used "no" often when Diane erred, rather than finding a positive way to address the learning situation. Nancy used highlighting, another auditory-verbal technique, "This is Diane's *boots*, [italics added] Diane's *boots*. [italics added] This is for you. Diane's boots" (obs. 2). On several occasions, Nancy asked Diane to imitate a two-word phrase

"Diane's boots. Say that: Diane's boots" and Diane complied. Nancy was observed to respond to a gesture from Diane instead of a verbal comment: when Nancy went to get her glasses for reading, Diane pointed to the glasses and Nancy said "so I can read" (obs. 2). Thus, she responded to the child's communicative intent, but did not attempt to have the child verbalize that intent. Nancy also attempted speech correction when Diane produced an "m" instead of a "b". Nancy repeated what Diane said "more, more, more, more" (obs. 2) and also interpreted what she said, even expanding on occasion "*juice?* [italics added] O.K., let's go and get some *juice, juice, juice* [italics added] (obs. 2). Although Nancy appeared tired upon my arrival each time, she demonstrated a warm rapport with Diane and seemed genuinely proud of her accomplishments.

At one point, Diane used the sound for a word and Nancy attempted to transfer that sound to a real word: "D: meow; N: a cat" (obs. 2). Nancy followed Diane's lead in conversation: when Diane said "psh, psh", Nancy replied "swish, swish, ya that's fish" (obs. 2). Nancy also introduced new vocabulary, "That's not apple. This one is a *tangerine*" [italics added] (obs. 2).

Although I did not observe this, Nancy stated that Diane helps her do the laundry by placing the coins in the machines and carrying clothes upstairs (obs. 3). She reinforced directions related to daily routines, "Go and put it in your room", "Go and put it in the garbage" (obs. 3). When Diane went to the bathroom, Nancy said, "I hear that" as Diane urinated (obs. 3). Although Nancy talked a lot at each of the observations and used several auditory-verbal techniques, she did not ask Diane to use expressive language frequently. Nancy seemed to take pleasure in being with Diane and they embraced, saying "I love you" at the end of the last observation.

*Microsystem**Personal Characteristics*

When asked about her life before the detection of Diane's hearing loss, Nancy replied, "We were happy, go about our business" (p. 2, 1.4). She indicated that there was a history of hearing loss in her family, "my aunt on my mother's side of the family. I was worried before she was born (laughs)" (p.1, 1.19-20, 1.27). Nancy described her reaction to the news of the hearing loss, "Ya it get me so depressed (snickers). Get me so depressed ... it was harder. I have to put out more energy. It [was] much harder to care for her because she [was] not hearing me" (p.2, 1.9-11).

When asked how her life had changed after the detection of the hearing loss and the introduction of auditory-verbal therapy, Nancy responded, "I didn't know I would go back to these days (laughs) (p. 16, 1.23). She added, "Well I think my privilege ... it is gone (laughs). I spend most time at home ... I can't go out like socialize now" (p. 4, 1.16-18). She felt that she does "more talking" (p. 11, 1.2). She did not perceive the hearing loss as a problem, "I don't take it as a problem because it's my child ... Sometimes I'm losing a day but sometimes I go to work. I work for like 6 hours 5 hours. I come home. I take her" (p. 4, 1.3-5).

Nancy described herself as, "shy, well I just quiet. It's just my family" (p. 10, 1. 21- 24). Nancy did feel that she has changed through exposure to the auditory-verbal process and that she has more patience and "I'm now, I'm more outgoing" (p. 11, 1.15). There was a sense of personal growth on Nancy's part, "That's why I'm doing a driving course ... so I can be more independent" (p. 20, 1.1-3). Nancy stated that her role is, "(laughs) I'm not only the mother. I'm the father and the mother for her too ... so I have to take on all the responsibility" (p. 10, 1.15-17). At the end of my last observation, Nancy invited me to watch a video depicting Jamaica. It also happened to be

a video of her father's funeral. As we watched, Nancy sang along with some of the hymns and then told me that religion helped her get through everything with Diane (obs. 3).

Although religion seemed to be an important element of Nancy's life, she found it difficult to attend church, "With Diane in the winter it was very difficult but I am going tomorrow" (p. 10, 1.1).

Nancy described Diane as very independent and persistent. Certainly during the observations Diane was very interactive with me, attempting to engage me in the activities she was doing with her mother (obs. 1, 2, 3). When the telephone rang, Diane ran to answer it and imitated her mother's "bye bye" at the end of the conversation (obs. 2). Nancy stated that at times Diane is difficult, "Sometimes she's so difficult (laughs) ... not really difficult, but sometimes she's not in the mood" (obs. 1). In summary, Nancy felt that she had become more outgoing since she had embarked on auditory-verbal therapy with her daughter, and that she had developed more patience. Diane's ebullient personality was viewed as a challenge from a behavioural perspective.

Family Interactions

During the observations, it was apparent that Nancy and Diane have a close relationship and a good rapport. Nancy stated that, "I really enjoy her a lot because she's my company. Most times it's just me and her on our own (laughs) ... and we go out together. We go down to the mall and we shop ... and when we clean she helps me do up the dishes" (p. 10, 1.5-11). As Nancy had to go to work full-time in Jamaica when her older daughter, Linda, was 7, Nancy's sister took care of Linda, who is now 19. Nancy stated, "Because I spend more time with Diane ... Linda mostly stayed around other kids back home ... Diane is basically closer. She's much closer to me (laughs)" (p. 7, 1.8-9, 17).

Nancy indicated that Linda was very upset when she found out that her mother was pregnant and that the baby had a hearing loss. When Linda arrived home during one observation there was no exchange of greetings on her entrance (obs. 1). She did interact with me during the last observation when she came into the living room to help with the video equipment (obs. 3). Nancy stated that the relationship between the siblings is "O.K. but sometimes she gets mad when Diane wants the computer" (p. 13, l.18). Nancy added, "Sometimes I think sometimes she's jealous" (p. 13, l.4). Nancy explained that Linda is "Mostly on her own" (p. 13, l.8). However, she does help out with Diane, "Sometimes she takes her there (hospital)" (p. 4, l.1). When asked if Linda resents having to help with Diane, Nancy replied, "Ya, very much" (p. 6, l.16). Then she qualified that, "She doesn't help financially. She just stays with the baby ... that's why she's working just a few days" (p. 6, l.18-19).

Nancy's relationship with her ex-spouse is not amicable. Nancy said that Diane's father does not "have anything to do with her (laughs)" (p. 4, l.19). She had to "take him to family court to get support" (p. 5, l.24).

Two of Nancy's sisters and one brother-in-law came to Ottawa when Diane received her cochlear implant. One of her sisters telephoned her from Toronto while I was visiting (obs. 2). When asked what her sister thinks of the implant, Nancy replied, "It's good ... just hope and pray" (p. 3, l.5-6). Diane's paternal grandmother sends presents for Diane's birthday and at Christmas but does not see her very frequently. Diane also had a step-sister by her father and Nancy described her as "very close to me" (p. 20, l.16). In summary, the bond between Nancy and Diane seemed very strong. Linda, Diane's older sister, was not as close with Nancy or Diane. Linda seemed to resent the added responsibilities that she is required to

shoulder on account of Diane. While Nancy received little support from her ex-spouse, she did appear to derive benefit from the support of her siblings, but felt isolated socially.

Summary-Barriers and Facilitators

When considering the barriers and facilitators to the transition to auditory-verbal therapy at the microsystem level, Nancy indicated that Diane is very independent and persistent and that her behaviour is difficult at times. Nancy's restricted social interactions also appeared to be a barrier. Nancy felt that the support of her extended family was a facilitating element.

Mesosystem

Choice

When asked why she had chosen auditory-verbal therapy for her daughter, Nancy replied, "Well, they introduce it to her so I accept it" (p. 3, 1.8). When discussing choice again later in the interview, Nancy added, "Well (laughs) like I said they tell me and show me (p. 26, 1.21). I trust the doctors, what they say" (p. 26, 1.4). She added, "Well I saw some videos. They gave me some videos to encourage me and I saw the children who did it and they were successful. Frances's daughter too" (p. 25, 1.19-22). Clearly, the theme of choice is associated with trust in health professionals, a theme that will be addressed later in this section.

Compliance

Diane was fitted with a hearing aid prior to receipt of the cochlear implant. Nancy compared the two instruments, "Well the implant is much more easier for me ... because she can hear more ... with the hearing aid you have to talk really loud and sometimes she don't hear" (p. 3, 1.1-3). Nancy added, "Well she get more, she has more understanding. When she don't hear, when she not hear with the hearing aid she get so frustrated ... especially when we talking at [hospital] but she mostly understand. She reads lips a lot" (p. 5, 1.5-7). When she discussed

taking a trip with Diane, Nancy mentioned, "I have to take the battery and stuff ... there is a thing that I use to charge the battery. The battery only lasts 12 hours" (p. 15, 1.6-13). Simone thought that compliance with cochlear implant use would be burdensome for Nancy, "I would imagine in terms of just getting it on her and so on that that would be an additional burden, remembering to charge the batteries" (p. 4, 1.1-2). Despite the additional tasks involved, compliance with use of the cochlear implant is a priority for Nancy, as she is pleased with Diane's ease of communication when wearing it.

When discussing the effect of going to the hospital and doing auditory-verbal therapy, Nancy emphasized that transportation has been a particular hardship, "Well like to get there sometimes is very difficult (laughs) ... ya I take the ... he has this van ... the driver he charge me a flat rate like \$10, \$20, both ways ... but in the summer I take the bus" (p. 3, 1.12-17). Nancy added, "We try and work around the schedule. If I can't go, Linda takes her" (p. 18, 1.19). Simone concurred with this view, "Going home from work, taking a bus with this small child, getting to [the hospital], taking the bus back to you know transfer of bus and all that kind of thing so huge hurdles just in terms of practicality" (p. 4, 1.12-14). When asked about the auditory-verbal techniques, Nancy said, "Well some of them were a little bit hard and you know time-consuming ... I didn't have much time ... but I just did it because I said I ... Because I wasn't thinking of doing this again (laughs)" (p. 16, 1.19-21). Simone reported, "I'm starting to perceive that there is some more participation but I think that it was until recently too overwhelming a task for there to be much of a change in routine" (p. 4, 1.3-5). Nancy indicated that she had learned "how to say things" (p. 18, 1.1) "and how to approach Diane doing certain things ... making up a schedule for her, the kinds of toys" (p. 17, 1.17-19). She offered an example: "I have to start a new one ... like Simone said I must take some money like cent and take some stuff and

put it in a bag and then she pay me for it like going shopping” (p. 18, 1.9-12). In summary, despite significant transportation problems, Nancy perceived that she was complying as best she could with the demands of auditory-verbal therapy. Simone felt that while there were major hurdles remaining, there seemed to be greater participation on Nancy’s part.

Support

Health-Hospital.

Nancy described the hospital in this way, “If it wasn’t for them (little laugh) I don’t know what I would do” (p. 24, 1.16). When asked about the availability of audiological services, Nancy commented, “Well no problem and the workers there are very nice ... very nice. I enjoy it and Diane always looks forward” (p. 19, 1.5-11). She added, “Sometimes Simone comes” (p. 18, 1.23). Nancy also mentioned the social work assistant (Marilyn) at the hospital as a support and Simone added, “Marilyn has also spoken to the mum a few times about services and so on and helped her pull together the Special Services at Home application for instance” (p. 21, 1.26-27, p. 22, 1.1). Simone felt that attendance was an issue and “I know that home visiting has been a huge thing ... and if I don’t do home visits long periods of time go by and I don’t see them” (p. 12, 1.1-2, 8-9). Simone felt that she had to modify the traditional way of providing auditory-verbal therapy when dealing with Nancy, “I don’t think I was going about it ... I think I’ve been going about it in a way that’s structured enough and clear enough” (p. 5, 1.21-23). She added, “With this particular mother at this point in time, I’ve just been working on getting her to be more communicative verbally” (p. 10, 1.11-12).

In terms of audiological follow-up, Simone felt that “There have been some delays in overcoming audiological hurdles ... not months but you know in terms of audiological but maybe weeks” (p. 13, 1.5-7). In summary, while Nancy felt that the support of the audiology and

auditory-verbal therapy services was crucial to her transition, transportation problems prevented her from attending frequently. Simone facilitated her participation by visiting the home.

Workplace.

Nancy's work life has been a consideration in scheduling auditory-verbal therapy, "Because I'm not full-time so when I lose a day I don't get paid for it" (p. 3, 1.25). She added, "Well I can't take any work apart from 7 to 3 because I have to be home. Linda works in the afternoon so I have to be home" (p. 22, 1.2-3). Simone agreed, "She's had to organize her work life around therapy. She's had to take some time off work ... My sense is that probably has to make up the time" (p. 13, 1.19, p. 14, 1.1). In summary, Nancy's workplace allowed her some flexibility in her schedule to accommodate her visits to the hospital.

Voice.

Voice is a group of parents of children with hearing loss that meets monthly and organizes speakers for the parents and theme-based parties for the entire family. Nancy indicated that she was not involved with the local chapter of Voice at all. She added, "Every time I should go I just don't have the time" (laughs) (p. 19, 1.20). Simone stated that "She hasn't been interested in participating in Voice in any way" (p. 15, 1.18). She added, "Although you know this mum hasn't benefitted from Voice directly this particular mum that's a parent tutor (Frances) is a member of that kind of community of parents of deaf kids" (p. 18, 1.19-23). In summary, while Nancy has not attended any Voice meetings, she did benefit from having a tutor who was a member.

Community.

At first when she was asked about community support, Nancy answered that she didn't

have any, perhaps because she was comparing her current situation to that in Jamaica where she said, “We had neighbors around to help” (p. 8, 1.13). It was obvious that Nancy missed that informal sense of community that she had experienced in Jamaica. She said,

I want to go back as soon as Diane get bigger and can manage. I prefer it in Jamaica ... here you know not much social things going on ... and we don't see much people ... but in Jamaica we go to church activities ... and you know people come and visit you and everybody sit down and talk ... and eat together. (p. 9, 1.5-17).

She reported that she had had the services of a woman from the Infant Development Programme but that service had been discontinued when Diane turned two years of age. Nancy also considered Diane's babysitter, Janet, a support. Simone, however viewed the babysitting arrangement as a barrier because, “babysitter's bilingual-Arabic and English and most of the other children speak Arabic only” (p. 15, 1.25). The Ministry of Community and Social Services has a programme called Special Services at Home that provides funding for tutors to go into the home and do therapy with the children. Simone arranged for the parent of an older girl who wears a cochlear implant to visit Diane for four hours each week. Simone described this service, “the parent tutor is huge” (p. 14, 1.5). Simone reported that, “The tutor picks Diane up at the babysitter who's down the hall ... and takes Diane back to Diane's apartment and does therapy ... two hours are spent doing that and two other hours she takes her to a play group” (p. 15, 1.4-9). When the parent tutor was mentioned, Nancy responded, “Frances takes her (Diane) to the play group and she said she seem like the rest of the children” (p. 16, 1.9). In summary, Nancy felt that the health system and the community facilitated her transition, as did the flexibility of her workplace. She did not participate in any Voice functions.

Summary-Barriers and Facilitators

When considering the elements that facilitated and impeded the transition to auditory-verbal therapy at the level of the mesosystem, Nancy felt that the cochlear implant has been very beneficial to her transition. She acknowledged as well the support provided by the Audiology service at the hospital and by her auditory-verbal therapist, although lamenting the barrier that transportation presented for her. She was appreciative of the parent tutor, funded by the Ministry of Community and Social Services, as was Simone. While Nancy considered the babysitter to be a facilitator, Simone viewed this arrangement as a barrier, "The other big thing is she spends all day in a non-English environment ... so I'm just thinking that's the next big hurdle to overcome" (p. 20, 1.1-2, 1.8-9). Nancy felt that, although she had to make up time missed from work, her employer was quite flexible about her schedule. Simone concluded that "Just getting to therapy, interfacing with us, those kinds of things, very difficult for this family (p. 5, 1.4-5).

I think the mum is in a slightly better place since I've been on Marilyn's (the social work assistant) advice letting go of previous expectations and just trying to assess ... where she's at ... it seems the mum is a little bit less intimidated, a little bit more on board (p. 24, 1.8-9, 22-23).

Exosystem

Support

Health-Provincial.

Clearly, the availability of cochlear implants through the Ministry of Health has had a major impact on this family. When asked about this issue, Simone said, "She got a cochlear implant ... she would never have been able to afford it if it hadn't been paid for" (p. 17, 1.6-8). Nancy added, "Because in Jamaica, if Diane was in Jamaica she would have to stay that way ...

because they don't have it costs a lot of money to do that ... and they don't have it there (laughs)" (p. 1, 1.21-23). The availability of audiological services and auditory-verbal therapy, also provided by the Ministry of Health, is essential.

Community.

The availability of the Special Services at Home Programme, which was funded by the Ministry of Community and Social Services "is a wonderful thing of great benefit" (p. 16, 1.24) according to Simone. Nancy also appreciated the Infant Development Programme, offered by the Ministry of Community and Social Services.

Voice.

The provincial chapter of Voice, Voice Ontario, publishes an informative newsletter and advocates on behalf of children with hearing loss and their families at the Ministries of Health and Education. They support outreach programmes that provide auditory-verbal therapy service across the province and are involved in organizing workshops for parents and professionals on all aspects of auditory-verbal therapy. However, Nancy seemed unaware of their role.

Summary-Barriers and Facilitators

When considering the transition to auditory-verbal therapy at the level of the exosystem, Nancy perceived that the programmes provided by the Ministries of Health and Community and Social Services facilitated her transition to auditory-verbal therapy. While Voice Ontario performs an advocacy role from which Nancy is likely benefitting, she did not seem aware of it. No barriers were mentioned at this level.

*Macrosystem**Accessibility*

Nancy was very appreciative of the services that were available to Diane, "Because as I said hearing loss in Jamaica she would have to stay that way. I didn't know (laughs) they have such techniques" (p. 25, l.4-5). The availability of the cochlear implant too has been pivotal for Diane and Nancy. Access to role models who are oral has influenced Nancy's transition as well. Simone commented, "The fact that she has a parent tutor who is the parent of a kid with a cochlear implant ... the community is now big enough that there are supports within the community of parents of hearing impaired kids" (p. 18, l.16-19). Nancy mentioned that a teller at her bank has a hearing loss and "I spoke to him, no problem" (p. 26, l. 14). This encounter seemed to support her goal of teaching her daughter to speak. Diane had been exposed to a signing deaf adult in Jamaica, as her maternal aunt had been deaf and used sign language to communicate. Despite this exposure to sign language, Simone indicated that Nancy had told her that she "wants her child to learn how to listen and talk" (p. 19, l.6). In summary, Nancy recognized that the availability of the cochlear implant was an advantage that she would not have had in Jamaica. Access to oral adults with hearing impairment in the community was very encouraging to her.

Inclusion

Although Diane was not yet enrolled in school, she attended a play group with hearing children. Simone commented, "Inclusion is something that appears to be welcomed at the play group that she goes to so the whole notion of mainstreaming ... is something that facilitates this kid becoming an auditory-verbal kid" (p. 18, l.8-11). Nancy seemed to seek

normalcy for her daughter. She stated, "She's you know she go on like the normal kids ... I just treat her like a normal child" (p. 12, 1.3-4). In summary, Nancy sought inclusion for her daughter, as her goal was to normalize her as much as possible.

Summary-Barriers and Facilitators

When considering the transition to auditory-verbal therapy at the level of the macrosystem, it appeared that accessibility both to technology and to services were facilitators. In addition, the inclusive nature of community resources facilitated the transition to auditory-verbal therapy.

Current Perceptions of the Transition

When she first embarked on the process of auditory-verbal therapy, Nancy felt quite unhappy and overwhelmed. She and her older daughter, Linda, had been content with their lives and found the unexpected birth of Diane, followed by the detection of her hearing loss, a burden initially. When asked how she is feeling now, instead of responding about her own state, she commented on Diane's progress, "She's doing very well".

Margaret Briggs and Jean Dupuis and Family

When I arrived at Margaret Briggs' home she warmly welcomed me into the livingroom where a Christmas tree adorned the room. She immediately engaged Melanie in our conversation by asking her to show me her birthday presents. Melanie smiled shyly at me but seemed reluctant to comply with her mother's request. After Margaret had asked her to go upstairs twice and had gestured to accompany her request, she finally went up with Melanie and they brought down some bears to show me. Margaret used sabotage, a technique whereby she omitted an element from a situation so that Melanie would have to supply the missing word. She also used

highlighting, a technique where the speaker puts emphasis on a word to make it more audible to the listener. Margaret appeared to be aware of the language goals for Melanie and she tried to incorporate them into their conversation (eg: “You got many ... this is just a *few* and that's *many*” [italics added] - obs. 1; the use of “you” instead of the child's name - obs. 1). Margaret used repetition to ensure that Melanie understood her request (eg: “Want to count them? Why don't you count them? Let's count them - obs.1). Margaret interpreted Melanie's vocalizations to mean something related to the context they were discussing. She occasionally asked Melanie to repeat her vocalizations with more clarity (“You say ‘ juice please”- obs.1), however she limited these requests to two word phrases when Melanie was later heard to spontaneously produce three to four word phrases. Margaret observed during our visit that “Auditory-verbal therapy is a big commitment and you're told that ... but we weren't prepared for how hard it would be” (obs. 1). It was apparent to me that Margaret was attempting to incorporate the therapy targets into their everyday life, however at times it seemed that she was unsure of what Melanie actually comprehended (eg: “We're going to go swimming soon - go in water” - obs.1) and what she was capable of producing at that point. There was a lot of laughter and playfulness between the two as they interacted (obs. 1). Throughout their interaction, Margaret included me in their play or made comments about the process. At one point she stated her concern about the frustration felt by children with hearing loss when they can't express themselves (obs. 1). Margaret did some homework assigned by Melanie's itinerant teacher and remarked that she enjoyed being given homework because it made her work more diligently with Melanie. At one point the two began singing “Jingle Bells” together, thoroughly enjoying the moment.

At the second observation, all four members of the family were present. It was 8:00 p.m. and Mark, Melanie's older brother, was tired after having had a late-night sleep over and having

watched a three-hour Harry Potter movie. When I entered, Margaret, Melanie and Mark were lying on the couch, watching T.V. When Mark and Melanie had a scuffle about a toy, Jean who had joined them downstairs, intervened and told Mark to tell Melanie what he wanted. As Margaret watched the T.V. show with Melanie, she explained what was happening in age-appropriate language using highlighting. At one point, Mark came downstairs and announced that he was not going to bed. Margaret ordered him to go upstairs, but he did not go. When Jean told him to go up, he complied. During this visit, Jean too was seen to interpret Melanie's meaning and to use highlighting. At one point, Jean asked Melanie a question, Margaret answered it and then Melanie vocalized an answer.

When I arrived for the third observation in the morning, Margaret was downstairs and the children were upstairs. Margaret had been watching a family video taken when Melanie's hearing loss was first detected. She commented on how much progress Melanie had made since that time.

Microsystem

Personal Characteristics

When asked about life before the detection of the hearing loss, Margaret indicated that it felt like a long time ago, three or four years ago. She explained that they had done a lot of outdoor activities as they had lived in the country. She added that "We didn't really do anything different than you normally would like you're bringing up your child" (p. 1, 1.30-31).

Prior to my arrival for our interview, she had been watching a video of the children which had been made in September, 1997 when Melanie was about 9 months old. She observed that Melanie was quiet in the video and she expressed guilt about Melanie's late detection at the age of 2 1/2, "Oh, how could I have not seen that she was deaf because you could see she wasn't

making any noises and the mother-in-law was trying to get her to make noises" (p. 1, 1.7-9). Jean also spoke of his guilt about not detecting Melanie's hearing loss earlier. Margaret observed that in the video there appeared to be more attention paid to Melanie than to Mark. She seemed to be encouraging Mark to play with Melanie frequently.

Margaret then recounted that initially they had been concerned about Melanie's balance because "She was constantly tripping all the time" (p. 2, 1.16). Later, they were concerned because of her lack of response to sound, "She wouldn't move if her back was towards the car. You know you'd honk the horn and she wouldn't hear it" (p. 2, 1.22-23). They were also worried about her lack of speech. When they expressed their concern to their doctor in the summer of 1998, when Melanie was about 18 months old, he said, "Let's wait 'til she's 2 so I think she's just late talking" (p. 2, 1.28-29). They then went back to the doctor and insisted on being referred for a hearing test. When discussing the detection of Melanie's hearing loss at the age of 2 1/2 , Margaret stated, "It was pretty devastating ... that was a real big blow, like no matter how much you detect it, it's still very hard. Even to talk about it, it's still hard (crying)" (p. 3, 1.25, 30-31).

After the detection, Margaret indicated that they still did the same activities with the children, but were more cautious around water, for example, because of the equipment (the hearing aids). She added that, "The first thing we think about if we're going to do anything is how is it gonna affect her" (p. 12, 1.3-4). If they spent the day at the water park, that meant that Melanie was not hearing for that time. When their grandparents wanted to take Melanie and Mark to Florida, Margaret and Jean were reluctant because they felt that the grandparents weren't conscientious enough about handling Melanie's equipment. She noticed a change in the way they did some activities. When reading, "We were making sure more that she could see the picture ...

in holding the book up to *your* [italics added] face so that she could read your lips but also see the picture too” (p. 4, 1.25-28). She also felt that they were careful not to have excess noise in the environment. Jean seemed ambivalent about changes after the detection. At first, he indicated, “Nothing changed, we did the same things” (p. 1, 1.9). Later he changed his opinion, “Our life changed ... after we found out, bought more toys to help her language - bought similar toys to them (hospital) because it’s hard to do what they do at the [hospital] without similar toys” (p. 1, 1.10-11). Jean added that her hearing kept dropping and that she went from small hearing aids to bigger hearing aids. Margaret indicated that she and Jean would alternate being with each of the children, as they felt it was very important to give each child individual attention.

Margaret described herself as “very very stressed ... I’ve always been the kind of person to be very happy-go-lucky ... find that I’ve gotten very serious over the years ... very demanding ... I find that I’m very fatigued” (p. 9, 1.5-7). She added, “It has affected my work, it has affected everyday relationships” (p. 9, 1.11). She suggested that her role as advocate for Melanie had taken its toll. “I was always totally consumed with trying to be an advocate and being a member of the SEAC (Special Education Advisory Committee) and you know you’re always trying to push for what’s right” (p. 9, 1.12-14). She considered her loud voice to be an asset in doing auditory-verbal therapy and added, “G-d obviously gave me a loud voice for a reason now (laughs) funny” (p. 14, 1.11). She described herself as very patient, “I’m good at being able to get children to do things when they really don’t want to” (p. 14, 1.12-13). Jean felt that, “It gave me more patience” (p. 2, 1.26). He added that he experienced a lot of stress as well but that, “Stress is starting to go down now and patience is back up there” (p. 2, 1.26-27). Margaret felt

that both she and Jean had experienced personal growth in the area of parenting, “You learn so much as a parent. You’re learning so much as a hearing impaired parent. I mean you’re learning how to communicate with your child so that it’s gonna make their life easier and your life easier” (p. 21, 1.6-8).

Margaret observed that Melanie has “always been a happy little girl” (p. 9, 1.33) but after the detection of the hearing loss and the fitting of the hearing aids, “Her personality has just bloomed like she’s it doesn’t bother her at all like I mean it doesn’t she doesn’t feel different than any other child ...” (p. 9, 1.33- 38). Margaret considered Melanie’s personality to be an asset in the transition to auditory-verbal therapy because “she’s very outgoing and not shy ... I think that’s really helped in her just always wanting to be involved and being so cheerful ... she’s got a really *strong* [italics added] personality ... She really *wants* [italics added] to try new things (p. 15, 1.12-18). In summary, both Jean and Margaret felt that life had been quite normal prior to the detection of the hearing loss, although they had been concerned about Melanie’s speech and hearing for some time before the actual diagnosis was made. They described their feelings of guilt and grief after the detection of Melanie’s hearing loss. They both considered that their patience was an asset in dealing with the transition, as was Melanie’s outgoing personality.

Family Interactions

It was apparent from my observations that Margaret and Melanie had a very good rapport (obs. 1-3) and Margaret concurred, “We’re really close ... she really loves to play, she really likes to play together” (p. 15, 1.34-36). Margaret added that Melanie seemed to enjoy playing games one-on-one with her mother “because she was getting that feedback from me, whereas

with Mark “it would be more like ‘wait your turn’” (p. 16, 1.8-9). Margaret seemed concerned about the level of language to use with Melanie. She feared that her language level was not challenging enough for her daughter and yet worried that if she spoke at a level too advanced for Melanie that she would feel left out and would not understand. Although Jean was present only at one of the observations, I did note that he too seemed to have a warm relationship with Melanie (obs. 2). When asked about the relationship between him and Margaret, Jean stated, “You hear in other cases - having a handicapped child is very hard on the family and things can happen” (p. 2, 1. 6-10). Margaret stated that Jean was “really helpful in you know just arranging going to auditory-verbal therapy and appointments, taking the time out to spend time with Mark if I wanted to spend time with Melanie or vice versa” (p. 17, 1.5-7). Although they were separating, Margaret felt that the transition to auditory-verbal therapy had actually brought them closer “because nobody else can understand that doesn’t have, they don’t have a hearing impaired child” (p. 16, 1.41-42).

The relationship between Mark and Melanie did not appear to be close. Jean commented that it was difficult to be with both children because they were at two different language levels. Margaret agreed that they spent time with each child individually because of the difference in communication and understanding between the two. Margaret seemed to feel that the difficulty in communication was a cause of the incompatibility between the children. She explained, “When neither of the parents are playing with *her* [italics added] and say it’s just her and Mark she’s lost, I mean you can see that she’s lost like she’s just not she’s not understanding everything that’s going on” (p. 16, 1.2-3). She added “*He* [italics added] was frustrated too because she’s

not listening to what he's saying and or *he's* [italics added] not able to *explain* [italics added] it to her in a way that *we* [italics added] could explain it to her" (p. 13, l.15-17, 22-23).

Margaret described Mark as a very angry boy, but she added that he did help his sister at school. She commented that Mark realized that Melanie didn't understand everything, therefore he would speak more slowly and guide her with actions. Margaret indicated that she had requested an assessment with a psychologist at the hospital but had not heard anything and did not pursue this "because we felt things did get better" (p. 11, l.29). When asked to describe the relationship between Melanie and Mark, initially Jean indicated, "They're both stubborn so it's quite a challenge for them to communicate with each other" (p. 2, l.3-4). He added that while "before he didn't play with her much ... now I think it's better ... she can understand what he's saying" (p. 3, l. 16-18).

When asked about behaviour management, Jean admitted that although he tried to treat the children in the same way, he was often harder on Mark because Mark could misbehave with Melanie and she couldn't report it. Margaret stated, "We wanted her to be treated the same way as Mark ... but you know we felt so *sorry* [italics added] for her and we *knew* [italics added] that she couldn't express herself so we *knew* [italics added] it was frustrating" (p. 12, l.33-36). Initially, Margaret reported that, "We would always be blaming Mark" (p. 13, l.2) because he would push his sister. She added that they were treated differently because of their different personalities, with Melanie not being as physically aggressive as Mark. When asked if Melanie ever got a time-out, Margaret replied that she wouldn't understand and that because her behaviour was not aggressive, it didn't warrant a time-out. She noted that since Melanie's language had improved, she was teasing Mark more and Margaret had had to reprimand her.

It appeared that their extended family was very supportive. It was Jean's parents who insisted that they take Melanie to have her hearing tested after they performed some tests at home and didn't observe any response to sound. Once the diagnosis was confirmed, Margaret reported that the grandparents "really tried to introduce new sounds all the time, explaining things, like little things" (p. 6, l.12-13). As Margaret worked in Ottawa, her mother-in-law would pick Melanie up at her daycare in Quebec and meet her at the hospital for the auditory-verbal therapy sessions. Margaret explained that Jean's parents took Melanie to the summer camp sponsored by Voice because she couldn't take the time off work and "they *really* [italics added] enjoyed sitting in on the sessions because it taught them so much" (p. 26, l.15-16). Jean qualified this by adding, "We didn't ask for help. I don't think they understood what we're going through. It's natural for us to understand more because we lived it. It's like part of your everyday life" (p. 3, l.25-26). Although Margaret's parents did babysit for them sometimes, Jean indicated that he and Margaret didn't go out together much because "we didn't want to impose on anybody" (p. 5, l.2-3). In summary, it appeared that the relationship between Melanie and her parents was very close, but that Mark and Melanie were not very compatible. Margaret worried about her communicative interaction with Melanie and felt that communication difficulties alienated Mark and Melanie. While Margaret indicated that her in-laws were very supportive, Jean stated that he did not like to impose on them.

Summary-Barriers and Facilitators

Jean and Margaret indicated that Melanie's outgoing personality and their patience helped their transition to auditory-verbal therapy. Both parents spoke of the stress they felt in making this transition and the toll it took on their family. Although they had a warm relationship with Melanie, which facilitated their transition, Mark's relationship with his sister was often fraught with tension, thus was a barrier. The communication difficulties with Melanie seemed to present significant challenges in terms of behaviour management and sibling interaction. Margaret found Jean very supportive, and this facilitated the transition for her. She implied that she experienced isolation throughout the transition when she mentioned that no one but her husband could understand her feelings. While Margaret acknowledged the extensive support provided by the grandparents, Jean indicated that they were reluctant to impose on their own parents too much and that to a great extent they shouldered their responsibilities on their own.

*Mesosystem**Choice*

For Margaret and Jean this was not only a question of choice of intervention method but also choice of language to be spoken at home since Margaret's native language was English and Jean's was French. When asked why they had chosen auditory-verbal therapy, Jean replied, "because she was young and I'd like her to speak like any other child. Sign's O.K. but I'd like to hear her voice. I'd like her to be just like any other little girl" (p. 1, 1.25-26). While Margaret concurred with Jean's view about wanting to raise Melanie as a hearing child, she added, "That's the only way the hospital said she's going to get better is by using that ... we felt well ... this is what the hospital's saying and they know best so you know we might as well ..." (p. 7, 1.27, 33-

35). Sarah added, "because she was initially diagnosed with a moderate to severe loss and we were very encouraging that a child with that kind of hearing loss would easily be able to learn to listen and talk" (p. 21, 1.7-8). When Melanie's hearing deteriorated during a period of four months, Jean and Margaret became very discouraged and frustrated. Margaret recalled that they inquired about courses in American Sign Language (ASL) and then "we were told that you know well there is this thing called a cochlear implant" (p. 5, 1.38-39). Sarah remembered that initially Jean and Margaret "weren't even interested in research in sign" (p. 21, 1.10). She added that when her progress seemed slow and her hearing began to deteriorate, they inquired about supplementing with sign language.

Margaret explained that Jean's parents very much wanted the children to learn French and in fact Mark had begun his schooling in French. However, once Melanie's hearing loss was detected and they learned that "You have to make a deci ... and we knew it was gonna be English because that's all we spoke at home anyway" (p. 6, 1.36-37). Margaret added that Jean "didn't have a problem with that and his parents were accepting of that and ... once they understood that you know she had to learn one language at a time ... then they were O.K." (p. 19, 1.20-21). In summary, both Jean and Margaret chose the auditory-verbal method because they wanted their daughter to learn to speak and they were told by the hospital that auditory-verbal therapy was the best way to reach that goal. They were also told that it was best to speak one language to their daughter in order to foster her speech and language development, therefore they chose English, as that was Margaret's native language and it was already used predominantly in their home.

Compliance

Margaret recalled that Melanie "really didn't like having her hearing aids off" (p. 6, 1.19). Jean felt that Melanie was stressed prior to receiving her implant, perhaps as her hearing

was decreasing. He added, "She's happier now" (p. 2, 1.33). Both parents were pleased that Melanie had taken on the responsibility of charging her batteries, and putting on and taking off the processor at appropriate times. Jean had noticed a big difference in the 18 months since Melanie received her implant. He enthused, "[She] can finally communicate. It was frustrating before the implant but now it's easier to understand what she wants" (p. 1, 1.19-20) ... "I think she's glad that she can talk, communicate with other kids. She's a happy kid" (p. 2, 1.1).

When asked about the implementation of auditory-verbal therapy, Jean replied, "I just knew it was going to be a lot of work" (p. 1, 1.29). Margaret added that doing auditory-verbal therapy required time and advocacy. She found herself having to advocate for Melanie with relatives and the school, "That was even more so than the time because that consumed a lot of your time" (p. 8, 1.19-22). When asked what required explanation, Margaret elaborated, "that she needs to have one-on-one therapy during the day, that she needs to have these type of toys, books to speak clearly and slowly in a very simple way" (p.8, 1.23-27). Sarah commented that "they made coming in for therapy a priority and felt that was really important" (p. 2, 1.4).

Jean found application of auditory-verbal techniques difficult and felt guilty about that, "I don't practice enough with her ... because to actually sit down is hard. I try to repeat myself a lot. I try to listen to what she's saying ... to use words at her level" (p. 2, 1.21-23). When given some examples of auditory-verbal techniques, such as covering one's mouth, Jean replied, "Oh, I forget because we don't do it anymore" (p. 4, 1.15). He added, "We always read every night. That was my own way of doing a-v therapy" (p. 3, 1. 5-6). Margaret also found it a daunting task initially to remember the assigned language targets and to apply them, but was proud of the fact that she started to be able to integrate the therapy ideas into her everyday routine,

When you're going to therapy and you see the way it's done there they make it look so easy ... and it's like when you go home you've got these notes but you don't have the materials to work with like they do ... but you just don't *think* [italics added] of using *that* [italics added] toy to do *that* [italics added], so with the Uno I started doing things like when we started going through colours. That was excellent because we were able to teach her her colours ... and then then the *numbers* [italics added] ... That's when we started, like oh well it's not so bad (p. 16, 1.14-15, 1.17-21, 1.22-24, 1.27-28, 1.31-32).

Initially, Margaret and Jean were quite concerned about Melanie's slow progress and expressed this to their therapist, "As a parent you have so much expectations for your child and that you want ... them to excel and you want them to start speaking. You want to hear them say mummy and daddy" (p. 15, 1.5-7). Margaret added that it is important for the therapist to reassure the family and tell them that there is a "light at the end of the tunnel. It's just gonna take time" (p. 15, 1.4). She very much appreciated the guidance she received from Sarah and found it useful to talk about Melanie's development with her, "I think that most of these people should be psychologists too in what they have to deal with (both laugh) ... audio-verbal therapists are having to deal so much with the emotions of parents as well" (p. 21, 1.26-29). She found that she looked forward to the therapy sessions because when she was feeling discouraged about the progress there was always some sign of encouragement during the session "It just gives you that hope to go on" (p. 21, 1.35). During one of the observations she commented that she appreciated receiving homework so that she knew exactly what to do (obs. 1). When other members of the family and daycare workers questioned Margaret and Jean about Melanie's progress, it created doubts in their minds. Margaret recalled, "That was difficult for Jean and I because we really

believed we were doing the right thing and we really believed in what the [hospital] was doing with her" (p. 10, 1.4-5, 1.7-9).

Sarah expressed concern about the fact that Margaret spent a lot of her time advocating for service for Melanie, although she did feel that "what you told them to do they did, so that was a plus" (p. 9, 1.2). Sarah was frustrated by Melanie's daycare placement, "despite my having discussed frequently with them that a bilingual daycare setting was totally inappropriate" (p. 5, 1.5- 6). In summary, Jean commented on the marked improvement in Melanie's communication skills in the 18 months since she had received her cochlear implant. Both parents had found the implementation of auditory-verbal therapy to be a formidable task initially. While Jean expressed guilt at not being able to adequately use the techniques he had learned, Margaret felt more confident in her abilities and reported that she was now able to incorporate the therapy targets into her daily life.

Support

Health-Hospital.

Both Margaret and Jean were very pleased with the services they had received from the hospital. Jean said, "I mean it's great. If there was none there we'd be stuck" (p. 4, 1.23). Margaret added, "We just find it's a godsend because there's there's nothing in Quebec" (p. 21, 1.22-23). Margaret appreciated the comment from Dr. Smith, the surgeon, that they will probably notice some improvement in Melanie's language after she had worn the cochlear implant for 18 months.

She added that parents like to know what to expect, even though she understood that it is difficult to make a prediction about future development, as each child is different. Margaret expressed concern that there were not enough audiologists on staff at the hospital. She stated that they benefitted from health care in both provinces as they used the audiological services in

Ontario and received the hearing aids, earmolds, FM system and accessories at no cost, through the Quebec health care system. In most previous instances, families had been advised that they must take their child to Quebec city for cochlear implant surgery and then stay there for three months post-surgery to undergo therapy and programming of the implant processor. For this reason, they had anticipated a struggle when they applied to have the surgery performed in Ontario, as had been the case with previous requests from other families. Sarah cited the case of a young woman whose application had been refused and later accepted due to negative publicity in the media. In her opinion, this precedent had expedited Melanie's application.

Sarah commented that because the family had been living in Quebec when Melanie's hearing loss was first diagnosed, their choice of hearing aids was limited to those for which the provincial government would pay and "they had a much harder time with their earmolds" (p. 17, l.17). Sarah lauded the close liaison between audiology and auditory-verbal therapy at the hospital. It had been difficult to determine the extent of Melanie's hearing loss initially and therefore she had received regular audiological monitoring which intensified even more when her hearing started to deteriorate. Sarah said, "Had she been someone where she didn't have the audiological support I wonder how much longer her hearing could have been down" (p. 15, l.28-29).

Margaret recalled that she was asked about Melanie's sibling during the pre-implant assessment. When she reported that Mark had been diagnosed with ADHD, the psychologist indicated that she would evaluate him, once the family physician had made a referral for a psychological evaluation. Margaret did not receive any further contact regarding an appointment with the psychologist.

Margaret would have liked to have been better informed regarding services available in Ontario, after she moved to that province. She also found that she had to spend a lot of time researching the resources available in Quebec, "Living in Quebec and speaking English had to be the hardest hurdle because there is not a lot of things available to English-speaking Quebecers especially in health care" (p. 9, 1.19-22).

Education-Local.

Jean mentioned that they did receive some provincial funding for service through their daycare and that Sarah visited the daycare to train the person who was providing service to Melanie. Sarah indicated that this person "really caught on to it and she was terrific but that was one hour a day ... and 90% of the kids at the daycare were Francophone" (p. 5, 1.22-25). Margaret added that the daycare subsidy provided by the Quebec government is considerable and made it difficult for them to leave, from a financial standpoint, even though they were aware that Melanie needed to be exposed to English-speaking peers.

Both parents were very disappointed in the services that the Quebec provincial government offered in school to children with hearing loss. Sarah added that Margaret spent hours in communication with the board regarding service and "some of it was obviously beneficial because Melanie got more services than near anyone else in the Board" (p. 11, 1.1-2). Jean recounted that Margaret had to fight a lot with the board. She finally decided that they had to move, despite the fact that Melanie was receiving service from a teaching assistant, who was being trained by Sarah on a biweekly basis. Margaret reported that the timing was crucial and that they had to ensure that Melanie was getting support in her early years. This prompted their move to Ontario. This "has been just [a] huge change" (p. 28, 1.24), according to Margaret. Sarah explained, "There was never going to be a teacher of the hearing impaired ... [a teaching assistant

is] just not the same as having a teacher of the hearing impaired there four times a week plus a teaching assistant” (p. 11, 1.18-19, 1.28-29). When the family moved to Ontario, she did receive this latter service.

Since Melanie had been enrolled in school in an Ontario board, Jean stated,

It's easier now that she has help everyday. Before it was once a week and it was our job ... we're not professionals. That's what I find hard. We try to do what Sarah and Monica (itinerant teacher of the hearing impaired) do and it's hard. They push her to the limit and we don't. (p. 4, 1.2-7).

Although Margaret was very pleased with the service Melanie was receiving from the Ontario school board, she felt that the teaching assistant required more training from the teacher of the hearing impaired. She also expressed concern about Melanie's future attainments in school, “She's doing much better in certain things than even he (Mark) is ... but as far as doing mathematical uh and other things later on like oral presentations those I'm a bit more concerned about” (p. 31, 1.34-37).

Workplace.

Sarah indicated that one of their strengths was the family's commitment to regular attendance at therapy, however it did take a toll on them. Jean explained, “You just wish your employer would understand more. Some do. Some don't. You have to go ... You learn stuff every time you go” (p. 4, 1.20-21). Margaret acknowledged that while her employer was very accommodating, Jean's was not, “If ... your boss is ... giving you a hard time about taking off it makes it that much more stressful” (p. 25, 1.23-25).

Voice.

Both Jean and Margaret enjoyed meeting other families through the social functions that Voice sponsored, although Jean stated that they were not very involved. He added that Margaret had attended one seminar sponsored by Voice but had found that it was more for teachers not for her. Margaret regretted that there wasn't more parent interaction on a one-on-one basis. She also felt that Voice was not very well-informed about services available to residents of western Quebec. While she appreciated the summer camp sponsored by Voice, she suggested that a daycare, even one day a week, run by older teens with hearing loss, for younger children with hearing impairment would be beneficial.

Community.

Margaret indicated that for the most part they had no difficulty finding babysitters. Since their move to Ontario they have been receiving Assistance for Children with Severe Disabilities, which Margaret obtained on her own. Jean also mentioned that Margaret had received some support from one of the cochlear implant companies and was in contact with them via Internet. In summary, Margaret and Jean felt that they had received a lot of support from the health care system and less from the education system and from Jean's place of work.

Summary-Barriers and Facilitators

The availability of the cochlear implant and Melanie's acceptance of the technology facilitated the transition for her parents. The presence of two languages in the family was a potential barrier that the family surmounted, although Sarah would have liked to see them address the language issue with regard to daycare earlier in the process. The requirement for time and advocacy in order to implement auditory-verbal techniques was a barrier to the transition. Both Margaret and Jean indicated that this was not an easy task, however they felt that they had

devised methods of implementation with which they were each comfortable. Although Melanie's slow progress initially presented a barrier, the family's continued persistence mitigated the effects of this slow start. Both parents agreed that the services at the hospital in Ontario facilitated their transition. Sarah mentioned some limitations in terms of the kinds of hearing aids and earmolds available to them in Quebec. The significant barriers presented to them by the schools in Quebec and by Jean's workplace were also mentioned. Other facilitators included the opportunities to meet other families through Voice and the information provided by the cochlear implant company.

Exosystem

Support

Health-Provincial.

The policies for purchase of hearing aids in the province of Quebec limited the choice of instrumentation for Melanie. This was an additional concern in her case as her hearing deteriorated over a short time period. While there was a stringent policy on cochlear implantation in Quebec this policy was waived for Melanie's family in consideration of the distance they would have had to travel and the disruption to their family life that a three month stay in Quebec City would have meant. Jean lamented the fact that there were no auditory-verbal therapy services in western Quebec, "They have so much here that I'm surprised they don't have more there ... There are so many English people in Gatineau, Hull, etc ... Why can't they have the same?" (p. 5, l.31-33).

Education-Provincial.

The school board in western Quebec does not hire auditory-verbal therapists to work with children who have hearing impairment. This situation presented a barrier to this family's

transition. It was primarily because they felt Melanie would not receive appropriate service in school that the family moved to Ontario. Sarah said of their move, "I think it was a good decision on her (Margaret's) part" (p. 11, l.15). It was Sarah's view that the school would have liked to have been able to offer Melanie more service, but "they just didn't have the funding ... the funding doesn't exist" (p. 20, l.2-3). She added that it wasn't clear to her whether the funding was not made available at the Ministry level or at the school board level. While the daycare subsidy did help this family financially, the fact that they could not find a daycare that offered service in English was a huge barrier to their transition.

Community.

Margaret found that the provision of funding by the Ministry of Community and Social Services in Ontario was very useful, however she complained that she had to do the research to learn about this funding. Jean stated that they were offered respite services by one community agency but they felt they had their parents close by, as well as a babysitter, and therefore they didn't need to avail themselves of that service. Sarah commented that when the family requested a sign warning that a deaf child was at play in the neighbourhood, the signage provided by Ontario was much clearer than that provided by Quebec.

Voice.

While Voice Ontario publishes a newsletter, performs advocacy functions, and provides training opportunities for therapists, Margaret felt that it "had no impact at all" (p. 25, l. 34). She did mention that she had heard some speakers whom she had found educational, however she was informed that it was the local chapter of Voice that sponsored them, not the provincial chapter. In summary, while the Quebec Ministry of Health removed a potential barrier for this family by granting them permission to have the cochlear implant surgery in Ontario, the Ministry

of Education provided an obstacle which they could not overcome, that is the absence of auditory-verbal therapy service in the school. This led to their eventual move to Ontario.

Summary-Barriers and Facilitators

While some of the Quebec health policies and its policies regarding the education of children with hearing loss presented barriers to the family's transition, the Ontario health, education and community programmes facilitated this transition. The family seemed to feel that Voice Ontario had no impact on them.

Macrosystem

Accessibility

Both Jean and Margaret acknowledged that the cochlear implant has had a very positive influence on their lives. Jean stated, "This thing is like a miracle" (p. 6, l.26). They realized that they were fortunate to be living in times when the technology for the cochlear implant was available and in a community where it was accessible to all who needed it. Their move to another province for service indicated the enormity of the impact that lack of service can have on a family who, according to Sarah, "desperately wanted her (Melanie) to speak" (p. 7, l. 11-12). Another issue this family confronted was the lack of understanding of the role of an auditory-verbal therapist. Margaret tried to convince the Quebec authorities that there is a difference between auditory-verbal therapy and speech therapy, however the provincial authorities felt their speech therapists were qualified to perform auditory-verbal therapy. In summary, the accessibility of the cochlear implant facilitated this family's transition to auditory-verbal therapy. The lack of auditory-verbal therapy in Quebec presented a hurdle which they surmounted by moving out of the province.

Inclusion

Margaret was grateful that the education systems in both Ontario and Quebec were supportive of children with differences in the regular classroom. She felt that Melanie's peers were accepting and the teachers "were very good to educate the other kids in the class and Melanie's peers ... so then they understand that she's normal like everybody else" (p. 32, 1.12-17). Both parents acknowledged the influence of the Deaf culture on society. Margaret offered that she is often asked whether she or Melanie knows sign language. She explained,

We wanted to raise her as a hearing child so we didn't want to have to learn sign language if we didn't have to ... and the only way we were going to be able to do that was with the AVT (p. 7, 1.36-39).

Sarah recalled that the family had knowledge of some oral anglophone children with hearing loss in the Quebec board. In summary, although both parents acknowledged the influence of the Deaf culture on society in general, they both felt that they wanted to give Melanie the opportunity to learn to speak and were grateful that schools offered an inclusive environment.

Summary-Barriers and Facilitators

The access to cochlear implants and the current societal emphasis on inclusion have facilitated this family's transition to auditory-verbal therapy. Quebec's lack of specialists in auditory-verbal therapy was a significant barrier for this family.

Current Perceptions of the Transition

Clearly the detection of Melanie's hearing loss wrought significant changes in the lives of her and her family members. While they had initially been devastated by the news of the loss, they now seemed to be adjusting to it. When asked how she was feeling now, Margaret

commented, “more hopeful, much more hopeful because we see a lot more progress more in the last 4 months ... that she *really* [italics added] has starting to talk ... we see that she is gonna be O.K ... she's gonna be fine ... she's gonna you know be able to do well in whatever she's gonna do you know in the future” (p. 19, 1.24-30).

Susan and Zach Owen and Family

I was greeted at the front door of the Owen's spacious home by Susan and Sean, the oldest child. We entered the kitchen where the first observation began. While Kate, the Owen's daughter and Peter, their younger son initially accompanied us, they soon drifted out of the room, leaving Susan and Zach to complete the Family Information Questionnaire. Sean stayed to listen and contribute to the questionnaire. In fact, at each of my visits, Sean attempted to be part of the conversation, even asking me to interview him, which I did. After a while he went to play the piano in the living room. Peter returned to the kitchen, drew a picture and gave it to his mother. She spoke to him using a normal rate of speech, not slowing her rate to accommodate his hearing. After Sean had finished playing piano, Susan and Peter went to the living room for Peter's piano practice. Susan suggested that Sean go upstairs and do his homework to which he replied that he hated when Peter was doing music. During their time at the piano, Susan continued to carry on a conversation with Peter, interpreting his meaning and highlighting new vocabulary (eg: “There two *notes*, [italics added] Peter. Look, that's a *note* [italics added] . It's a *note* [italics added]” - obs. 1). She expanded on Peter's phrases (eg: P: “Two cracks”; S: “Two cracks, one on each side”) but did not ask Peter to repeat these. At one point, Susan did not understand one of Peter's comments but did not pursue the topic. At the end of the first observation when it was bedtime, I asked Peter a question which he did not understand and Susan took on the role of interpreter between us. As Zach read a bedtime story to Peter his voice

exhibited a varying intonation pattern and his rate of speech was slower than normal, accommodating Peter's hearing loss.

When I arrived at the second observation, Peter and Susan greeted me and I remarked on the snowman on the front lawn. Susan replied that Sean, Peter and one of the neighbours had built it, but that only one of the neighbours played with her children for various reasons including age and temperament. When Susan explained to Peter that he could have no more computer time, he threw a temper tantrum and Susan held him for three minutes until his tantrum had subsided. She reported to me that he used to take his cochlear implant off when he was angry and that she began to use this technique of behaviour management to avoid his removing his implant. She added that his behaviour had been difficult both at home and at school this week. She then offered him a choice of two activities, and he chose to draw a picture for his grandmother's birthday. She didn't shorten her sentences when speaking to Peter and carried on at a normal rate of speech. Following this, the two boys went downstairs to the recreation room and Sean and Zach played the violin. As Susan and Peter had had an altercation, Susan indicated that it was doubtful that Peter would cooperate with her in doing any further activities, and she asked Zach to do some of Peter's Kumon with him. It was observed that Zach also used a normal rate of speech with Peter and grew impatient with him as he was not cooperating. He did not attempt to cover his mouth or to emphasize hearing when addressing his son.

My last observation with the Owen family took place at 7:30 a.m. at Susan's suggestion. She had said that if I really wanted to see the family in action that an early morning was the best time. I was greeted by Susan and Peter, wearing Zach's tie. When addressing Peter, Susan used repetition and moved closer to access his hearing better. Kate also used repetition and a slower rate of speech when addressing her brother. Peter had another tantrum and pulled off his speech

processor. Susan dealt with this amidst serving the rest of the family breakfast. At one point, Peter called Sean three times but did not succeed in getting his attention, despite the fact that Zach told Sean that Peter was trying to talk to him. Susan expanded Peter's vocabulary by commenting on his spontaneous utterance (eg: P: "I want some more please"; S: "Are you thirsty? You're *thirsty*" [italics added]).

Microsystem

Personal Characteristics

Zach described the period prior to the hearing loss, "You got healthy kids, you know, you've got good employment, good job, you're you know, everything's rolling along" (p. 12, 1.17-18). Susan remembered that they were doing a lot of "little kid stuff" (p. 2, 1.8), like diapering and playing outside. She also recalled that they were dealing with some severe gastrointestinal issues with their daughter, Kate.

Peter's meningitis around his first birthday devastated both parents. Susan reported that "For the first few months, I stopped work and we spent all our time on the Internet trying to find out solutions and educating ourselves" (p. 7, 1.5-6). Susan said that it took about two to two and a half years for Peter to function as he had previously. Zach indicated that they were not in a routine for a long time "because ... the illness lasted a month plus all of the operations ... there was a lot of work there and thereafter as well" (p. 3, 1.16-18). Zach added that there were huge expenses associated with Peter's therapy, including the hiring of a nanny, the purchase of a third car as well as the buying of many toys and materials. He stated, "When you have a kid just let it be healthy because it will change your life absolutely if you don't" (p. 13, 1.1-2). He added that, "I'll always know that I've got a certain amount of limitation to the future that I had before" (p. 42, 1.8-11).

Susan described herself as “not a talkative person really” (p. 20, 1.8). She added that she found it “difficult to talk to a young child that doesn’t understand” (p. 20, 1.13-14). Zach agreed that it’s not Susan’s strength “to talk all day long, to talk and talk and talk”. Susan stated that the decision to stay home with the children or to work was a difficult one for her. As Susan felt that she could not do auditory-verbal therapy satisfactorily, she decided to continue to work and to hire a nanny who would provide auditory-verbal therapy for Peter. Susan indicated that she learned from having gone through the auditory-verbal process that it is important

to always communicate things with the kids and talk about things that you see ... and give them language ... whether it be a deaf child or any child, and I kind of wish I’d known that with Kate and Sean ... cause you just take it for granted (p. 14, 1.3-5, 1.7, 9, 11, 19).

When describing her role, Susan said she was equipment manager as well as the one who attended therapy sessions. Zach also attributed to her the role of facilitator of relationships with other children, “It’s Susan’s ability to get to know the parents at school ... dedicate and cultivate relationships just like we did with our other two kids ... and a nanny doesn’t do that ... so that’s a big reason she quit her job” (p. 7, 1.7-9, 13-14). Susan reported that she had facilitated social interaction for one of her older children but she felt that Peter would need her help in this area more than his hearing sibling.

When asked to describe his personality, Zach indicated, “I don’t have a lot of patience especially with very young kids” (p. 27, 1.6-7). He added that he is effective at “leveraging the things for him in his best interest” (p. 26, 1.14). He also felt that he had tenacity, “This is actually what Susan and I both have is that if Peter needs X, he gets X” (p. 25, 1.22-23). Zach spoke about his grief following his son’s meningitis,

It's been a very dramatic loss for Peter and for us (p. 11, 1.10-12) ... I would say I've changed. I'm not as happy a person as I used to be ... and that's a function of going through something like that (p. 11, 1.20-22) ... I lost a lot of my optimism over the course of the last couple of years for sure, and it's coming back slowly ... It's come back to, I'd say pretty well normal (p. 12, 1.6-9).

While Zach "certainly had to do some of the A-V therapy" (p. 23, 1.23), he considered that he "played a tertiary role" (p. 25, 1.2). Susan added that Zach was "even more isolated, away from it than I was" (p. 31, 1.18) because "he worked absolutely full-time and he absolutely had to support the family" (p. 31, 1.20). She felt it was really hard for fathers to be involved because of the hours they work. She added, "I think an awareness is really important and that's what they had and they can do their bit when they have the time" (Discussion Group- D.G.). Zach had been advised not to "have any expectations for him (Peter) that are any different than your other two" (p. 41, 1.20-21). Earlier in the interview he had expressed concern about his son's future, "We just anticipate more, more support from us required" (p. 15, 1.6). He and Susan expected that they would need to have savings set aside for any eventualities that might arise in Peter's life. Not only did he express worry about Peter's future but he also indicated that he has some concerns about his daughter.

Both Susan and Zach described Peter's personality in positive terms. Susan said, "He's very determined ... he's a great kid, he's gonna do well" (p.15, 1.17-18). She added that "He's got a positive outlook on most things" (p. 23, 1.1). Although he is able to sit down and focus when he wants to and work for a long time, she felt that his strong personality also prevented him from doing so at times. Susan attributed his temper tantrums to this strong personality and also to the fact that he might be frustrated when trying to communicate. Zach indicated that for the most

part, "He's developing into a happy little guy, well adjusted it seems" (p. 16, l.1-2). Susan added that she thought personality played a huge role in the transition to auditory-verbal therapy and that "There's no way we could do auditory-verbal therapy with some kids (laughs)" (D.G.). She was referring to her daughter who had ADD. She felt it would be difficult to manage both these needs in one child. Both Susan and Zach expressed concern about Peter's social development. Zach stated that the reason Susan is staying home now "is because we recognize that Peter's issues will be much more of a social nature at this point, or at least these will begin" (p. 7, l.4-5). Susan suggested that it might be beneficial for children with hearing loss in Junior and Senior Kindergarten to get together in groups during their afternoons off, so that socialization might be encouraged. She added, "If they find it difficult with regular kids, if they can see each other and kind of help each other ... it'd be kind of interesting and maybe develop friendships there to kind of kick them off" (p. 49, l.10-14). In summary, despite their daughter's gastrointestinal difficulties, Zach and Susan described life prior to Peter's meningitis as quite normal. After his illness, Susan took some time off work and both parents did a lot of research on the Internet in order to educate themselves regarding their son's condition. They decided to hire a nanny to do auditory-verbal therapy with Peter, as Susan did not feel she could be talkative enough to do it, to her satisfaction. Zach described them as tenacious in pursuing the best options for their son, whom they both characterized as a happy little boy.

Family Interactions

Both Zach and Susan felt that they had a good relationship with Peter. Susan added that "If we had a bad relationship, I don't think it (auditory-verbal therapy) would be possible (laughs)" (p. 23, l.16). Susan said that in the past

it wasn't really an issue because I didn't do a lot of the formal therapy ... and we're doing it now but I do it more informally ... I just don't really sit down at the kitchen table, like what Sarah does ... I do it more informally" (p. 23, 1.8- 12).

Zach indicated, "I've had an odd relationship with Peter in some ways because he bonds to me like crazy ... It's always Daddy ... like for the last three years, it's always Daddy, Daddy, Daddy, Daddy" (p. 33, 1.18-21). He added that he did not think that Peter associated him with the auditory-verbal therapy.

When describing their relationship, Susan indicated that, "We've always both agreed that we want the best for him" (p. 24, 1.4). Zach added, "In terms of our relationship, I think we have a similar view on what needs to be done. We're like that with most things" (p. 37, 1.9-13).

Susan reported that the older two children, Sean and Kate, didn't play very much with Peter and played more with each other. Although Kate had attended some auditory-verbal therapy sessions with Peter when she was younger and did use some of the techniques that she had observed at these (obs. 3), Susan didn't demand their use of auditory-verbal techniques as she didn't "want Sean and Kate to have any more stress than they already have" (p. 28, 1.12). She found that the older two children played more with each other than with Peter, possibly due to their age difference. Susan added that the increased attention Peter received may have had an effect on the other children but this was minimized because a lot of it happened during the day when they were not at home. They tried to treat him like the other children as much as possible (D.G.). Zach indicated that both he and Susan are very conscious of "the time we spend or don't spend with the other two" (p. 18, 1.17-18) and therefore don't permit Peter to dominate all their time. He found that the older children "have never shown to be jealous of him (Peter)" (p. 19,

1.4). He concluded that because they recognized that Peter had a challenge, they've been very considerate of him, more so than of each other.

As far as behaviour management issues, Susan felt that she parented each child individually and differently depending on his or her strengths and weaknesses. Zach commented that he thought Susan prided herself in trying to deal with the children all the same, but he added, "I am more ... lenient with Peter to a degree ... I let him stretch just a little bit more" (p. 22, 1.21-23) ... but not where he's like throwing his temper tantrums ... I have zero-tolerance ... for that kind of thing" (p. 23, 1.2-5). He explained, "It's gonna be tough for him ... I'll give him a little extra this or a little extra that. He wants to have a second helping of dessert, sure ... especially if he articulates it well" (p. 23, 1.7-9). In the discussion group, Susan commented that although she had thought that they had been quite successful at treating their children equally, a recent remark from her brother-in-law made her realize that in fact they were being stricter with Peter now. She stated, "As he understands cognitively and linguistically more, we can demand and expect more from him and enforce more sophisticated discipline" (D.G.).

Susan described her mother as a source of support in that "she was just somebody I could just call at the drop of a hat" (p. 38, 1.20). Although Susan's mother was very helpful and did accompany her to the occasional appointment at the hospital and did care for Peter now and then when Susan needed a break, she indicated that "I didn't want to impose on her" (p. 39, 1.2). She added that extended family treated Peter "as any other child ... which is what we want" (p. 37, 1.3-5). Zach agreed that the proximity of Susan's family has been very helpful and that they have been "very supportive" (p. 64, 1.10). Now that Zach's sister has moved to the city, they see more of her and she has a son Peter's age, "which is very beneficial for Peter" (p. 40, 1.10-11). In summary, both parents felt that their relationship with Peter was strong. While Zach felt that the

older children were supportive of Peter, Susan indicated that they weren't very involved with Peter. While Susan tried to treat each child according to his or her needs, Zach acknowledged that his treatment of Peter was preferential at times. Susan did acknowledge that when Peter's comprehension was not as advanced, it had been more difficult to manage his behaviour. Susan and Zach held the same goals for Peter and therefore seldom disagreed.

Summary-Barriers and Facilitators

When considering barriers to the transition, Susan felt that their concern about their daughter's health issues did detract somewhat from their attention to Peter. Although she considered her quiet personality to have been a barrier, the family adapted by hiring a nanny to do auditory-verbal therapy with Peter. This enabled them to concentrate on the family's other needs. Zach felt that their tenacity facilitated their transition as did Peter's happy nature and ability to focus on tasks. His temper tantrums were a challenge with which they were coping. Their relationship with Peter facilitated their transition, as did the support they received from extended family. While Zach perceived Peter's siblings to be facilitators, Susan considered them to be less involved with their brother.

Mesosystem

Choice

When asked why they chose auditory-verbal therapy, Zach replied that they did a lot of research and collected all the data they needed including viewing some "one-sided documentaries" (p. 7, 1.17-18). Despite the fact that they came across "a lot of literature and media that's anti-cochlear implant" (p. 7, 1.22-23), he felt that "You give a cochlear implant so the child can learn to speak" (p. 8, 1.5). Zach added that auditory-verbal therapy seemed the obvious choice for them given their desire for him to be able to converse with all members of the

immediate and extended family and that they “have no infrastructure to support sign language” (p. 8, l.7-8). Susan added,

If there's a chance he can hear, function in the hearing world, that's what we're gonna do.

Like we didn't even sit down and debate it cause we didn't want him to be locked into a smaller world, if he didn't need to be, he didn't have to be (p. 55, l.13-18).

Sarah explained, “He would have been developing some comprehension of language before the meningitis ... the family was wanting to do anything to make that development continue to happen. So, I think they were quite eager to pursue the auditory-verbal approach” (p. 1, l.17-21). Thus for Susan and Zach, the choice of auditory-verbal therapy for Peter seemed an obvious one based upon their desire for him to learn to speak.

Compliance

During the discussion group, Susan commented that Peter pulled his hearing aids out often. Sarah recalled that they didn't have as much difficulty keeping the hearing aids on Peter as with some 14-month-old babies, because he had heard normally prior to the meningitis. Susan stated, “They tried hearing aids which didn't do anything” (p. 7, l.20). Sarah indicated that “there wasn't a very long period with the hearing aids at all” (p. 4, l.17-18). Both Zach and Susan considered the hearing aids to be “marginal” (p. 52, l.23) and didn't want to wait for a cochlear implant. They admitted that there was an initial period where “we hadn't accepted it fully ... maybe we can get over this ... we were looking at alternatives and doing all the research” (D.G.). Zach added, “You gotta go through this transition in your own mind, right? And accept the fact” (p. 52, l.17-19). When they were ready for action, they found that they were going to have to wait. As they feared that Peter's cochlea might ossify if they waited any longer, they spoke with their auditory-verbal therapist, Sarah, and with the surgeon, Dr. Smith, and succeeded in

obtaining the implant a month later. Susan reported that 12 out of 24 electrodes were implanted and so they were pleased that they had advocated on behalf of their son. She added, "I think we could be more aggressive here with meningitis kids" (D.G.).

When asked about the changes brought about by the introduction of auditory-verbal therapy, Zach commented,

Wouldn't say they've changed that much with respect to the things we have to do. The way we do them might be different, especially with Peter now, obviously because the way we talk has a huge impact on what we do ... the way the kids talk has a big impact and the way they behave with Peter, all that changes" (p. 4, 1.6-16).

When asked about the effect of doing auditory-verbal therapy, Zach responded that "It takes a great deal of time and effort" (p. 10, 1.2). Susan agreed that "it is a time commitment. I put it a top priority, one of our top priorities" (p. 33, 1.10-12). She considered, "talking itself" (p. 31, 1.6) to be hard. She felt "someone could probably talk a lot more and a lot better than I can" (p. 12, 1. 11). Zach explained that because Susan wasn't confident that talking was her strength, they "sought out to get a nanny who was first and foremost someone who could do speech therapy" (p. 5, 1.20-21). Susan returned to work and hired a nanny, Helen, who had worked for the school board as a teacher for a number of years, to come in and do auditory-verbal therapy with Peter. Susan felt, "she would know a lot more about this than I would. I'm just a mother" (p. 13, 1.15-17). While this decision was a difficult one for her, she explained, "I was afraid of not doing a good enough job for him definitely" (p. 43, 1.21-22). Zach offered that the advantage of that situation was that the nanny would do the formal stuff with Peter and they would "do the informal stuff" (p. 24, 1.17).

Initially, they thought it was going to be odd to talk clearly and slowly but Zach claimed, "It does become second nature" (p. 6, 1.13-14). Sarah, their auditory-verbal therapist, commented that, "Susan did take time off work and stayed home with him, and has been very consistent in coming to the sessions and really trying very hard to do what was expected ... and I think in most ways achieved that" (p. 2, 1.15-19). She added that they were able to do "the formal teaching kind of stuff, but in terms of expecting him to listen and expecting him to talk just daily, they had a much harder time getting that, but that has come over the years" (p. 3, 1.9-13). She summarized by saying "They certainly have done a lot in terms of making sure that it was an auditory-verbal lifestyle" (p. 3, 1.2-3).

When asked about auditory-verbal strategies they used, Susan replied that some of them, like covering their mouths and repeating, were not difficult and came naturally once they were demonstrated. Zach said that they spoke in simple sentences to their daughter, who had been identified with ADD, as well as to Peter and that they probably did this unconsciously. Susan added that it is more difficult to work on expressive language when the child is younger and at earlier stages and easier when the child is older and more advanced. Zach stated, "I don't accommodate his hearing right now ... sure I do, but not to the same degree" (p. 31, 1.3-4). He did feel however that they needed to work more on making Peter use his language rather than letting him "get away with not saying anything" (p. 45, 1.21).

Susan found that the initial stages of therapy were "not rewarding" (p. 21, 1.1) but that "it's more fun now because he's at an age where you can see the difference you're making" (p. 20, 1.18-19). She indicated that she followed through on what she was told to do but needed "to be assigned those things to be done (laughs) and then I can do it right" (D.G.). Sarah agreed with this statement, "If you tell her how to do it, she can easily go home and do it quite well" (p. 15,

1.10). Susan explained that she liked doing Kumon with Peter because there were prescribed homework sheets to do. She would have liked similarly structured activities to do with Peter when developing his speech and language, "I can do that if I have something concrete in front of me" (D.G.). She added that she would have liked to have had materials and activities to "take the brainwork out of it" (D.G.). She also mentioned a system in another city where children attended Junior and Senior Kindergarten full days. They were mainstreamed in the morning and were in a class with a teacher of the hearing impaired and an educational assistant in the afternoon. She felt that was amazing and would "get those kids going" (p. 50, 1.13). She also felt such a system would "take a huge burden off the families" (p. 50, 1.15).

Zach expressed frustration because it's "very hard to notice the progress" (p. 28, 1.11-12). He felt that he had "no clue if he's on track or not" (p. 29, 1.13) or "how he's doing relative to where he's supposed to be" (p. 28, 1.13-14). Although he had been told that Peter's comprehension is at the level of a normally hearing 4-year-old, he was doubtful of that because, "I clearly see him with other children, and I clearly see him not understand where other children do of the same age" (p. 30, 1.13-14).

Zach mentioned some of the barriers to auditory-verbal therapy including cost and expertise. He said, "If there's one big change, it was expenses ... we do and will spend what is required to give Peter an uncompromised support network to learn to speak" (p. 6, 1.7-9). Susan agreed that it "was financially draining" (p. 43, 1.1). They found that the availability of people who were able to do it was a barrier, "we had to get a nanny who could do it, so we had to get somebody who was willing to learn it, teach it, practice it appropriately" (p. 9, 1.8-12). Zach added that creativity is a challenge because "You gotta come up with a schedule and a curriculum that he's intrigued by" (p. 10, 1.22-23). During the discussion group, when asked to

name the three elements that most facilitated the transition, Susan listed the cochlear implant first, followed by the people - therapists, audiologists and their own family and its resources and lastly, Peter's personality "in that he can concentrate well and can be cooperative" (D.G.). The barriers she listed included Peter's personality because "he's very independent and determined" (D.G.). She also included a lack of consistency on the part of family members,

Getting everyone to adopt the same to treat him the same and talk to him and trying to elevate his level of speech and comprehension because it's easy to talk to him at the level he understands so getting everybody to challenge him (D.G.).

In summary, Zach and Susan felt that while they had adopted auditory-verbal therapy techniques in the initial stages with Peter, they tended to speak more normally now. They acknowledged that their nanny provided much of the formal therapy to Peter and that their contribution was more at the informal level. Susan would have liked to receive more structured activities and materials from the hospital. While Susan mentioned the difficulty in using language to challenge Peter's comprehension, Zach indicated that they needed to extend Peter's expressive language more. Both parents felt they wanted to know how their son's progress compared with other children who wore cochlear implants.

Support

Health-Hospital.

When asked about the support provided by the health system, Susan replied, "I guess the health system has been good to us" (p. 55, 1.6). She added, "I thought the therapy was really quite good" (D.G.). Both parents mentioned that they consider themselves fortunate to be so close to the [hospital]. Zach commented, "I know there are a lot of people in more rural areas. For them to get access is pretty difficult" (p. 48, 1.12-15). He added that,

If the [hospital] wasn't known to be a great audiology centre, we'd move somewhere else to where there is a great one, same with surgery, the services ... (p. 49, 1.11-14) ... You want him near the Centre where he gets support. You want him near the resources where he gets that, you want him near places where he's going to be successful (p. 14, 1.6-9).

Zach reported that Peter's hearing had been tested in his hospital room and that a cochlear implant was mentioned right away. Susan was appreciative of the fact that they were set up with an array of services in a timely fashion. She added, "You hear about people who don't have any other services. You wonder, how in the same city can that happen?" (p. 34, 1.18-19). She was appreciative of the audiology services, the therapy services, as well as those offered at the treatment centre. She mentioned that it had been recommended that Peter receive a psychological evaluation before entering school, but that this evaluation had been delayed. Sarah remarked,

They've had no trouble maintaining his equipment and keeping it on and fully operational. All of our families face no obstacles at all in terms, except maybe for some monetary, but even still that's just one extra step to get the funding from agencies ... we usually get it some way or other ... so everybody gets what they need and it's kept well for them ... cause that wouldn't necessarily be the same elsewhere (p. 21, 1.15-23, p. 22, 1.2-5).

Zach commended the counselling provided to him by a physician (perhaps a neuropsychologist) while Peter was in the hospital. That doctor reassured him that while Peter's hearing would not return, he would likely do fine given the appropriate equipment. Zach also appreciated the accessibility he had to the surgeon who performed the cochlear implant surgery. As he had a science background, Zach had "read all the latest journal articles and research in

terms of cochlear implants" (p. 55, l.23). They went to the surgeon and said, "We want to do it right now and this is why and he said 'sure', had a surgery scheduled in 2 weeks" (p. 8, l.10-11).

Education-Local.

Both Susan and Zach were pleased with the support Peter was receiving from his itinerant teacher, provided by the school board. Although he did not have an educational assistant in his classroom, he did receive therapy three times a week from his itinerant teacher, in addition to his weekly sessions at the hospital with Sarah. Zach indicated, however, that he was not pleased with FM technology that has been available to his son. Sarah concurred "... frustrations here and there with the FM system or like - the moisture (condensation) thing. You know it doesn't prevent them from developing or anything. It's just one of these little frustrations the families have to deal with" (p. 26, l.11-12, 19-21). She explained that Peter did have an FM system available to him at school but it was compatible only with his body speech processor and the family wanted one compatible with the ear-level speech processor.

Workplace.

While both Zach and Susan agreed that the adoption of auditory-verbal therapy had not affected Zach's work life very much, they felt that Susan's employer had been "very accommodating" (D.G.). When Susan took six months off work after Peter's illness, she was fully paid. Upon her return to work she requested a half-day off each week to attend therapy at the hospital and was granted that. She later reduced her work week to four days and then to three days and they were very flexible in permitting these changes. At the time of our interview, she had left work because she "felt our needs changed, and I could see that Sean and Kate needed me home more and Peter was getting fed up too" (p. 27, l.16-18).

Voice.

Susan and Zach have attended some of the functions sponsored by Voice and this has put them in contact with other families who have children with cochlear implants. Zach commented that some of the children were "doing beyond our expectation" (p. 50, 1.3-4). He added that meeting other parents

helped us understand our options ... just other parents having a different view of the situation helped us understand options ... You hear something from a parent of a child like that versus someone who's say ... a practitioner on the medical side. It's a very different sense (p. 50, 1.6-9).

Sarah agreed that it had been beneficial for Susan and Zach to meet other families and "just being able to get more information not directly from us" (p. 22, 1.5). Susan remarked that she found it interesting to meet other children Peter's age. Although she used the Internet a lot and found it helpful to meet other people, she added, "I think you have to for the most part deal with it on your own" (D.G.). This comment seemed to be a reference to the isolation she felt as she dealt with the demands of having a child with a hearing loss.

Community.

When asked about community support, Susan stated, "The Special Services at Home have been really good to me" (p. 44, 1.19). Susan added that their parent tutor, Rita, "helped out a great deal" (p. 10, 1.3). This service, funded by the Ministry of Community and Social Services, provided home tutoring for Peter three times a week. Zach explained "It provided both Helen (their nanny) and Susan with greater skills in that area ... and even now, it gives Susan a good break" (p. 65, 1.13-16). Their nanny, Helen, "was fundamental" (p. 62, 1.5), according to Zach. Hiring her "alleviated a lot for us" (p. 62, 1.16). Susan said that they did have some support from

the Infant Development Programme as well. When the children were younger, they didn't often hire babysitters because there were few available, and also because Susan found her children were challenging and she didn't feel comfortable leaving them with an inexperienced young person "who wouldn't have a clue" (p. 37, l.9-11). Sarah added that Peter had a Special Integration Support Worker when he started attending Montessori. The role of that person was to go "into the school a few times and just kind of set up things so that there was something, some understanding of him needing some special considerations" (p. 24, l.10-12). Sarah indicated that Peter also was involved in music lessons and Susan mentioned his participation in Kumon for math and reading. Zach commented that their access to a Listserv of parents "gave us a lot of data as well" (p. 50, l.21). In summary, Zach and Susan reported that they received support from the health and education systems, as well as from the community, the workplace and Voice, but that the transition was basically an isolating experience.

Summary-Barriers and Facilitators

While both Zach and Susan considered the time and effort involved in the adoption of auditory-verbal therapy to be a barrier, they overcame that obstacle by hiring a nanny who did most of the formal therapy with Peter. This enabled them to do the therapy in more of an informal fashion and to devote themselves to the needs of their other children. They both considered that they needed to challenge Peter's understanding and expression of language. They found that the delay in receiving the cochlear implant was a potential barrier that they overcame by doing research and speaking with their auditory-verbal therapist and the surgeon. They considered that the support they received from the health system, the education system, the workplace, Voice and the community facilitated their transition, however Susan added that it was a lonely journey.

Exosystem

Support

Health-Provincial.

Susan and Zach were grateful to the provincial health system for the funding of the cochlear implant surgery, therapy and audiological testing. Susan indicated that after the meningitis, it was not certain whether Peter had suffered any brain damage. Although this was not raised as an issue when candidacy was discussed it could have been. Susan stated "As you look at the cost of health care, it's expensive" (p. 56, 1.21). Although the minimal age at which children were being implanted at that time was 18 months, this was waived by Health Canada on compassionate grounds, due to the meningitis, and he received it at 15 months. Unfortunately, the surgery was delayed by two weeks due to unavailability of operating room nurses.

Education-Provincial.

Susan mentioned that one of the barriers presented by the education system was, "I can't get a hearing impaired teacher to go in the private system. I find that's a huge barrier because that eliminates choice, and my prior experience with my kids is they are doing better in private" (p. 53, 1.8-9, 1.11-14). She also felt that there should be a need statement in the IPRC "that hearing impaired kids [should] be in small classes" (p. 54, 1.4-5). She added, "of course they don't consider that a need ... because it costs money (laughs)" (p. 54, 1.7-9). She lamented the fact that, "class sizes ... are way too big in the public system" (p. 53, 1.18-20). This year, she had gone out of boundary to find a Junior Kindergarten with a small class size, 17. Another barrier she mentioned was the school's management of behaviour issues, "Their first response is zero tolerance and threat of suspension" (p. 55, 1.4).

Voice.

Both Susan and Zach stated that they have had little involvement with Voice Ontario. Susan added that there has been no impact “except the e-mails with questions that I never got any responses - zero” (p. 51, 1.1).

Community.

Zach regarded the funding from Community and Social Services as “very helpful” (p. 65, 1.9) and said “that supplemented his therapy quite a bit” (p. 65, 1.11). Susan also appreciated the support they had received from the Infant Development Programme which is funded by the Ministry of Community and Social Services. In summary, the funding from the Ministries of Health, Education and Community and Social Services was considered valuable to the family in their transition. Susan did feel that the Ministry of Education could provide additional money for smaller classes that contain children with special needs. As well, she felt that itinerant teachers of the hearing impaired should be available in private schools.

Summary-Barriers and Facilitators

While the support provided by the Ministries of Health and Community and Social Services has facilitated the transition of this family to auditory-verbal therapy, they had some criticisms of the programmes offered by the Ministry of Education. They were very pleased with the service of their itinerant teacher of the hearing impaired, however Susan felt that the policy dealing with behavioural issues was not appropriate. Although class size could have presented a barrier, due to her advocacy, Susan succeeded in arranging a cross boundary transfer which afforded Peter enrollment in a small class.

*Macrosystem**Accessibility*

Both Susan and Zach have been very pleased with their access to services and have advocated for those that were not available to their satisfaction. When asked to discuss facilitators of their transition, Susan named the cochlear implant, and Zach stated, "What an amazing piece of technology ... I think it's a medical miracle" (p. 75, 1.16-17). They felt that their exposure to other children who were speaking was beneficial. Zach indicated that if excellent services had not been accessible to them, they would have moved. In summary, both parents were grateful for the access to technology, therapy and speaking role models.

Inclusion

Susan and Zach very much wanted Peter to speak and be a part of the hearing world and felt that they could accomplish this through auditory-verbal therapy. Susan stated, "Well the doors were open, we went through them. A door was open, we went through it" (p. 57, 1.5-6). Both parents seemed to seek normalcy for their son as well as for their whole family. Susan summarized the way they managed auditory-verbal therapy in their lives, "Pretty much what we did is hired the best for him and kind of kept him in that world ... and kept the other two in a different world cause they were going to school full-time" (p. 16, 1. 6-20). She added that when she and Zach came home from work, "his A-V day was over" (p. 17, 1.7). She explained, "We kind of treated them like two different families cause he would be home all day with Helen doing his work and then when the other two came home, we just treated everybody like a normal family" (p. 17, 1.2-5).

The pervasiveness of Deaf culture was mentioned by Zach. He indicated that because of Peter's cochlear implant, he was often asked his opinion about Deaf culture and the effect of the

implant on it. He responded, "I have no opinion about that because I have no information about it really" (p. 76, 1.7-8). Zach did address the issue of stigma and said,

given all the issues, hearing's not that big a deal, relatively speaking it's not a big deal.

He's a normal boy, he's happy. He doesn't know he has a disability at this point ... so you know, our lives are kind of normal, really" (p. 13, 1.12-14, 1.18).

In summary, Susan and Zach sought opportunities to maintain normalcy for their family.

Summary-Barriers and Facilitators

Both Zach and Susan felt that the access to technology and services were facilitators to their transition to auditory-verbal therapy. They indicated that the inclusive nature of the education and community services also facilitated their transition. Although Peter's realization of his disability presented a potential barrier, at this point both parents felt that their family was functioning quite normally in mainstream society.

Current Perceptions of the Transition

When asked about their current feelings regarding the transition, Susan replied, "great ... it's coming together" (p. 29, 1.15-17). She expressed some concern, however as to whether Peter is at the level where he should be, "There's no measuring stick to know where he should be and where he's at and it's taken us a long time to understand that (laughs)" (p. 29, 1.19-21). Zach commented, "I've accepted it ... making the best of it ... recognizing that we're going to need to be entirely optimistic" (p. 41, 1.11-14). He added, "I wouldn't say, you know in retrospect I wouldn't say it was a ... it's not a negative experience" (p. 6, 1.18-19).

Evelyn and Dave Wright and Family

When I arrived at the Wright's townhouse, I was greeted by Evelyn who ushered me into their open-concept living room/kitchen where Allison and Melissa were seated. I remarked on the various crafts which were displayed on the walls and we briefly discussed their origins. Evelyn reported that Allison had just returned from a week at her maternal grandmother's house and she was not in a good mood. In fact, I noted that Allison seemed to scowl a good deal during my visit.

Evelyn set the girls up with some water and books in which they could paint. When discussing the required paintbrushes, Evelyn asked Allison several times if she knew where the brush was and finally highlighted the word "brush" (E: "yes, I know the picture, but where's the *brush?*"[italics added]). At another time, Evelyn required that Allison imitate a two to three word phrase, (E: "Can you open it please?" A: "Open please") before she received an object. Evelyn did not cover her mouth when talking to Allison. I noticed that the girls did not chat as they painted. Evelyn asked Allison what the object she was painting with was called (a pom pom) then gave her the answer, which Allison repeated without being asked. At one point, I asked Evelyn how long Allison had had her cochlear implant and she replied three years but you wouldn't know it. Soon after that, she reiterated laughingly that Allison had had a rough morning and Evelyn was ready to give up "A-V" and send her to a school for the deaf. When I made a positive remark about Allison's language, Evelyn replied "when she wants to" (obs. 1). During their interactions, I noticed that Evelyn understood Allison's comments, even when they were not intelligible to me, and responded to them without asking Allison to repeat them more intelligibly. Evelyn also slowed down her rate of speech when addressing Allison in order to enhance her daughter's comprehension, "It's O.K., it will dry" (obs. 1). At another time, the girls

argued about a doll and Evelyn explained to Allison that she had to ask Melissa before taking her doll, to which Allison shouted “No, I don’t know” (obs. 1). Evelyn retorted that she didn’t have to shout and called her a “grump”. In fact, Evelyn referred to Allison in negative terms several times during the observations, calling her a brat as well. Each time it was said humourously and lovingly. In fact, she was firm but kind and humourous with both girls. When they played with their Barbie dolls and house, there was some talking between the girls but mostly Allison talked to herself, “What’s that?, You coming?, Aw, c’mon, it’s O.K.” (obs. 1), while Melissa remained silent. When they had an altercation about the dolls, Evelyn spoke to Melissa about it and encouraged her to talk to Allison. She then explained to me that “they still have a problem talking to each other” (obs. 1).

When I arrived for the second observation, I met Therese, Evelyn’s mother, who was visiting for a few days. Allison was outside with the dog and Melissa was upstairs. Allison responded to Evelyn’s voice from a distance of approximately 50 feet. When I commented that she seemed to hear well with her cochlear implant, Evelyn responded, “She hears well, but she’s stubborn, doesn’t want to talk” (obs. 2). Therese added that she wondered whether the programme (on the speech processor) needed to be changed because Allison was complaining about loud noises at her house. When the girls were found upstairs watching T.V., they were summoned downstairs to do puzzles instead. Therese attempted to help Allison but Allison screamed for her mother. They spent the rest of my visit assembling puzzles, with Melissa working on her own on a 24-piece puzzle and Allison and Evelyn working on a 100-piece puzzle. Evelyn had suggested that they all work on one puzzle but Allison had said, “No, Mummy me”. Melissa asked Evelyn to help her several times. When Evelyn finally agreed, she asked if Allison could join them. As Allison was looking for something, Evelyn slowly

explained, “They’re missing” and then used highlighting to explain, “They’re *upstairs* [italics added]. Did you look in your *suitcase*?” [italics added] (obs. 2). At another time, Evelyn repeated one of Allison’s phrases using correct grammar but not requiring Allison to imitate it (A: “It go off;” E: “It goes off?”). Both Evelyn and Therese again expressed concern about Allison’s sensitivity to loud sounds and I encouraged them to have her speech processor checked at the hospital.

My last observation took place in the evening and all the members of the immediate family were present: Evelyn, Dave, Mitchell, Melissa and Allison. Although Evelyn was not feeling very well, she had encouraged me to visit anyway. When Evelyn couldn’t understand Allison, she said, “I don’t understand, can you use nice words?” (obs. 3) and then checked her cochlear implant by asking her to repeat sounds. Dave volunteered that she had been hearing before and then Evelyn mentioned her concern about the level of the sensitivity again. She added that Allison had just been to the hospital for an evaluation last week, but she found her speech “slushy”. Dave completed some homework with Mitchell, while Melissa and Allison drew at a table. At one point, Allison tattled on Melissa, “Mom, look, Melissa”, but Evelyn informed her that she should let Melissa do what she wanted and Allison should do what she wanted as well. Evelyn showed Allison a sticker and asked her what the animal said. When she didn’t answer, Evelyn told her that it was a bird and then expanded her vocabulary by adding, “It’s an owl” (obs. 3). Allison then repeated “owl”. When Evelyn asked Allison if she wanted a marker, she accepted Allison’s nod as an answer rather than asking her to verbalize her answer. Dave called to Allison and asked her “Where’s Daddy?” to which she did not respond. Allison pointed to some objects in a picture willingly upon Evelyn’s request, but refused to comply when Mitchell

asked her to point to one item. Evelyn explained to Mitchell that Allison didn't want to play anymore.

Microsystem

Personal Characteristics

When asked to describe life before the detection of the hearing loss, Dave spoke of their time with their son before the twins were born. He indicated that their first year with Mitchell had been "seamless" (p. 4, 1.1). While they had to adjust to a new baby, Evelyn's experience with nieces and nephews helped enormously, and they enjoyed watching him "starting to develop, realize things, trying to crawl, good stuff" (p. 4, 1.13). Mitchell was only 1 year old when his sisters were born. Dave explained that they had decided to move up north and had sold their house and were living with Dave's parents, when the twins were born at the gestational age of 25 weeks. They postponed their departure date, but Dave did move up to Iqaluit when the twins were 9 months of age. Evelyn joined him with the children when the twins were 14 months old and their brother was 26 months old. Evelyn recalled that for the first four months of the girls' lives, "Everything pretty much revolved around the [hospital] three to four times a week for appointments" (p. 4, 1.21-22). She added that for the first months their routine consisted of feeding "around the clock and laundry" (p. 2, 1.50). After six months they did attend a playgroup. Dave reported that the twins required oxygen and had reflux problems when they were first brought home and "that was hell all alone" (laughs) (p. 1, 1.25).

Although Allison's hearing loss was not confirmed until she was about 1 year old, Evelyn had suspected the loss when she was about 6 months old, "just by having a twin and observing both of them you know just the development and the speech and just everything was so different" (p. 1, 1.26-28). As Allison had frequent ear infections, a definitive diagnosis could not

be made sooner, despite the fact that she had undergone several hearing tests. Dave was working up north when the hearing loss was confirmed and Evelyn reported that he was devastated by the news, “and he’s like oh what’s she gonna do in her life, you know what’s she gonna become, where’s she gonna work?” (p. 22, 1.1-2). As Evelyn had suspected the loss, she had done some reading and felt more prepared. She commented “You do what you gotta do” (p. 22, 1.5). Evelyn had expected the twins not to be “perfect” (Discussion Group- D.G.) because of the prematurity. They had been told that the twins had a 30% chance of survival and that if they survived they would likely be handicapped (D.G.).

Evelyn described herself as “not a very talkative person” (p. 15, 1.26-27). When she was told that she was going to need to talk to her daughter a lot, she said, “Like that’s just not me and I’ve tried to change as much as I could but I’m still not a very talkative person” (p. 16, 1.3-4). Evelyn also found it difficult to sit down and have a “session” with Allison, “I just couldn’t do it” (p. 16, 1.7-8). She added that she didn’t talk to her son very much either. Evelyn indicated that as a result of the transition to auditory-verbal therapy, “I’ve had to grow up a little bit faster” (p.16, 1.30).

Dave indicated that when they learned about the hearing loss, Evelyn read about deaf children and talked to different people about their options. He also attributed to her the services Allison received at school, “If Evelyn hadn’t called a meeting I’m sure we wouldn’t have had somebody for Allison but maybe we would have” (p. 21, 1.8-9). When describing her role, Evelyn stated, “I’m her mom, ya her teacher. I’m definitely *no* [italics added] teacher (both laugh). I would never be able to home school my kids, uh disciplinary, tried that, failed. I don’t know, hear and listen for her, hear for her” (p. 21, 1.3-5).

Dave indicated that he is not a very patient person but that his patience has increased since Allison's diagnosis. He stated that at the beginning "It was like I can't do this" (p. 7, 1.26) but as time went on "I've gotten a lot of patience because ... I mean you can't get upset. It's not her, you can't do anything. That's the way it is" (p. 7, 1.33-35). He added that he felt that he had to become more involved, "not so much in raising of the children but in getting Allison to repeat sounds" (p. 11, 1.4-5). He indicated that he felt helping Allison was part of his job and reported that he would go to educational stores and purchase materials that were related to Allison's learning.

When describing Allison's personality, Evelyn indicated that she's a "very strong-willed, outgoing stubborn child" (p. 22, 1.10), as well as being very creative. Evelyn explained that Allison had had to be stubborn in order to survive. She remarked that Allison seemed to be happier before she got her cochlear implant, "She was like the happiest child. She wasn't frustrated" (p. 17, 1.18). Evelyn noticed that she had changed, "I don't know if now she knows that you know people are forcing her to talk" (p. 17, 1.24-25). Evelyn seemed worried that by obtaining a cochlear implant for Allison they were forcing her to adopt a mode of communication that she did not really want to use. Dave concurred that Allison is very stubborn and added that she is smart and very serious. Dave recalled that even as a new-born in her incubator Allison preferred not to be touched and her heart rate would decrease if she were handled. She added that Allison is a "little artist" (p. 6, 1.26) who wanted her pictures to be "perfect the first time" (p. 6, 1.27). During the discussion group, which took place 9 months after the observations and individual interviews, Evelyn added that she found Allison "has a really good personality with me anyway, she's very outgoing and very funny" (D.G.). She also noted that Allison is a "loner" (D.G.). In summary, Evelyn indicated that she is not a talkative person.

Dave felt that his patience had increased and that his role was one of helping to teach Allison as well as to purchase educational materials for her. Both parents agreed that Allison is stubborn. Evelyn added that she is creative and a loner, while Dave considered her smart.

Family Interactions

Evelyn stated that the relationship between Allison and her was closer than that between Dave and Allison, possibly because she was the primary caregiver or perhaps because Allison and Dave are similar in personality and therefore clash more frequently. Dave agreed that although he and Allison have gotten closer, "Allison and I butt heads but I think that's because we're more alike than anything" (p. 14, 1.5-6). Evelyn used lipreading to communicate with Allison "which isn't always a good thing but if you don't have sign then it's something" (p. 6, 1.21-22).

Evelyn stated that Dave was more pessimistic about Allison's progress than she was and this was a source of contention between them. Evelyn felt that Dave blamed her for not having done more therapy with Allison and for giving Allison preferential treatment. Dave felt guilty about not having been with Evelyn when she learned about Allison's diagnosis, however he was proud of the fact that they worked together as a team, "I mean a lot of things happened so we had to adjust and I think we did that well and now things are moving along so it worked out" (p. 13, 1.4-5). He added, "Dealing with the deafness and all so it's brought us closer together" (p. 15, 1.2-3). He felt that it had also made the family unit closer "You know if you're playing games we're gonna play with all the kids" (p. 9, 1.31-32).

Evelyn and Dave had their three children in one year and Evelyn felt that having her children so close in age was difficult and "for Melissa it's the hardest, the twin" (p. 18, 1.22). She added that she had envisioned the twins as being close, but if another child is involved, Melissa

will go off with the other child. She added that if she asked Melissa to include Allison in her playing with a neighbour, Melissa replied, "She just doesn't understand. I don't understand what she's saying half the time" (D.G.). Evelyn remarked that she was saddened by that, but Allison didn't seem to care. Evelyn stated that if she didn't talk to Allison the other children would. Dave commented that her siblings gestured to Allison a lot and that he and Evelyn had to explain to them "to talk to her and let her know what you want or what you're upset about" (p. 15, 1.9-10). Communication difficulties seemed to create a barrier between the siblings.

Although Sarah had advised them to treat Allison like the other children, Evelyn admitted, "We don't punish her the way we punish the other two" (p. 18, 1.27). She explained that she and Dave always felt sorry for her,

So of course when it comes to discipline she's not disciplined as the other kids are because we figure she doesn't understand, and we still use that as an excuse and I know we shouldn't, but sometimes it's just easier to let it go than to try and fight with her because she doesn't understand (p. 43, 1.2-5).

She added that the other two children are starting to question the difference in treatment. She stated, "I have to stop doing that. I think it's not fair to the other ones" (p. 19, 1.13). During the discussion group, Evelyn revealed that "[now] her comprehension's really good ... so she gets the same punishment" (D.G.) Dave felt that they "let Allison get away with a lot more" (p. 10, 1.9). He added that sometimes Allison took her speech processor off so she didn't have to hear them. Although they told the extended family not to treat Allison preferentially, Evelyn indicated that "grandmas, grandpa still treat her differently" (D.G.).

Evelyn was grateful for the support that she received from her mother and her in-laws and Dave added, "I don't know what we'd do without them" (p. 19, 1.6). The grandparents were

apprehensive about taking them overnight when Allison was younger because of concerns about her hearing aids. The children go regularly to their grandparents for sleep overs now, as they feel more comfortable with the cochlear implant and Allison is better able to tell them if her processor is malfunctioning. In summary, both Evelyn and Dave felt that Evelyn was closer with Allison. While her siblings talked somewhat to her, a lot of their communication was nonverbal and these communication difficulties seemed to alienate the siblings from Allison. Both parents felt that they treated Allison preferentially, but were attempting to change that. While Evelyn felt that the two did not agree on Allison's progress, Dave was proud of the way they had supported each other through stressful times. They were both grateful for the close relationship they and their children had with the extended family.

Summary-Barriers and Facilitators

The premature birth of the twins one year after their brother was born was a stressful time for Dave and Evelyn, whose first year with Mitchell had been uneventful. Allison's stubborn behaviour, Evelyn's quiet personality and the communication difficulties experienced by the siblings appeared to present challenges to their transition, however the relationship between Dave and Evelyn was a facilitator, as was their rapport with their extended family. Both parents admitted that their preferential treatment of Allison was an obstacle to their transition and were trying to change that, especially since the other children were challenging them on it.

Mesosystem

Choice

Evelyn stated that she was told that you "start with a trial with hearing aids then a cochlear implant or you go for sign language" (p. 15, 1.8-9). She was told "If I wanted my child to talk it was AVT" (p. 15, 1.13-14). She added that they (the professionals) didn't make the

decision for her but rather informed her that [auditory-verbal therapy] was “probably the best thing for her with her degree of hearing loss” (p. 15, l.20 -21). She claimed that cued speech was mentioned briefly “but it was more like, ‘but you don’t want to do that’” (p. 15, l.15-16). In view of Allison’s young age, Evelyn said that they had had to make the decision for her. They considered their family situation as well, “We were hearing parents, our other two children are hearing so it was either she learned one language, our language, or we all learn sign language” (p. 42, l.15-17). She didn’t think it was fair to expose her other two children to sign language when there were other options. She explained, “That was our main focus, was to keep the other two kids, the family life as normal as possible for them and try and kind of include Allison into it without like you know totally disrupting everybody’s lives (laughs)” (p. 25, l.5-7). She added, “As soon as they ... told me about auditory-verbal therapy we knew that that was the route we wanted to go, that we wanted her to learn how to speak” (p. 42, l.17-19). Sarah concurred that the parents knew it would have been difficult to teach the whole family to sign and so the fact that auditory-verbal therapy was available “made the choice that they wanted to make real easy to make” (p. 13, l.15-16). Sarah added, “Despite the fact that Allison wasn’t progressing particularly well, there was never any question of should we add sign language to it. There was just never any question” (p. 13, l. 29-30). Although Evelyn felt that auditory-verbal therapy was the best option for their family, she didn’t know whether it was the best decision for Allison, “For her personally, it’s something I’ll never know. I don’t know until she can tell me” (p. 18, l.19-20). In summary, Evelyn and Dave chose auditory-verbal therapy because they wanted their daughter to learn to speak and also because they wanted to maintain a normal family life for their other two children.

Compliance

Evelyn reported that Allison had been fitted with hearing aids at about one year of age. It was difficult keeping the hearing aids on her, however, as she pulled them out constantly. In order to keep them on Evelyn stated, “For the first two years of her life (laughs) she wore a bonnet on her head” (p. 10, 1.1). Allison’s hearing loss was very profound and because of this Evelyn stated “We knew that hearing aids probably wouldn’t do very much” (p. 5, 1.30). Evelyn had been told “Not that there’s no hope, it’s just that there’s you know she’s probably not getting anything with her hearing aids” (p. 8, 1.1-2).

Soon after she received her digital hearing aids, Allison had to exchange them for amplification which was not as advanced because the family moved to Iqaluit and the technology to support digital hearing aids was not available there. In addition, they had difficulty getting earmolds that fit Allison properly and so “For three out of the seven months she didn’t have any hearing aids at all” (p. 9, 1.5-6). Sarah recalled that after the family moved to Iqaluit, they talked by telephone a couple of times, “She was having very little success keeping the hearing aids on so that early amplification period, that early A-V time from one to two, pretty much was a frustrating experience for them I would expect and not particularly successful” (p. 2, 1.16-18). Sarah added that when they moved back they continued to try to keep the hearing aids on with little success.

Evelyn remembered that they had to wait until Allison was 27 months before she could receive the implant as her head size was too small prior to that time. Once the family knew she was getting a cochlear implant the hearing aids were used even less, “These things aren’t any good anyways, why bother? Why fight with her to keep them on?” (p. 9, 1.25-26). Evelyn indicated that she felt they lost time while waiting for the implant, “I mean if they implant now at

12 months or even younger, I mean she lost like a whole almost two years of hearing” (D.G.).

Sarah added, “The implant was much easier and the implant was accepted pretty much immediately” (p. 2, 1.21-22). Dave felt encouraged when he was told that the cochlear implant would provide Allison with the opportunity to hear.

When describing the changes that the transition to auditory-verbal therapy brought to their lives, Dave commented, “Probably the biggest thing is knowledge and learning how we had to change the way we did things at home, the way we talked” (p. 4, 1.22-23). Evelyn felt very guilty about not spending enough time with Allison doing therapy,

I didn’t have enough time to spend with her one-on-one because I had her twin who also had disabilities, I had her brother who was 12 months older (laughs) so I had no time to sit and play like you know do the AVT, um, with her like on a one-on-one basis” (D.G.).

Evelyn felt that the auditory-verbal therapy techniques were not difficult to learn but it was hard to get Allison to cooperate with formal lessons. She added that with three small children in tow it was hard to make the lessons fun, and Allison didn’t want to do anything where she would be forced to listen and talk. Allison did enjoy doing informal play with her mother,

If I lie down on the floor with her and play with her little doll houses or Barbies she’s really into, then that’s more of a then Mommy’s playing with me. She’s not you know forcing me to do anything I don’t want to do” (p. 30, 1.8-11).

During the discussion group, Evelyn explained that although she loved her children and felt they were well cared for, she was not the kind of mother who played with her children a lot because she had household chores to do. She felt “horrible about it” (p. 29, 1.9) and reasoned “Maybe that’s why she’s not as advanced as you know maybe a child a single child like a single child singleton who has all of his parent’s attention” (p. 29, 1.9-10). She added, “Allison does what she

wants when she wants ... She will not do it if she doesn't feel like it, so you can try rewards but it doesn't work" (D.G.). At the beginning, Dave felt that he wouldn't be able to do auditory-verbal therapy because of the different ways he was asked to interact with her, "covering up the mouth and trying to say the words" (p. 6, 1.9-10). After a while, he approached this new task as he would any new job.

Both Evelyn and Dave expressed concern about Allison's slow progress. Evelyn stated, "I don't know if she'll ever be there. I don't know if is there another learning disability ... I'm not doing anything about it because I don't think I want to know the results" (p. 43, 1.10-12). She recalled that when they came back from Iqaluit, Allison had 10 sounds and it was difficult to work with her "when you don't see results" (p. 7, 1.21). She added, "I don't know if maybe I just wasn't trying very hard because I knew it wasn't going to work anyways so what's the point?" (p. 6, 1.1-2). Dave indicated that while Evelyn felt she was progressing well, he did not. While she had made progress since obtaining the implant, "I still get worried about is it all one day gonna click or is it gonna take forever because ... with all the stuff we've done over the last 2 1/2 years I expected her to be further" (p. 8, 1.1-3). Sarah concurred that doing auditory-verbal therapy was "tough for her (Evelyn) but she wasn't seeing the progress and she (Allison) had behaviour issues" (p. 4, 1.34-35). Sarah recalled that "Evelyn was trying at first and had it been a different child probably it would have worked out cause I think she tried. I really think she did try" (p. 5, 1.26-27). She added that Allison's siblings were usually at therapy sessions and "There was a bit of multi-managing, multi-child managing for some of the sessions" (p. 9, 1.1). This was positive at times because she could reinforce communication techniques amongst the children but negative when there was friction amongst them.

Evelyn suggested that she required more structure in order to be able to follow up on activities at home,

Like a box of toys and I'm just like I don't know what to do with it (laughs). I wouldn't know how to think of ... even though I saw it everyday because I had Rita (parent tutor) everyday for four days a week plus I had the [hospital] once a week" (D.G.).

Sarah remembered, "The integrating it into everyday she was good at that kind of stuff if you could if she could do something with a craft" (p. 6, l.15-16). When asked to list the factors that most facilitated her transition, Evelyn named the cochlear implant first "because without it she wouldn't be where she is today. She'd be signing. There's no way that the hearing aids were going to do it for her" (D.G.). She also mentioned the therapists, the environment at the hospital and her extended family. The biggest obstacles were the other children, the fact that her husband was away "for most of the kids' first four years" (D.G.) and Allison's stubbornness, her personality. In summary, compliance with hearing aid use was not consistent because of distance from the Audiology centre and also because of the severity of the hearing loss and Allison's rejection of the amplification. There was consistent use of the cochlear implant, however. Both Evelyn and Dave were discouraged by Allison's slow progress with auditory-verbal therapy. Evelyn stated that she found it difficult to play with her daughter due to lack of time and the needs of her other two children. She would have preferred to receive structured materials to use with Allison.

Support

Health-Hospital.

Evelyn stated, "We've had great support through the [hospital]" (p. 35, l.5). She regretted that the auditory-verbal therapy programme ended when the child turned 5. She indicated that

she had not known that the sessions ended at that age and that she would have attended more regularly if she had known. She found it very difficult to bring the other children to sessions with her and suggested that the hospital organize babysitting for siblings during sessions. She added that she felt guilty about her poor attendance but the children were often sick especially in the winter. Interestingly, Sarah recalled that “She was fairly consistent about coming to therapy” (p. 3, l.32-33). Dave commented,

I love the [hospital] so that’s I don’t know what I would’ve done without it. It’s a it’s just a great place to have everything there that ... if we had to go to Toronto for part of it it would be ... that would have more of an effect on the family but having everything right here is fantastic (p. 18, l.20-22).

Sarah concurred, “They had full access to getting the implant reasonably quickly and having a good explanation of how it worked and good access to getting equipment replaced whenever they needed it and they used that service appropriately” (p. 10, l.9-11). Dave added that at visits to the auditory-verbal therapist, they would receive instruction on how to help Allison if she was making sounds incorrectly, “They’re trained and they have that, they’ve been doing it for awhile so they have that knowledge” (p. 17, l.29-30). Dave commended Evelyn, Sarah and Rita (the parent tutor) for all they did “With me just I don’t think she’d be where she is, but with all of them the help’s quite good” (p. 17, l.13-14). He remarked that while waiting for appointments at the hospital they met other children with cochlear implants, “I was there once I saw this little girl and she was yakkity yak yak and I didn’t know she had one ‘til Evelyn told me” (p. 5, l.37-38). Dave valued the support he got from Sarah and Rita “You needed that other person there doing getting you going, organizing it” (p. 17, l.1-2).

Education-Local.

When Allison first entered school there was a meeting held at which the itinerant teacher, the parents, the twins, the principal, as well as the liaison teacher from the centre where Melissa was seen for physiotherapy, were present. Evelyn reported that initially the principal seemed overwhelmed by their requests for service and equipment, however the itinerant teacher allayed his concerns by informing him that she would take care of it. Evelyn enthused, "It's been absolutely incredible the work that they've done there, of course we weren't silent either as parents" (p. 44, 1.7-9). Allison and Melissa were in the same class at school and were going to be the following year as well, even though Melissa objected. Evelyn noted that Allison was seen by the itinerant teacher of the hearing impaired four times each week for 45 minutes each time. However, she remarked that when Allison's itinerant teacher was away on sick leave for two periods of about one month the previous year, a substitute teacher was not hired. Evelyn felt that there were not enough teachers of the hearing impaired in the school board. Evelyn added,

There's nothing more I can do for her as her parent, as her teacher. I can't do anything more for her like it's up to the school because I've tried and I've tried and I've tried to help her and nothing's worked (D.G.).

She expressed concern about the following school year, "Next year's Grade 1 and I don't know if she's gonna be ready" (p. 28, 1.4). Dave also worried about how Allison will perform in Grade 1. Evelyn inquired as to whether there is an oral school for the deaf in Ottawa. She explained that a school for children with physical handicaps exists at the treatment centre. She didn't think such a placement would be appropriate for Melissa "because all the other kids are in wheelchairs or like they're wheelchair-bound and need assistance" (p. 39, 1.27-28). She indicated that she would consider sending Allison to a self-contained class, but then added that she felt the presence of

normally hearing peers was important. Dave was also pleased with the services at school and credited Evelyn for having arranged the meeting where services were discussed. Sarah agreed that support in the school boards is very accessible to children with hearing loss, "We send a letter to them saying here comes so and so who has this kind of hearing loss, put in place what's needed and there it is" (p. 12, l.14-15).

Workplace.

Dave commented that although they had to leave Iqaluit, "just for the services required" (p. 19, l.26), his work life was not affected in any other way. He reported that Evelyn attended 90% of the appointments at the [hospital] and therapy sessions" (p. 19, l.29) and that if he had to be present at an appointment his employer was very flexible about granting him permission. Evelyn worked part-time at a florist's and felt that she couldn't work full-time because it would have been difficult to find a babysitter who would "take two kids on with disabilities" (p. 31, l.10). She also considered that it would have been very expensive to send three children to daycare. She concluded, "Even though I'm not, I wasn't working with her per se all the time or consistently I probably did more than a babysitter would" (p. 32, l.23-25).

Voice.

Evelyn stated that she had attended a picnic organized by Voice and was a member, so she did receive their newsletter, but she felt that it was geared more towards school-aged children and also more advanced children. She was very active in the Twins' Association and was their current president as well as the editor of their newsletter. She found the Voice summer programme very useful and had sent Allison to it the previous summer. She would prefer that they offer a full-day camp rather than two mornings a week for an hour, which was the

traditional format of the summer programme. Dave reiterated the fact that they were very involved with the Twins' Association and less so with Voice.

Community.

Evelyn attended Well Baby clinics with the children before they moved to the north. Once they were in Iqaluit, in order to combat the isolation, she became involved with the Special Needs registry through Multiple Births Canada and carried on correspondence by e-mail with a few women who had multiple children. She also wrote to the pen pal column of the Today's Parent magazine.

She appreciated the Twins' Association which was "not only with the twins but just with everything special needs" (p. 33, 1.17). Both Dave and Evelyn lamented the fact that initially they did not know about any resources. They did not know that they could have had a homecare worker come in to their house and help with the children. Evelyn added that they did not learn about Special Services at Home or Infant Development until Melissa was diagnosed with cerebral palsy. At that time, a social worker at the treatment centre informed her of those resources, as well as Assistance for Children with Severe Disabilities, which provided funding for babysitting, and other expenses related to having a child with special needs.

Evelyn stated that Special Services at Home funded a parent tutor, Rita, who came to their home four times a week. Dave found the tutor's visits very helpful because "we still had somebody three days to look at her, you know to keep reminding us do this, do that, try this" (p. 20, 1.9-12). He also reported that Allison had befriended one of the neighbour's children and that she was playing with other children more. Evelyn reported that some of the couple friends they had had before the children had stopped contacting them. In summary, Dave and Evelyn appreciated the service they received at the hospital, however Evelyn would have liked to have

continued attendance at the auditory-verbal therapy sessions after Allison turned 5. They found the school very supportive, although Evelyn wondered whether a self-contained class for children with hearing loss might have proven beneficial for Allison. Dave had to leave his job in Iqaluit in order to obtain service for their daughters, while Evelyn held a part-time job as she did not feel that she would be able to find a babysitter who would care for two children with handicaps. They had attended a Voice meeting but were more involved with the Twins' Association. While the family benefitted from community resources, they felt they had not found out about them early enough. Evelyn commented on the isolation she felt since having the children.

Summary-Barriers and Facilitators

When considering the barriers and facilitators at the level of the mesosystem, it appeared that the cochlear implant facilitated the transition, as did the provision of audiological and auditory-verbal therapy services. The support of an itinerant teacher of the hearing impaired and the presence of an educational assistant in the classroom were also facilitators. The workplace was flexible when Dave required time off, however Evelyn felt that she could not go to work full-time because she would not have found a babysitter to take care of her two children with special needs. While the family benefitted from community resources such as Special Services at Home, a significant barrier was the delay in their access to these resources.

Exosystem

Support

Health- Provincial.

The Wright family benefitted greatly from the provision of audiological services and auditory-verbal therapy at the hospital and in fact, had left Iqaluit so that they could access those

services on a regular basis. The cochlear implant surgery, programming of the processor and therapy were funded by the provincial Ministry of Health. Sarah commented, "Certainly they didn't have to pay for that - that's a huge help and the fact that A-V therapy is paid for by the Ministry of Health as well makes it accessible" (p. 12, l.24- 27). One barrier that existed for this family was the fact that they had to wait for their daughter's head to grow before she could obtain an implant, due to the requirements of the technology available at the time.

Education-Provincial.

Evelyn and Dave were very pleased with the support Allison was receiving at school from an itinerant teacher as well as from an educational assistant. At their first meeting with the school personnel, the itinerant teacher mentioned provincial grants that would fund FM equipment, as well as part of the itinerant's service. Evelyn was appreciative of the Ministry of Education's requirement for an Individual Education Plan which outlines the goals for each child with special needs. One barrier that Evelyn mentioned was the lack of a self-contained oral class for children with hearing impairment.

Voice.

Neither Evelyn nor Dave felt that Voice Ontario had had an impact on their transition. Sarah too indicated that Voice Ontario had not had any influence on them.

Community.

Evelyn initiated contact with several community resources including Multiple Births Canada and Today's Parent Magazine, when they were in Iqaluit, "because it's so isolated up there" (p. 33, l.8). Both Evelyn and Dave found that the programmes offered by the Ministry of Community and Social Services were beneficial, however they would have liked to have accessed them earlier. In summary, Evelyn and Dave perceived that the funding provided by the

Ministries of Health, Education and Community and Social Services facilitated their transition to auditory-verbal therapy.

Summary-Barriers and Facilitators

The support offered by the Ministries of Health, Education and Community and Social Services was a facilitating factor, however the delay in receiving the implant was an unavoidable obstacle created by Allison's small head size and a lack of technology to accommodate it. They were not aware of any impact of Voice Ontario.

Macrosystem

Accessibility

Dave and Evelyn left Iqaluit because they felt that services for their daughters were not adequate there. They were both grateful for access to the cochlear implant, as well as for the services at the hospital. Moreover, the general population seemed to be more aware of cochlear implants through their exposure in the media. Dave recalled a conversation he had had with some coworkers regarding a T.V. movie that depicted two families who were trying to decide whether to have their children implanted. Access to other children with cochlear implants who speak was very encouraging to them as well. In summary, Dave and Evelyn moved to an urban centre where they could have access to services that they felt were appropriate for their daughters.

Inclusion

Evelyn stated that they had chosen auditory-verbal therapy because they wanted Allison to learn to speak but also because they wanted to maintain a normal family life for their other two children. As Evelyn observed Allison's progress, she seemed more ambivalent about inclusion and suggested that perhaps Allison would do better in a class where she was with other children who are hearing impaired. When Dave was a child, his neighbours were deaf and he had

been friendly with one of their daughters who was hearing. He had been exposed to many of the assistive devices that his neighbours used, such as flashing lights for the doorbell. When he learned of Allison's hearing loss, he thought her future would be limited and he struggled with the concept of disability. In summary, Dave and Evelyn were grateful for services that enabled their daughter to be included in the mainstream, thereby normalizing life for them and for their other children.

Summary-Barriers and Facilitators

Both Dave and Evelyn appreciated the technology, the services and the possibilities for inclusion which facilitated their transition. They felt that such support enabled them to provide normalcy for their family.

Current Perceptions of the Transition

Evelyn and Dave continued to express worry regarding Allison's progress. Dave stated, "I'd prefer that I didn't have to do it but uh it's been I think a good experience actually. It's something new to me and it's basically a necessity in order to have Allison evolve into the best person that she can be (p. 16, 1.28-30).

He added, "Just the fact that she's actually hearing is and for her to come out with any type of words and sentences now I think that's great because that wouldn't happen before" (p. 13, 1.19-20). He concluded, "Now she can hear. It's not ideal hearing like we have but she can hear and she can talk and those two things I didn't know that was going to be happening when I first heard about it" (p. 23, 1.28-30). Evelyn remarked,

The pain never goes away like it's always there like it's a loss it's a hearing loss it's like she lost a part of her that she'll never have again. Even though she has a cochlear implant, it's still a loss and uh for every wish you make on a cake, for every like shooting star or

falling star, whatever, your wish will always be I wish my child could hear and that's just the way it is (p. 42, 1.6-11).

Evelyn added, "We were lucky, we're we're lucky that all that's wrong with them is what's wrong cause it could have been so much worse" (p. 45, 1.12-13).

Kyla and Jared Jones and Family

I entered the Jones' spacious sun-filled home by the garage, as the main entrance was still under construction. Shelley was eating her lunch and had two books beside her plate. Her grandmother, Patricia, was in the kitchen with her. Before we began completing the consent form, Kyla inquired whether Shelley wanted more to eat. When Shelley replied no, Kyla asked, "Are you sure?" to which Shelley responded, "Yes". Kyla then asked her to say, "Yes, I am sure". Shelley complied by imitating the required phrase. After we completed the Family Information Questionnaire, Kyla attempted to engage Shelley in an activity, however she seemed somewhat reluctant. Kyla cajoled and hugged her and after refusing several of her mother's suggestions, Shelley agreed to draw. As the whiteboard was dirty, Kyla seized the opportunity to teach the word, "corner", "It's wet in the *corner* [italics added]. It's wet in the *corner*" [italics added] (obs. 1), highlighting and repeating this new word. Kyla used questions and comments to elicit from Shelley what her drawings were depicting and expanded her daughter's short phrases. However, she did not often ask Shelley to repeat these expanded phrases, (Sh: Light uh oh; K: Is there a light?; Sh: ?; K: Is it a street light?; Sh: Yes, it light; K: Oh *street* [italics added] light; Sh: ? broken; K: Oh *street* [italics added] light is broken?; Sh: Yes; K: Oh, it must be dark then; Sh: Yes, it dark - obs. 1). Through use of her daughter's drawings, Kyla was able to encourage her to predict and hypothesize future events. When speaking to her mother-in-law, who was in the adjoining room, Kyla used Tamil, their native language. Patricia addressed Shelley in English

(Sh: ? light. On light; P: Light on), however did not expand her phrases. When Shelley was assigning names to her figures, there was a discussion about which name to choose and much laughter around different names jokingly suggested by Shelley.

Later, Kyla initiated a discussion about a craft Shelley had made at school. She encouraged Shelley to explain to her grandmother how she had made the necklace and who had helped her. When Shelley did not reply, Kyla provided the name of the assistant at school but did not pursue the topic further. At several times during the course of the observation, Kyla introduced new vocabulary, appropriate to the situation under discussion. At one point she and Shelley laughingly played with various pronunciations of a word “empty” (obs. 1). Kyla seemed to appreciate Shelley’s sense of humour and kissed her. When examining Shelley’s fingers, Kyla noticed a scratch and Shelley told her mother “No uh Sally” (obs. 1) to which Kyla replied that she would ask Sally about it. Kyla then initiated a game of concentration and told Shelley to ask her grandmother to join them. It took several repetitions before Shelley understood her mother’s request, but Kyla persisted and Patricia agreed to participate. During the game, Patricia and Kyla addressed each other in Tamil and Shelley in English. Kyla seized every opportunity to teach the language of games, “my turn, your turn, shuffling, pair, upside down, right side up” and to ensure that Shelley abided by the rules. All the participants seemed to enjoy the game and there was much laughter throughout.

At the second observation, Jared and Sally were also present. Jared greeted me at the door and introduced himself. He then excused himself, as he was helping Sally upstairs with a school project. When Shelley and Kyla emerged, I asked Shelley how she was and where she had been. She did not seem to understand these questions and Kyla helped her answer them. Kyla then went to the kitchen to make tea and Shelley joined her. Kyla spoke using a natural rate

of speech and sometimes highlighted words if Shelley did not understand them. When they were setting the table, Shelley offered, “? Patricia glass” to which Kyla responded, “Patricia glass. You’re right. Patricia needs a glass”, however she did not ask her to repeat this expanded phrase. Kyla again used this activity to teach new vocabulary. Kyla reported to me that Sally was doing a project on the ear and had just finished a speech on the cochlear implant. While we drank tea, Kyla expressed some concerns about school where Shelley was not talking to the other children. Jared, who had finished his tea, followed Shelley to the family room where they began to draw with Sally. At one point, Sally referred to Shelley as a copycat because she was drawing the same picture. Shelley then erased both hers and her sister’s pictures and Jared told Sally to draw on the other side. When Jared told Shelley that she had drawn a “baby bed”, Sally expanded her sister’s vocabulary by explaining, “That means it’s a crib, Shelley. Crib”. Jared taught both girls new vocabulary words, “cuboid rectangle” for Sally and “yawning” for Shelley. Kyla then joined them at the blackboard and Sally guessed the picture Shelley was drawing. While Jared played chess with Sally, Kyla discussed Shelley’s picture further.

At my third observation, Shelley and Sally were playing on the computer. Kyla accompanied their play with language as did Sally, who talked clearly and slowly to her sister. At one point, Kyla asked Shelley, “Papa play?”, using an abridged form of the question and later said “All done computer”, again using an abridged form. When Jared invited Sally to continue working on her project with him, Kyla continued to ask Shelley questions and give her directions related to the computer from behind her back. Shelley then wanted to join her father and sister and Kyla accompanied her. Shelley was given some modelling clay and Kyla proceeded to follow her lead in deciding what to make with the clay. When Kyla used the word “mittens” to describe oven mitts, Sally provided her mother with the correct term. Later she explained to her

sister that one part of the ear is called the pinna. Kyla asked Shelley the functions of several items and explained to me that this was one of the weekly targets, assigned by Sarah. After Kyla left the room, Jared expanded and highlighted some vocabulary and reinforced Shelley's use of the conjunction "and" (obs. 3).

Microsystem

Personal Characteristics

Kyla indicated that prior to the detection of the hearing loss, life consisted of "just routine things" (p. 2, 1.4-5). Their older daughter, Sally, was involved in several extracurricular activities such as swimming, skating and story time at the library. Shelley accompanied her mother and older sister to all these activities. Sally was encouraged by her mother to speak their native language, Tamil, at home, "Even I used to give some incentive to Sally to speak in Tamil" (p. 10, 1.6). Jared agreed that they engaged in routine activities prior to the hearing loss. He was involved in diapering Shelley and feeding her. He explained, "Sally pretty much didn't have any problems at all" (p. 6, 1.15). He added, "Until now you know it's been pretty much hunky-dory you know smooth sailing, no big problems, no big hassles in life" (p. 16, 1.13-15). He was very involved in his work prior to the detection, "I was actually more involved with my work you know. I would when I go to work I would work long hours, sometimes during the weekends" (p. 4, 1.3-4).

They began to suspect that Shelley had a hearing loss and Jared began to do research on the Internet because "I remember I couldn't really concentrate at work at all" (p. 7, 1.15). Shelley's hearing loss was confirmed when she was 10 months old and she was fitted with hearing aids at the age of 11 months. After the detection, the family used only English when speaking with the children.

When describing herself, Kyla stated, “I don’t have much patience but I have a little bit of patience (laughs). I think that helped me (laughs)” (p. 20, 1.5-6). She added that she gets angry occasionally, but her husband never gets angry. She commented that when she sees other children at the hospital, she feels her family is fortunate, “So I don’t feel in a negative sense. I take it in a positive sense” (p. 13, 1.10). She was optimistic about Shelley’s future, “When she’s I think around 6 or 7 years old she’ll be perfectly OK.” (p. 35, 1.9). She attempted to transmit this optimism to Sally, “I have to reassure her all the time. ‘It’s O.K. After awhile she’ll be perfectly O.K.’” (p. 17, 1.14-16). Kyla felt that, “I learned a lot because of her. So which is anyway she’s a teacher for me because I didn’t know *anything* [italics added] about all these things” (p. 13, 1.5-6).

When discussing her role, Kyla indicated that she had a lot of administrative work to do, such as invoicing Special Services at Home and paying the tutors, maintaining the parking pass for the hospital, arranging appointments, in addition to all the talking, “like teaching you could say” (p. 19, 1.4). She attributed her improved English to the fact that she has had to interact with so many different professionals who have dealt with Shelley. Kyla did not complain about her role, “I don’t see it like a problem. I see it’s our duty. I am a stay-at-home mom and then I feel the first definitely 5 years I should be home with the kids definitely” (p. 12, 1.14-15, 17). It was Kyla who did the therapy with Shelley and she explained that Jared’s “involvement with this field is not that much” (p. 23, 1.16), although “he’s getting better now” (p. 50, 1.22). She added that Jared knew very little about the appointments, but she was trying to encourage him to attend therapy occasionally.

Jared considered himself to be very patient and positive. Kyla concurred with him about both these qualities, “He never gets angry. That’s the biggest problem that I have (laughs) (p. 27,

l. 3-4). She also described him as “consoling he’s very great” (p. 26, l.21) and “*very* [italics added] positive in everything” (p. 26, l.10). Jared corroborated that opinion when he stated, “You know there’s such a thing as cochlear implants that can really help us hear ... and the life is not really you know all that bad” (p. 20, l.12-14). He added, “I think of all the good things that I’ve had and I look at the glass as being half-full not half-empty” (p. 19, l.10). He indicated that his attitude towards work has “completely changed. Work is there to survive, you know I need it very well ... but there are bigger priority items” (p. 11, l.21). He felt that dealing with Shelley’s hearing loss had helped him mature,

It has made us mentally tougher ... unless you come face to face with the hard facts of life you never do get to mature and we felt you know we’ve matured one step in life ... having gone through something like this (p. 16, l.2, 8-11).

Although he worked less outside of regular hours than he used to, he still thought he should be participating more in Shelley’s therapy. Jared considered that his spirituality guided him through these difficult times, “That’s when it brings out in you the religious side in you ... and the spiritual side in you as well ... you know that really helps settle things down I would say” (p. 19, l.12-16).

Jared indicated that before the diagnosis was confirmed, he got a lot of information but wouldn’t always report it to Kyla because he didn’t want to worry her, “because one thing you don’t want to do, especially for a guy, is to show your negative feelings in the family and in the process weaken the family” (p. 19, l.22- 23). He lamented the fact that usually fathers see their children only for two or three hours a day and that that did not promote bonding. He was proud of the fact that he bathed Shelley and styled her hair, “She lets me do it and she really enjoys”

(p. 14, 1.8). Although he reported that they did not do formal therapy sessions at home, he did try to reinforce the concepts that Kyla learned at the hospital.

Kyla described Shelley as “an artist. Her fine motor skills are *excellent*” [italics added] (p. 8, 1.6). She added that Shelley “has a lot of patience ... like her dad” (p. 23, 1.4-6). She also considered Shelley to be “a very good listener” (p. 21, 1.7). She indicated that “She can stay on with Sarah for 1½ hours or 2 hours *together* (italics added). Her concentration is *excellent*” [italics added] (p. 21, 1.3). Kyla did express some worry about how she will deal with Shelley’s feelings about her hearing loss, “I don’t know what to answer her when she asks of course” (p. 15, 1.5). Jared agreed that Shelley is very easy-going and will sit with anyone and do her therapy, “but you can’t really overdo with her” (p. 11, 1.8). He added that she is “extremely loving girl” (p. 11, 1.9). Jared stated that even in other situations where she has been physically hurt, she did not get upset, “She knows how to overcome the pain” (p. 22, 1.4-5). He felt that her personality was an asset because

You know there will be situations where people are constantly trying to correct you or you know doing therapy ... unless you have that coping attitude it’s difficult. I mean some kids might just get upset they will have behavioural problems (p. 23, 1.19-23).

In summary, Kyla and Jared have made some significant changes in lifestyle as they have incorporated auditory-verbal therapy into their lives: a change in language as well as a change in Jared’s work habits. They both considered themselves patient, and they regarded the transition to auditory-verbal therapy from a positive perspective. Shelley was described as a patient, loving child who has a long attention span.

Family Interactions

Both Kyla and Jared considered their relationship with Shelley to be a warm one, and this was certainly apparent from the observations. Jared indicated that doing therapy meant that they got more involved and gave more attention to Shelley. He felt that he and Kyla treated the two sisters the same behaviourally. He commented, “I wouldn’t really say there were any negative aspects at all in the relationship” (p. 24, l.13). Kyla agreed, “I don’t see any difference. It’s like mother and a child thing ... so she is doing it like a child she is doing it. Like a mother whatever I have to do I do” (p. 25, l.11-15).

Both Kyla and Jared felt that their relationship facilitated their transition. Jared remarked, “We really together we we faced all the challenges ... we were strong” (p. 25, l.1-3). Kyla reported that when she experienced discouragement about their situation, Jared “has helped me a lot because he has um he is very confident guy” (p. 26, l.8).

Kyla described Sally as “very caring” (p. 30, l.22) and indicated that although they have small fights now and then, the two sisters get along very well. She attributed this to the five-year age difference between the girls. She reported that Sally manages Shelley very well and was able to convince her to do activities when she was reluctant to do them. She added that Sally can change the battery on Shelley’s speech processor and that because Sally speaks unaccented English this is helpful to Shelley. In fact, I observed Sally correct her parents’ English twice and teach Shelley new vocabulary during my observations (obs. 2, 3).

Jared concurred that Sally was very caring towards her sister and took care of her, “Sally’s been *amazing*” [*italics added*] (p. 27, l.16-17). He said that the relationship had improved in the last year since Shelley was better able to communicate. Prior to that time, Sally would become frustrated because Shelley did not respond to her.

Kyla reported that meeting other children with hearing loss through Voice helped Sally realize that her sister was not that different. She recounted an incident that occurred in Sally's class: she was asked to answer the question "If you have a magic wand, what do you wish?" To which Sally replied, "I want my sister not to be hearing impaired? (Kyla's tears)" (p. 17, 1.24, p. 18, 1.2). Jared added that now that she has seen how Shelley has progressed Sally has realized "Hey it's just a matter of time before she gets to play with me, she gets to talk with me, she gets to fight with me" (p. 39, 1.9-10).

Both Kyla and Jared agreed that they managed Shelley's behaviour differently from Sally's. Kyla remarked, "because I sometimes let go which I should not but I let her go because maybe I'm pitying her or what ... I don't know that that's the reason but uh ya" (p. 18, 1.19-21). Jared added, "As much as you don't want it to be but it's hard to avoid" (p. 17, 1.6-8). During the observations, I noted one instance when there was a disagreement about a chalkboard and Jared suggested that Sally take the side that Shelley was not using (obs. 2). I did not note any altercations between the siblings or between the parents and Shelley.

Jared indicated that "Both sides of the family were supportive and they helped us face the challenges. They were very supportive. That definitely helped" (p. 50, 1.18-19). He explained that when he went back to India after the death of his father, Kyla visited her brother and aunt in Washington. It was during that visit that Kyla's aunt, who is a doctor, expressed concern about some stiffness in Shelley's movements and recommended that they investigate this on their return. This eventually led to the detection of her hearing loss and her diagnosis of mild cerebral palsy.

Kyla's parents lived in India and she acknowledged "It didn't help of course"

(p. 33, l. 9). She recalled that when she told them about Shelley's hearing loss they "had a shock. There was no one else in the family like this" (p. 33, l.11). She explained auditory-verbal therapy and cochlear implants, as they had never heard of these innovations. She added that the transition has brought the family closer together, "like more concerned and everything so ... more together" (p. 16, l.20-22). Jared reported that they receive regular calls and e-mails from family in India and that shortly after the detection of the hearing loss, Kyla returned to India for a visit with the two children. When Kyla's parents visited last year, her mother attended all the therapy sessions with her and Shelley. Kyla added that every Friday her mother does a kind of fast in India and prays for her granddaughter. She commented "She does all the praying. I do my work, so that's why it goes together" (p. 34, l.7-9). Jared's mother had been living with them for the past few months and Jared reported, "She's (Shelley) got a very good bond with my mom so she sits down and plays with her grandma" (p. 43, l.4-6). In summary, both parents felt that they had a warm relationship with Shelley and that she also enjoyed a close relationship with her sister. They benefitted from the support of one another as well as of their extended families.

Summary-Barriers and Facilitators

The fact that they had to abandon use of their native language, Tamil, with their children was a barrier for this family, but not one that they considered insurmountable. Their positive attitudes seemed to facilitate their transition, as did Shelley's caring and attentive nature. Although the distance of Kyla's family was a barrier, close communication with them was maintained by telephone and e-mail. The relationships between the members of the nuclear and extended families seemed to facilitate their transition.

*Mesosystem**Choice*

Both Kyla and Jared indicated that they chose auditory-verbal therapy because it had been recommended to them. Kyla added, "So everyone gave me the boost so I said O.K. then rather than going for sign language" (p. 12, 1.4-5). Kyla also believed that auditory-verbal therapy offered the possibility of her daughter being "like a normal child" (p. 12, 1.2). She clarified, "the main thing is actually is if she can be with a hearing child that's great" (p. 11, 1.23) and enthused, "A-V's definitely better. She can be like a normal child after 7 years. You know that's great" (p. 12, 1.7). In summary, Kyla and Jared chose auditory-verbal therapy because they trusted the recommendations made by professionals and because they believed this route would provide a normal life for their daughter.

Compliance

Sarah remarked that Shelley was fitted with her hearing aids before one year of age and received as much benefit as was possible with them prior to receiving the cochlear implant. She added, "They've always been very good about staying on top of her equipment" (p. 3, 1.9-10). Kyla reported, "As soon as she (Shelley) gets up in the morning she just says 'put it on'" (p. 15, 1.4).

When asked what changes the adoption of auditory-verbal therapy had meant in their lives, Kyla responded that they had additional appointments and that she talked a lot more to Shelley. The other major change was their switch to English from their native language. Jared indicated that he worked at home less and "got a lot more involved with the kids" (p. 11, 1.12). He also became more aware of activities related to his children, "I remember the first time I went on the Internet to find out about kids' stuff was after we found out about Shelley" (p. 6, 1.8-9).

He added, "It wasn't only the career anymore ... definitely I make it a point to come home on time and to be with the kids before they go to bed and everything" (p. 4, l.15-16).

Kyla indicated that she found auditory-verbal therapy "easy to do" (p. 37, l.18). As Shelley did not seem to like doing formal therapy with her mother, Kyla did not do formal lessons like Sarah, "I don't do the same stuff what Sarah does like I don't have the same toys the same things" (p. 38, l.2-3). She did do therapy in an informal way and remarked that Shelley "doesn't think that she's doing something" (p. 39, l.1). She added that they read a lot together and "that's sitting down. She doesn't care" (p. 38, l.24). Kyla noted that she had changed her rate of speech and covered her mouth when Shelley looked at her. While she used to speak fast, now "We have started doing speaking slowly and more clearly and repeating whenever she's not understanding" (p. 36, l.10-12). Kyla observed that this way of speaking "comes now instinctively. It's like eating our food" (p. 41, l.5). She remarked that sometimes when she was talking to a friend's child, if that child did not respond, then she repeated. She hadn't been aware of this until Sally commented, "Mama, she's not deaf. Speak the normal way. You're not talking to Shelley" (p. 36, l.15, l.20).

Jared agreed that they did not do formal lessons with Shelley, but that they talked to her from behind her back and tried to reinforce the theme of the week. He added that they did not cover their mouths, but they ensured that she did not lipread them by looking away from her. They did repeat sometimes, however he commented, "Maybe what we should do is we should wait for her to listen and understand and not repeat faster" (p. 34, l.22-23). They gave her directions from another room "just like you would normally do with kids" (p. 34, l.1) and he found "She picks up very normally" (p. 33, l.15). He indicated that extending her phrases was more difficult, "We haven't really been following up on that ... on the long sentences" (p. 34, l.8-

11). He added that they have encouraged Shelley's listening skills "because that comes naturally you know" (p. 34, 1.14). Sarah recalled that Kyla was very natural with Shelley and "Sitting down and playing and having fun with Shelley and spending lots of time with her was very easy for her (Kyla)" (p. 2, 1.7-8). Sarah continued, "Mom is a hard worker ... She understands ... what she's doing with Shelley ... although I know that they continue to be very sad about Shelley's deafness, they don't let that stand in the way" (p. 3, 1.2-6). Sarah reported that during the therapy sessions,

I don't have to do a whole lot of over-teaching with her (Kyla) anymore. You know frequently I'll you know I'll just quickly say that you know what kind of goal it is we're working on and she (Kyla) follows right along immediately. I mean she just picks up exactly what it is we're trying to do and you know expands on it and does a wonderful job with it right from you know the get-go (p. 5, 1.11-15).

She added,

She (Kyla) also has the benefit of you know Shelley progressing and so she sees her progressing ... and able to do learn these things and so she gets that reinforcement from Shelley as well so you know this is I consider this to be a very good auditory-verbal family (p. 6, 1.4-9).

Both Kyla and Jared commented on the fact that Shelley objected to doing formal therapy with them. Kyla reasoned, "It's different. I'm mom so she takes maybe advantage" (p. 38, 1.13). She added, "So we use whatever we have" (p. 38, 1.5). She noted that she had discussed this with Sarah, who had reassured Kyla that because she was talking all day long to Shelley she didn't need to do formal lessons in addition. Jared explained that Shelley would scream if asked to repeat something more than once or twice. He added that for the first day or two after therapy

they reinforced the use of longer sentences but after that they often forgot “and come back to one or two words” (p. 32, 1.12-13). Neither parent expressed discouragement about their daughter’s progress, however Kyla commented, “The only thing is that it’s of course I know that it’ll take some time for her” (p. 35, 1.10). In summary, this family demonstrated compliance with the use of hearing technology as well as with auditory-verbal therapy techniques. They found it easier to implement techniques that reinforced listening skills than those that emphasized use of language.

Support

Health-Hospital.

When asked about the support they had received from the health system, both parents reported their satisfaction. Kyla indicated, “It’s really great ... and I hate to miss any of the therapy lessons (laughs)” (p. 42, 1.5, 1.16). She added that she felt fortunate because some families had to come from other provinces where service was not as readily available, but “mine is just 25 minute drive and it’s like home for me” (p. 42, 1.12). Kyla added that she had been very encouraged by the neurologist who had reassured her that Shelley would “take some time for running and all those physical activities but she will do well” (p. 9, 1.7). He had also referred the family to the Infant Development Programme, which provided service to Shelley until she turned 2 years of age.

Jared also lauded the support of the health system, and referred to it as “excellent” (p. 36, 1.9). He added, “You see otherwise I’m not sure if we would have come this far” (p. 36, 1.9). He described the audiology service as “not just a bunch of professionals ... they’re part of the extended family” (p. 36, 1.17-19). He felt that regular attendance at the therapy sessions was very important as it gave them some focus and some assurance as to Shelley’s capabilities, “that hey you know she is normal or really close to being normal” (p. 35, 1.17). Sarah observed,

She got fit with her implant right away you know and she's been you know well-mapped and well taken care of in terms of equipment and everything so you know all of that equipment kinds of stuff and audiological management has you know happened seamlessly because we have such a great bunch of audiologists (p. 6, 1.19-22).

In summary, both Kyla and Jared were very satisfied with the services they received from the health system.

Education-Local.

Shelley attended a Montessori school and therefore did not receive the services of a teacher of the hearing impaired. Nevertheless, Kyla was very pleased with the support at the school and felt that the low ratio of children to teachers was an advantage for Shelley. She planned to enroll Shelley in a public school when she entered Grade 1. When Kyla was concerned that Shelley was not listening and talking at school, Helen, the tutor, accompanied her there and informed Shelley's teacher of her capabilities. Kyla expressed some concern about the new school Shelley will be attending in Grade 1, particularly what the other children will be like and whether "they are going to accept her. Montessori it's a very small group" (p. 15, 1.20). In summary, Kyla was pleased with the small pupil-teacher ratio afforded by the Montessori school, but worried somewhat about the reception Shelley would receive in the public school she will be attending next year.

Workplace.

Jared indicated that he had not attended therapy with Shelley because on the day that she had therapy, he had a very important weekly meeting at work. He added that as he works in the high tech industry and it has been quite unstable, he was reluctant to ask for time off even though he felt that it would have probably been granted to him. In summary, as Kyla did not intend to

work outside the home until her children were at least 5 years old, the detection of Shelley's hearing loss did not affect her work plans. As Jared worked in the high tech sector, he was concerned about job security and felt that he could not absent himself from work even though he believed that his employer would have been agreeable to such an arrangement.

Voice.

Kyla reported that they had not been very involved with Voice, but they had attended one Christmas party, which both Shelley and Sally had enjoyed. Kyla and Jared felt that Shelley had been pleased to see other children who wear cochlear implants. Jared remarked that Sally "saw other kids with similar challenges and she saw O.K. this is not just our family. It's more common so it's not that abnormal to have a sister with hearing challenges" (p. 40, 1.6-12). He added, "I think in alone itself is worth going to those parties and meeting other kids that have similar challenges. Helps you cope with the challenges" (p. 40, 1.23 - p.41, 1.2). In addition, Kyla appreciated the information and e-mails she received from Voice. Sarah remarked that contact with Voice has helped the family "get some perspective on you know what they can expect for Shelley as she gets older" (p. 6, 1.29- p.7, 1.1). In summary, both Kyla and Jared appreciated meeting other families through Voice. Kyla also acknowledged the informational support that she gained from Voice.

Community.

Kyla recalled that they continued to receive physiotherapy and had attended occupational therapy for four to five months at the Child Development Service and that they had had an interventionist from the Infant Development Programme, both of which are sponsored by the Ministry of Community and Social Services. In addition, a Children's Integration Support worker attended Shelley's school to facilitate her integration into the Montessori programme.

Shelley also had benefitted from tutors who have visited her home since she began auditory-verbal therapy, to supplement the therapy provided by Sarah. Jared described this service as “a big help” (p. 48, 1.11). He felt it was important for Shelley to “listen to a lot of different people, a lot of different accents” (p. 42, 1.15-16).

The family has employed babysitters only occasionally and not until a year ago when their house was being built and Kyla had to complete tasks related to the construction. Sarah added that the family has found the tutor’s visits to the school to be “invaluable” (p. 8, 1.13) because she has helped them understand better Shelley’s capabilities “cause Shelley sometimes won’t do (laughs) if she can get away with it” (p. 8, 1.15-16).

Jared noted that their friends have been an important support to them, “There’s one close friend of ours that we often visit and whenever we have to take maybe Shelley to the hospital or some place they will take care of Sally” (p. 43, 1.10-13). He recalled that very soon after the diagnosis was confirmed, he and Kyla visited a friend in Chicago to take their minds “off what was imminently happening” (p. 25, 1.5- 6). He reported that it was very helpful and “We came back stronger and we knew at least what we had to do and put the things behind us and it’s time to move forward” (p. 26, 1.7-9). In summary, Kyla and Jared lauded the funding they had received through Special Services at Home. While they did not frequently hire babysitters, they did depend on a network of friends to support them.

Summary-Barriers and Facilitators

Kyla and Jared chose auditory-verbal therapy upon the recommendation of professionals and also because they believed it would offer normalcy for their daughter. They reported that the health, education and community services they received facilitated their transition to auditory-verbal therapy. Although Jared did not prevail on his workplace to allow him time off, he felt

they would have complied with that request. While the family had only occasional contact with Voice, they did feel that the exposure it provided to families undergoing similar challenges to theirs facilitated their transition.

Exosystem

Support

Health-Provincial.

Kyla alluded to her appreciation of the health services offered by the Ontario Ministry of Health when she compared the proximity of the health services to her home with the plight of those families from other provinces who came here for service. Jared too expressed his gratitude for the health services. Sarah added, "They (Ministry of Health) you know provide um support in terms of acquiring hearing aids and FM's and cochlear implants" (p. 9, 1.17-18). She continued, "It's certainly you know nice when you haven't had to exist with that financial stress because because of the provincial policies" (p. 10, 1. 2-3). In summary, both Kyla and Jared appreciated the support offered by the Ministry of Health.

Education-Provincial

Kyla was pleased with the pupil-teacher ratio available to her daughter in the Montessori school she attended. She planned to send Shelley to a public school when she entered Grade 1, just as she had done with Sally. Perhaps it was for that reason that she did not comment on the lack of service for children with hearing loss in the private school. However Sarah did mention this issue, "The education system doesn't choose to provide special services support to the private schools ... that's a barrier for them (p. 10, 1.5-11). In summary, while Shelley was not yet in the public school system, Sarah did comment that the lack of itinerant teachers in the private

schools did present a barrier to those who might want to choose such a system for their children with hearing loss.

Voice.

When asked about the impact of Voice Ontario on them, Jared deferred to his wife saying that he did not know if he could answer the question because, “Kyla is the one who deals mostly with Voice” (p. 39, 1.21-22). He did indicate that he read the provincial newsletter published by Voice. Kyla did not comment on provincial Voice, although Sarah indicated, “Well, they benefit from Voice Ontario just in terms of the fact that that means there’s a Voice Ottawa” (p. 8, 1.3-4). In summary, while both Jared and Kyla were aware of provincial Voice, they seemed to feel that it played a minor role in their transition.

Community.

When asked about the role of community supports, Jared responded, “I think Kyla’s the best person to answer that” (p. 46, 1.3). Kyla discussed her role in coordinating the resources provided by the Ministry of Community and Social Services, “I send the invoice to SSAH (Special Services at Home). They send it right away. The money goes to the bank so ... and the service is very good. When I call and O.K. my money is not deposited then he calls right away” (p. 53, 1.17-20). In summary, both parents were grateful for the funding provided by the Ministry of Community and Social Services, although Kyla was more involved with the administration of these funds.

Summary-Barriers and Facilitators

Jared and Kyla agreed that the support of the Ministries of Health and Community and Social Services had facilitated their transition to auditory-verbal therapy. Jared seemed less aware of the administrative aspect of the aid provided by the Ministry of Community and Social

Services, as this was Kyla's domain. While they did not note any barriers set up by the Ministry of Education, Sarah did feel that the lack of special services support to the private schools presented an obstacle for them. They solved this problem by requesting that their tutor, Helen, who was paid by the Ministry of Community and Social Services visit the school. In addition, their Integration Support Worker advised the school about Shelley's needs. Neither Jared nor Kyla seemed to consider that Voice Ontario impacted on their transition.

Macrosystem

Accessibility

Kyla and Jared were very grateful that they had access to the technology and therapy that was offered to them at the hospital. Kyla made reference to her native land, "The country itself was different so everything was different" (p. 68, l.12). She added, "because I know the difference too because here what we get in India it'll come but it'll take some time for them to get it" (p. 67, l.23-24).

They added that exposure to other children with cochlear implants who spoke was very encouraging for them. They recounted how in the park they had met another family with two children who wear cochlear implants. Kyla said that prior to that encounter, "I did not speak to anyone directly to the child how the child speaks normally" (p. 69, l.4). When she heard the older daughter, who was the same age as Sally, "that was *very* [italics added] encouraging that day ... it was *so* [italics added] soothing for me ... I know that when she grows like 6 or 7 years you know she'll be O.K. (laughs)" (p. 70, l.3-7). Jared described his reactions to meeting this family, "the first one is doing *extremely* [italics added] well. You can't really tell by just talking to her that she is going through these challenges. She is *amazing* [italics added]". He added, "and when we saw her like it was a different life you know and we said, 'Oh wow, this is what can happen to

Shelley”” (p. 50, 1.2-6). Kyla felt that this contact also encouraged Sally, “So whenever she (Sally) says something, ‘Oh Mama she’s not going to ...’ Well then I say, ‘Look at Amy. She’s perfectly fine and enjoying”” (p. 45, 1.16-17). In summary, Jared and Kyla were pleased with their access to services that supported them and their daughter.

Inclusion

Both Kyla and Jared seemed to seek normalcy for Shelley as well as for their family. In addition to attending a regular private school, she was also enrolled in skating and swimming lessons at the local community centre. Jared commented, “There were some occasional you know times when we wondered, ‘hey what has gone wrong?’, but you know other than that it’s been pretty normal I would say” (p. 31, 1.6-7). Kyla added, “I don’t think here still now she realizes that she’s hearing impaired. I don’t think that she knows the difference as yet” (p. 14, 1.21; p. 15, 1.9).

While there were no other people with hearing loss in either extended family, when she was a child Kyla had had a neighbour in India who had a hearing loss and signed. She had reacquainted herself with this woman, now an adult, during a visit to her parents’ home and had become somewhat worried when she learned that this woman did not work and was dependent on her parents, “So whenever I think that scares me” (p. 67, 1.4). Sarah recalled, “I don’t think they ever even talked about deaf culture” (p. 10, 1.15). In summary, Kyla and Jared appreciated the opportunities for inclusion that the community offered their daughter and sought to normalize their family’s experience as much as possible.

Summary-Barriers and Facilitators

Both Kyla and Jared felt that their access to technology and services facilitated their transition to auditory-verbal therapy. The opportunities for inclusion that were available in their community also served as facilitators.

Current Perceptions of the Transition

When asked about her current feelings about the transition, Kyla replied, "It's all great" (p. 34, l.23). Jared commented,

You don't realize it right at the moment you know it's only when you in a future time you reflect upon the past and you know like what has gone well and what hasn't and there's a lot of things that have really gone well. I wouldn't say anything has gone wrong at all from the *way* (italics added) we have handled the situation. I think we should be proud of ourselves" (p. 32, l.1-7).

He added, "Even now like it's a pretty normal life ... of course there are challenges ... therapy lessons and what are the targets ... and school and the hospital and other things but they are basically part of the ..." (p. 31, l.9-14). When I interjected, "part of your life now?" (p. 31, l.15), he replied, "Ya absolutely" (p. 31, l.16).

Review of Cases

In this section each of Bronfenbrenner's nested levels and the corresponding themes will again be considered. This time the findings for each family will be compared and contrasted. Although it is not the intent of case study methodology to provide generalizations, a between-case review offers the opportunity to revisit the findings and ponder their meaning.

*Microsystem**Personal Characteristics*

All the families reported that life had been quite normal prior to the detection of the hearing loss. Three of the five families had worried about their child's hearing prior to the detection, either because of prematurity, as in the case of Allison; or due to family history, as in the case of Diane; or because of delayed speech, as in Melanie's case. In Shelley's case, it was a maternal great aunt who alerted the parents to a potential problem in their baby, while in Peter's case, prior to his bout of meningitis, he had been developing normally.

All the parents spoke of their grief after the detection and each of them mentioned significant changes in their lifestyles. Peter's and Allison's families were not only dealing with hearing loss, but also with the illness that caused the hearing loss. Susan reported that she left work when Peter became ill and that she and Zach spent a lot of time on the Internet educating themselves. Evelyn sought information and support from Multiple Births Canada and the Internet. While Dave and Evelyn did carry out their plan to move to Iqaluit, this was short-lived, primarily due to the needs of their newborn twins. Margaret reported that their activities did not change drastically, but that they were very cautious about Melanie's equipment. In both Melanie's and Shelley's families, the detection meant that they had to choose one language for their families. Both families chose English. Nancy reported that her social life was curtailed after

Diane's birth and the detection of her hearing loss. Evelyn recalled that after the birth of their children they had not maintained contact with many of their friends.

Three of the mothers described themselves as quiet people who did not talk a lot. While Nancy felt that she had become more outgoing as a result of the demands of auditory-verbal therapy, Evelyn felt that she had not been able to modify this aspect of her personality. As Susan feared that she would not be able to meet the demands for talking required by auditory-verbal therapy, she and Zach hired a nanny who was very loquacious and interested in learning to do the therapy. Margaret and Kyla seemed quite comfortable with their role as teacher. Three mothers and three fathers described themselves as patient. Kyla and Jared were the only parents who emphasized their optimism in the face of this crisis. Although Nancy and Jared were the only ones who mentioned religion and spirituality as a source of strength, both Evelyn and Margaret referred to G-d, as having provided them with the voice and the temperament to carry on. When discussing their roles, only one of the mothers, Kyla, referred to herself as a teacher. The others referred to their role in attending therapy and as advocate for their child. In addition, Susan and Kyla noted their roles as administrators of equipment, funds and appointments. Two of the mothers, Nancy and Kyla indicated that they did not see their responsibilities as a problem because this was their child and they felt it was their duty to provide what their child needed. All the fathers except Jean referred to their tertiary role in therapy. All the fathers mentioned their role in buying toys to support the therapy at home. Three of them specifically mentioned their responsibility as providers for the family. All the mothers and one of the fathers, Jared, noted that they had experienced personal growth, in the form of maturity and learning about parenting, as a result of their transition to auditory-verbal therapy.

Three of the children were described as outgoing, however one of these three, Allison, was also described as stubborn and difficult. Four of the five children were considered “happy” by their parents, as well as persistent and determined.

Family Interactions

In all cases, the parents reported a close relationship with their child who had a hearing loss. The only instance where the interaction was sometimes considered problematic was that between Dave and Allison. Both Dave and Evelyn explained that this might be because they were so similar in personality. In their interactions with their child, all parents interpreted their child’s meaning and seemed intent on establishing communication with him/her.

Three of the five families had two parents living in the home. Of these, two felt they were very supportive of each other and concurred on most issues. In the third family, the mother, Evelyn, felt that Dave blamed her for Allison’s lack of progress. Dave, however, expressed pride in their functioning as a team during the crises they faced. In the case of Margaret and Jean, who were not living together but shared custody of the children, Margaret commented on the positive support Jean had provided her. Jean felt that dealing with the transition had been a source of stress in their marriage. Nancy received some financial support but no emotional support from her spouse.

In three of the five families conflict between the siblings was an issue. In Peter’s family, his two siblings, who were slightly older, tended to play together rather than with him. Shelley’s older sister, Sally, was the only one who took on the role of “teacher” during the observation sessions. Her parents mentioned her concern about the normalcy of her sister and her father anticipated fighting between her and her sister in the future. Eight of the nine parents addressed the issue of behaviour management and concurred that they treated their child with hearing loss

more leniently than their other children. Two of the mothers attributed this to a feeling of pity for their child. One of the mothers, Susan, was the only one who stated that she attempted to treat her children equally. She did admit that when Peter was younger and understood less this was more difficult. Evelyn too mentioned that with increased comprehension, equal treatment was more feasible.

All the parents expressed gratitude for the support they received from their extended families. In the case of Nancy's and Kyla's families, who lived at a distance, support came in the form of telephone calls, e-mails, and in Kyla's mother's case, prayers and fasting.

Summary - Barriers and Facilitators - Microsystem

All the parents considered that their lives had been quite normal prior to the detection of the hearing loss and that their transition to amplification and therapy had wrought considerable changes in their lives. Most parents characterized themselves as patient and felt that this experience had resulted in personal growth. Most of the fathers noted their role as providers for the family and as tertiary participants in the area of therapy. Four of the five children were described as "happy". Several mothers reported that they felt more isolated since their transition to auditory-verbal therapy.

Most families indicated that they had a warm relationship with their child who had a hearing loss. Despite their living arrangements, most parents felt that they had received support

Table 4

Facilitators and Barriers at the Microsystem Level

	Nancy	Margaret & Jean	Susan & Zach	Evelyn & Dave	Kyla & Jared
Facilitators					
Personality-Parent	Patience Spirituality	Patience	Patience Tenacity	Patience	Patience Optimism Spirituality
Personality-Child	Outgoing	Outgoing Happy	Outgoing Happy Persistent	Outgoing	Outgoing Happy Persistent
Parent-Child	Positive	Positive	Positive	Positive-Mom	Positive
Parent-Child		Supportive	Supportive	Supportive	Supportive
Child-Sibling					Supportive
Parent-Grandparent	Supportive	Supportive	Supportive	Supportive	Supportive
Barriers					
Personality-Parent	Quiet		Not talkative-Susan	Not talkative-Evelyn	
Personality-Child				Stubborn	
Parent-Child				Clash-Dad	
Parent-Parent	No support				
Child-Sibling	Resentful	Resentful		Resentful	
Parent-Grandparent	Positive	Positive	Positive	Positive	Positive

from their spouse at the time of the transition. Most children experienced some resentment towards their sibling with hearing loss and even when resentment was not expressed, the sibling seemed to be affected by the hearing loss, for example, Sally's involvement in school projects related to hearing impairment. A summary of the barriers and facilitators at the microsystem level can be seen in Table 4.

Mesosystem

Choice

Five of the eight parents who responded to this question indicated that it was their trust in the professionals' recommendations that led them to adopt auditory-verbal therapy. Other reasons for their choice were their desire for their child to speak and function in the hearing world and their wish for normalcy for their child. In addition, consideration of the siblings in the family was mentioned by Zach and Evelyn.

Compliance

In Peter's and Allison's cases, because of the degree of their hearing losses, hearing aids were of marginal benefit and use of them was inconsistent. The parents of both these children felt the cochlear implant was far more effective than the hearing aids had been. Two of the parents commented on the reduced frustration and increased comprehension experienced by their children as a result of receiving the cochlear implant. In Peter's case, his transition from hearing aids to cochlear implant was very rapid. As meningitis may result in ossification of the cochlea, implantation usually takes place soon after the detection of the hearing loss. Peter's parents had to accept the permanent nature of his hearing loss first, before they could choose the cochlear implant. Having made that decision, they extolled its virtues. All parents reported high compliance with use of the cochlear implant.

Each of the families found that the adoption of auditory-verbal therapy involved changes in their lifestyle. Dave and Zach mentioned that they did not change so much *what* [italics added] they did as the *way* [italics added] they did it. Two of the families reported that their transition to auditory-verbal therapy meant a change in the primary language used in the home. Three of the mothers mentioned the loneliness of the journey through auditory-verbal therapy.

When discussing implementation of auditory-verbal therapy, three of the fathers indicated that they had become more involved with their child since its introduction. However, all admitted that their wives and their therapist were the primary stimulators of language. Nancy was the only one of the parents who had to depend on public transportation to attend sessions at the hospital and found this to be a barrier to her consistent attendance. Evelyn recalled that the children's illness in the winter prevented her from attending regularly. The three mothers, who described themselves as quiet, found adoption of auditory-verbal techniques difficult. One of the fathers, Jean, also reported that he found the techniques difficult. He and Evelyn expressed guilt about not using the techniques enough. Three of the mothers reported that they found auditory-verbal therapy very time-consuming. Three mothers, Kyla, Margaret and Susan indicated that they incorporated the techniques into their daily lives. Kyla was the only one of the three who found it easy to adopt the therapy from the beginning and talked about using it with other small children, as it came very naturally to her. Zach too reported that it had become "second nature". Kyla, Susan and Evelyn reported that their children disliked doing "formal" lessons with their mothers. Few of the parents knew the names of the techniques. However, it was noted during the observations that most of them used some of the techniques including: repeating, highlighting, expanding vocabulary, modelling, extending sentence length and to a lesser extent, covering their mouths. Four of the mothers commented on the delay in seeing results with auditory-verbal therapy and

Zach concurred. Evelyn and Dave were the only parents who continued to express worry about their daughter's progress and reported that her language was very delayed. The other mothers seemed to find that doing therapy became more rewarding as the child grew older and his/her language advanced. Susan, Margaret and Evelyn indicated that they would have liked more structured materials for home use. Zach and Jared commented that they felt they needed to encourage their child's use of longer sentences. Both Susan and Zach were the only ones who stated that cost and expertise, that is finding a nanny who could do the therapy, were barriers for them.

Support

Health-Hospital.

All the parents praised the services they received through the health care system. Specifically, they were grateful for the auditory-verbal therapists' input which they found motivating, as well as for the audiologists' expertise. Zach mentioned that they would have moved if there had not been excellent services in this city. In fact, two of the families, Allison's and Melanie's, did move to avail themselves of better service for their children. Three of the parents recalled encouraging words offered to them at the beginning of their journeys, regarding their child's future functioning. Three of the parents reported delays in access to resources because they were not told about them. Two parents commented on delays in receiving psychological services. Susan felt the audiology service could be more aggressive in implanting children with meningitis.

Education-Local.

One of the children, Diane, was not yet in any formal school setting, hence her mother did not comment on this service. Two of the children, Peter and Shelley, attended private

preschools, and because of this did not have access to the services of an itinerant teacher of the hearing impaired. This was considered a barrier by Susan because it limited the educational options for her son, Peter. Four of the children were enrolled in schools and all of them received the service of an itinerant teacher of the hearing impaired several times each week. In addition, two of the children had the support of an educational assistant in the classroom. All the parents whose children attended school were very pleased with the service. Melanie's family had moved in order to obtain itinerant service which was not available in Quebec. One of the parents, Evelyn, expressed regret that the programme at the hospital did not continue after the child's fifth birthday. Another parent, Margaret, felt that the educational assistants required more training when working with children who wear cochlear implants. Susan suggested that the children at Kindergarten level might benefit from being in an inclusive setting in the mornings and with other hearing impaired children in the afternoon. Four parents, Evelyn, Dave, Kyla and Margaret expressed concern about their child's entry into Grade 1. Three parents, Susan, Kyla and Evelyn worried about their children's socialization with hearing peers at school.

Workplace.

Three of the mothers worked outside of the home and found their employers very flexible in allowing them to make up time missed to attend appointments at the hospital. All three, Nancy, Evelyn and Susan, altered their work arrangements to accommodate their children with hearing loss. Nancy worked day shifts so that she could pick her daughter up from daycare. Evelyn had a part-time job and had contemplated obtaining a full-time job but decided not to pursue this option as she felt a babysitter could not care for her children with special needs in the way that she could. Susan worked in order to pay for a nanny who provided Peter with auditory-verbal therapy. When his requirements were more of a social nature, Susan felt that she could

better meet his needs and those of his siblings by staying home. Three of the fathers reported that their employers allowed them to take time off for the occasional appointments they attended, however for the most part their work lives were unaffected by their transition to auditory-verbal therapy. Jean, who had attended therapy on a regular basis, noted that his employer was not very accommodating and that this had been stressful for him.

Voice-Ottawa.

All the parents except Nancy, had attended at least one Voice meeting. Two mothers and two fathers indicated that they enjoyed meeting other families who had children with hearing loss. Evelyn commented that she felt Voice was geared more for school-aged children and those who were excelling at auditory-verbal therapy. Margaret felt that its target audience was teachers. She suggested that Voice create a system whereby parents can meet one-on-one. She regretted that Voice did not offer information on services for anglophones who live in western Quebec. She and Evelyn recommended that Voice organize a summer day camp where children with hearing loss could attend full-day sessions daily.

Community.

All the children benefitted from funding provided by the Ministry of Community and Social Services. Susan, Kyla and Nancy had received service from the Infant Development Programme. In addition, Special Services at Home funded a tutor who came to the home several hours each week to follow up on the therapy goals established by the auditory-verbal therapist. Susan and Kyla reported that Peter and Shelley had also received the input of an Integration Support Worker when attending preschool. Evelyn received Special Services at Home funding, but had not been told about it until her twins were 18 months of age when she was informed by a social worker at the treatment centre. The daycare Melanie had attended in Quebec had received

funding for an interventionist, and since moving to Ontario, she received Assistance for Children with Severe Disabilities.

Summary - Barriers and Facilitators - Mesosystem

Most parents adopted auditory-verbal therapy because it had been recommended by professionals whom they trusted and because it offered the possibility of speech and hearing to their child, as well as normalcy for their family.

All the parents felt that there was high compliance with use of the cochlear implant and that this technology had contributed to their child's increased comprehension and reduced frustration. Most of them found that the transition to auditory-verbal therapy meant changes in their lifestyle: increased talking, more appointments, greater cost, transportation needs, the use of various techniques to improve their child's comprehension of language and greater expenditure of time with their child. Most of them reported that the progress with auditory-verbal therapy was slow initially, but that the longer they engaged in it, the more encouraging they found the outcomes.

The Ecological Transition to Auditory-Verbal Therapy

Table 5

Facilitators and Barriers at the Mesosystem Level

	Nancy	Margaret & Jean	Susan & Zach	Evelyn & Dave	Kyla & Jared
Facilitators					
Hospital	Support-AVT Support-Audiology Compliance	Support-AVT Support-Audiology Liaison-AVT-Audiology Support-E.N.T. Compliance	Support-AVT Support-Audiology Support-E.N.T. Proximity Compliance	Support-AVT Support-Audiology Compliance	Support-AVT Support-Audiology Support-E.N.T. Proximity Compliance
School		I.T.H.I., E.A.	I.T.H.I.	I.T.H.I., E.A.	
Local Voice	Meet other parents	Meet other parents Summer camp	Meet others Summer camp	Meet other parents Summer camp	Meet other parents
Community and Social Services	Tutor, I. D. P., I.S.W.	C.I.-chat line	Tutor, C.I.- chat line	Tutor, Well Baby Clinic, Multiple Births Canada	Tutor, I.D.P., I.S.W.
Work	Flexible schedule	Flexible schedule-M.	Flexible schedule		
Barriers					
Auditory-Verbal Therapy	Time, transportation	Time, slow progress, related service, guilt	Slow progress, cost, related service	Time, slow progress, guilt	
School			lack of I.T.H.I.-private sector	lack self-contained class	lack of I.T.H.I. -private sector
Local Voice		Target population		Target population	
Community and Social Services	Babysitter				
Work		Inflexible Schedule-Jean		Lack of babysitter	

Note. AVT = Auditory-Verbal Therapist; E.N.T. = Ear, Nose and Throat Physician; I.T.H.I.= Itinerant Teacher of the Hearing Impaired; E.A.= Educational Assistant; IDP = Infant Development Worker; ISW = Integration Support Worker; C.I.= Cochlear Implant

All the parents seemed very pleased with the health services they had received, although some did report delays in access due to lack of information. All those whose children were visited by itinerant teachers expressed satisfaction with this service. Most parents reported cooperation from employers in obtaining time away from work for appointments, however it was primarily working mothers who were implicated, rather than fathers. Most parents had attended at least one Voice meeting and appreciated this organization primarily for the exposure it provided to other children with hearing loss and their families. All the parents expressed satisfaction with the community services they had received, however some reported delays in access due to lack of information. Table 5 depicts the barriers and facilitators at the mesosystem level.

Exosystem

Support

Health-Provincial.

All the parents were grateful to the Ministry of Health for funding the cochlear implant, the accompanying surgery, programming and therapy, the cost of which would have been prohibitive without government subsidy. Both Nancy and Kyla acknowledged that such technology would not have been available to them in their native countries. Evelyn and Margaret had lived in provinces outside of Ontario and had experienced meager therapy services in the former case and the possibility of having to relocate for surgery in the latter case. Susan was appreciative of the candidacy criteria which made the cochlear implant available to children with meningitis regardless of age and additional problems.

Education-Provincial.

Three of the children were attending school in the public and separate school boards. One of them, Melanie, had moved from another province in order to obtain these services. Melanie had benefitted from subsidized daycare provided by the Ministry of Education in Quebec. Since this resource was not available to her in English, this proved to be a barrier for the family. Although two of the children had attended or were currently attending a private school, which did not offer itinerant service, only one of the parents, Susan, complained about this situation. In the other case, the auditory-verbal therapist expressed concern about this inequality. She had continued to provide therapy to this child to close this gap in service provision. Evelyn expressed gratitude for the provision of FM systems, (which improve the signal-to-noise ratio in the classroom) and teaching grants, that are provided by the provincial government. She was also appreciative of the Ministry-mandated Identification, Placement and Review Committee (IPRC) which ensures service to children with special needs. Susan felt that the Ministry of Education should mandate small class sizes for children with special needs.

Voice-Ontario.

The provincial organization of Voice publishes a newsletter and advocates for children with hearing loss, in addition to providing outreach therapy services across the province and workshops for parents and professionals. None of the parents reported any impact on their transition from Voice Ontario. Jared was the only one who mentioned reading their newsletter. Susan indicated that they had not responded to her e-mails.

Community.

All the parents whose children were tutored through the Ministry of Community and Social Service's programme, Special Services at Home, extolled the virtues of these tutors.

Although the three fathers involved were aware of the tutors and their beneficial role, it was the mothers who managed the funds and interacted with the Ministry representatives.

Summary - Barriers and Facilitators - Exosystem

The parents were unanimous in expressing satisfaction with the availability of the cochlear implant and its accompanying surgery, programming and therapy, all of which was funded by the Ministry of Health. Those whose children received support from an itinerant teacher of the hearing impaired in the school board were grateful for this service, as well as for FM systems, teaching grants and the Identification, Placement and Review Committee (IPRC) process. None of the parents felt that Voice Ontario had had any impact on their transition. They were all appreciative of the resources provided by the Ministry of Community and Social Services. The barriers and facilitators at the exosystem level are portrayed in Table 6.

Macrosystem

Accessibility

All the parents acknowledged that access to services and technology had been a pivotal factor in their transition to auditory-verbal therapy. Two of the families came from countries where such services were not available. Two other families experienced the lack of service in another part of the country. There was a recognition on the part of all parents that the cochlear implant has contributed enormously to their children's development. Margaret commented that they were fortunate to be living in times when the technology for the cochlear implant is available. Susan was grateful that children with additional disabilities were considered as candidates because the prognosis for Peter was uncertain when he received his implant. Several of the parents remarked on the proximity of the service to their homes.

The Ecological Transition to Auditory-Verbal Therapy

Table 6 *Facilitators and Barriers at the Exosystem Level*

Facilitators		Nancy	Margaret & Jean	Susan & Zach	Evelyn & Dave	Kyla & Jared
Prov. Health	Funding - C.I.- surg., prog., AVT	Funding- C.I., surg.,prog., AVT	Funding- C.I., surg.,prog., AVT	Funding-C.I.,surg, prog.,AVT	Funding-C.I., surg.,prog., AVT	funding-C.I.,surg.,prog. AVT
Prov. Education		Funding- F.M., I.T.H.I., E.A.	Funding- F.M., I.T.H.I.	Funding- F.M., I.T.H.I., E.A. I.E.P.	Funding- F.M., I.T.H.I., E.A. I.E.P.	
Com. Soc.	Funding- S.S.A.H., I.D.P.		Funding- S.S.A.H., I.D.P., I.S.W.	Funding-S.S.A.H., I.D.P., I.S.W.	Funding-S.S.A.H.	Funding-S.S.A.H., I.D.P., I.S.W.
Voice Ontario						read prov. newsletter
Barriers						
Prov. Health		limited choice of hearing aids-Quebec				
Prov. Education		No I.T.H.I.- Quebec	large class sizes, no I.T.H.I.-private schools	no AVT in Iqaluit so left	no I.T.H.I.	-private schools
Com. Soc.		Delayed access		Delayed access		
Voice Ontario	Unaware	No impact	No response to e- mails	No impact		

Note. AVT= Auditory-Verbal Therapy; C.I.= Cochlear Implant; E.A.= Educational Assistant; I.D.P.= Infant Development Programme; I.E.P.= Individual Education Plan; I.S.W.= Integration Support Worker; I.T.H.I.= Itinerant Teacher of the Hearing Impaired; Prog.= Programming;; Prov.= Provincial; S.S.A.H.= Special Services at Home; Surg.= Surgery

In addition, seven of the parents mentioned that they had met at least one child who wore a cochlear implant and talked, either at a Voice function or in the waiting room at the hospital or through their parent tutor. Such encounters were found to be very encouraging.

Inclusion

The fact that the community in which these families lived was receptive to the idea of integrating children with hearing loss was acknowledged by the participants as being a significant factor in their transition to auditory-verbal therapy. Margaret expressed gratitude for the acceptance Melanie had experienced in the mainstream settings in which she participated and stated that the opportunities for inclusion had increased since her own childhood.

When asked to describe their lives prior to the detection of the hearing loss, most parents indicated that they had engaged in routine activities with their children. The goal of all the parents seemed to be to return to that pre-detection state of normalcy, not only for the sake of the child with hearing loss, but also for the siblings and for the family as a unit. Five of the parents referred to the hearing loss as a disability. Although stigma was not mentioned, their desire for normalcy might have been their way of dealing with perceived stigma. Isolation was mentioned by most of the mothers and this might stem from their perception of stigma.

All the parents were aware of the Deaf culture and several mentioned that they were asked about sign language when people learned that they had a child with hearing loss. The pervasiveness of Deaf culture was acknowledged by most of the parents, many of whom had seen movies and documentaries that depicted deaf children and adults. Most had met signing deaf adults at some point in their lives. They all indicated that they wanted their children to learn to speak and that was the major reason they had chosen auditory-verbal therapy.

Summary - Barriers and Facilitators - Macrosystem

All the parents were appreciative of the access to technology and services that they enjoyed in Ontario, as well as of the opportunity to meet other children with cochlear implants who spoke. While they were aware of the Deaf culture, and in several instances had met members of that culture, they all wanted their children to speak. One parent articulated satisfaction with the inclusive nature of today's schools. All parents sought to normalize their experience for the sake of their children as well as for themselves. Table 7 depicts the barriers and facilitators at the macrosystem level.

Table 7

Facilitators and Barriers at the Macrosystem Level

	Nancy	Margaret & Jean	Susan & Zach	Evelyn & Dave	Kyla & Jared
Facilitators	access to cochlear implant and therapy	access to cochlear implant and therapy	access to cochlear implant and therapy	access to cochlear implant and therapy	access to cochlear implant and therapy
	encouraged by exposure to auditory-verbal children who speak	encouraged by exposure to auditory-verbal children who speak	encouraged by exposure to auditory-verbal children who speak	encouraged by exposure to auditory-verbal children who speak	encouraged by exposure to auditory-verbal children who speak
	inclusion at playgroup	inclusion in neighbourhood school	inclusion in neighbourhood school	inclusion in neighbourhood school	inclusion in private school
Barriers		auditory-verbal therapy not available in Quebec schools-moved for service		auditory-verbal therapy not available in Iqaluit-moved for service	

CHAPTER 5 - DISCUSSION

Hearing impairment in early childhood may have debilitating effects on the child in the form of delayed speech and language development, cognitive and psychosocial skills and academic achievement (Durieux-Smith, Seewald, et al., 2000). Robinshaw and Evans (2001) noted that hearing impairment impacts not only the child but also his/her parents and the whole family network. This view is espoused by family systems theory which regards the family as a whole unit and considers that it is affected by any change occurring in any one of its members (Minuchin, 1985). Yet family involvement has been found to be the factor most predictive of positive outcome in intervention with children who have hearing loss (Moeller, 2000). It has also been stated that the meaning attributed to a situation by its participants will determine their response to it (Seligman & Darling, 1997).

Bronfenbrenner's theory of the ecology of human development recognizes that children's development occurs in relation to the family, environment and services surrounding them (Dym, 1988). In the case of children with hearing loss, it is imperative to evaluate broader family dynamics in order to understand the differences in adjustment and outcomes of children with hearing loss and their families (Calderon & Greenberg, 1999). After the diagnosis of hearing loss in their child, parents may experience what Bronfenbrenner calls an ecological transition, which "takes place whenever during the life course, a person undergoes a change in role either within the same or in a different setting" (Bronfenbrenner & Crouter, 1983, p. 381). In the context of auditory-verbal therapy, the parents' role is pivotal in aiding their children to develop spoken language following normal developmental patterns (Dornan, 1999). Although this approach requires a significant commitment on the part of the parents, little is known about their

perceptions regarding this transition in their lives.

The present study proposed to answer the following major question: What are parents' experiences in making the transition to auditory-verbal therapy with their children who wear cochlear implants? In addition, the following secondary questions were investigated: (1) What are the parents' daily activities, roles and interpersonal relations and how are these changed by the transition to the auditory-verbal therapy process? (2) What personal and family characteristics impede and/or facilitate this transition at the level of the microsystem? (3) What elements of the auditory-verbal therapy model and workplace impede and/or facilitate this transition at the level of the mesosystem? (4) What elements of the public policies impede and/or facilitate this transition at the level of the exosystem? (5) What elements of the culture and belief system about hearing loss impede and/or facilitate this transition at the level of the macrosystem?

A qualitative case study approach was used to investigate these questions. The following data collection methods were employed: observation sessions, individual interviews, a discussion group and family information questionnaire. The results will be discussed as they relate to each of the research questions and in the context of the conceptual framework, which has been guided by Bronfenbrenner's theory of the ecology of human development and family systems theory.

Research Question 1 - What are the parents' daily activities, roles and interpersonal relations and how are these changed by the transition to auditory-verbal therapy?

Life Before the Detection

Most of the parents in this study reported that life had been quite uneventful prior to the detection of their child's hearing loss. These findings support those of Seligman and Darling

(1997) who noted that generally, adults expect to experience the normal life cycle events without incident. The birth of a child with a disability is considered traumatic in that it is “an unanticipated life event” (Seligman & Darling, 1997, p. 25). The available literature on children with hearing loss does not report on life before detection, but instead tends to concentrate on when and under what circumstances the diagnosis was made (Gregory, 1995). Most of the participants interviewed by Christiansen and Leigh (2002) noticed their child’s hearing loss gradually during the first months of their child’s life, similarly to the families in the present study. In some instances a third party, such as a grandparent was the one who alerted the parents to a problem. In the case of Shelley, her maternal great aunt suggested that her parents consult a specialist. In Peter’s case, the sudden onset of meningitis led to the detection of hearing loss. Most parents in this study were deeply saddened and shocked by the detection of a hearing loss in their child and expressed a sense of grief and loss which continued beyond the detection phase. This finding is supported by other authors (Luterman, 1999; Moses, 1985; Robinshaw & Evans, 2001).

Bronfenbrenner (1995) indicated that when confronted by an ecological transition, there are changes in one’s daily activities, roles and interactions. Bodner-Johnson (2001) reiterated this stance and stated that mothers and fathers of a child with hearing loss must take on new roles and responsibilities that they had not anticipated. Table 8 summarizes the changes in activities, roles and interactions of mothers and fathers.

Table 8

Changes in Activities, Roles and Interactions

	Mothers	Fathers
Changes in Activities	Search for information	Search for information
	Attendance at therapy (5/5)	Attendance at therapy (1/5)
Changes in Roles	Advocates	Providers
	Administrators and equipment managers	Supporters
	Facilitators of social interaction	
	Teachers	
Changes in Interactions	Reduced social interaction	
	Positive interactions with professionals	Positive interactions with professionals

Changes in Activities

Search for Information

One activity in which most parents engaged after the detection was the search for information. Five of the parents in this study recalled consulting the Internet. Susan and Zach attempted to obtain as much information as possible about meningitis. Evelyn made contact with Multiple Births Canada after the birth of her twins. This quest for information was also reported by Lloyd (1994) and Most and Zaidman-Zait (2003). Moreover, Robinshaw and Evans (2001) indicated that parents perceived lack of information as one of the largest gaps in service provision. Specifically, parents in their study sought information about different examples of

service provision, supporting the acquisition of communicative competence, managing difficult behaviour, educational choices, claiming allowances, digital hearing aids and cochlear implants. They acknowledged that they might not be ready to absorb all the information, however they wanted to be able to pursue questions as they saw the need. Most and Zaidman-Zait (2003) indicated that this search for information is a coping strategy that serves two purposes: it helps parents make decisions and it reduces their stress.

Attendance at Therapy

Attendance at regular therapy sessions and audiology appointments were also new activities that followed the detection of hearing loss. Evelyn had numerous appointments at the hospital in the first months of her premature twins' lives. Susan left her job for six months to care for Peter, after his bout of meningitis. This finding was also reported by Patterson (1991) who indicated that when faced with a child with disabilities, the family often must reallocate roles and one parent sometimes leaves work. Similarly to Luterman's (1999) observations, all five mothers mentioned that they were the ones who attended therapy regularly while only one father attended therapy on a regular basis.

Changes in Roles - Mothers

(1) Advocates

Margaret, Evelyn and Susan referred to themselves as advocates for their children. This finding has been reported by Durieux-Smith et al. (2001) and in testimonials by parents published in Estabrooks (1998). Meadow-Orlans (1990) also reported that after the initial reactions of grief, the family gradually reorganizes and the parents become more confident and some even assume advocacy roles for their children.

(2) Administrators and Equipment Managers

Kyla and Susan also spoke about their roles as administrators and equipment managers. Their administrative role was mentioned as it related to the management of equipment and funds provided by the Ministries of Health and Community and Social Services. As this funding is not widely available in other parts of the world, these parental roles have not been reported by other investigators.

(3) Facilitators of Social Interaction

Susan indicated that she had assisted in the social interaction of one of her older hearing children but not the other. She felt that this role would be even more important with Peter. This finding is similar to that reported by Duquette et al. (2002).

(4) Teachers

Kyla referred to herself as a teacher, as was noted of the caregivers in Champion's study (1983). Several of the parents interviewed by Christiansen and Leigh (2002) whose children were enrolled in auditory-verbal therapy programmes, commented on the therapy they did at home with their children, although they did not specifically refer to themselves as teachers. Koester and Meadow-Orlans (1990) and Kashyap (1986) noted that mothers of children with hearing loss often feel pressure to stay home and become their child's full-time teacher. Seligman and Darling (1997) cautioned that it is important to verify with the parents as to their comfort in taking on a teaching role. They claim that overburdening one family function may cause stress and have negative consequences for other family functions. This was true for Margaret and Jean who reported a significant amount of stress related to the diagnosis. Indeed, other authors have also reported increased stress among parents of children who wear cochlear implants (Purdy et al.,

1995; Quittner et al., 1991). This finding will be discussed further in the next section on personal characteristics.

Changes in Roles - Fathers

(1) Provider of Materials

Most of the fathers considered themselves tertiary to the auditory-verbal therapy process and mentioned their role as provider for the family. In addition, they purchased toys that they felt were appropriate for therapy. Meadow-Orlans (1995) also reported that despite the recent move to greater sharing of family responsibilities by mothers and fathers, mothers continue to perform the majority of household and child-related tasks and fathers continue to perceive themselves as breadwinners. She added that this pattern seems to be even more entrenched when there is a child with hearing loss in the family.

McNeil and Chabassol (1984) argued that fathers in their study were involved with their children but in different ways from the mothers. The investigators conducted individual interviews with 20 sets of mothers and fathers of children enrolled in a total communication programme in British Columbia, Canada. Similarly to the reports of fathers in the present study, they found that fathers would change their work schedules in order to participate in some important aspect of the child's programme and they had refused job promotions or changed jobs in order to be near their child's treatment programme.

(2) Support

Margaret and Kyla mentioned the importance of the support offered to them by their spouses. Jared indicated that he felt it was part of the father's role to be strong for the family. Meadow-Orlans and Steinberg (1993) emphasized the importance of spousal support, in addition

to that of extended family and friends. The topic of support will be explored further in later sections of this dissertation.

Changes in Social Interaction

Interactions with Friends

Nancy and Evelyn commented on their reduced social interactions following the birth and subsequent detection of hearing loss in their children. This sense of isolation was also mentioned by Susan during the discussion group. Margaret implied the same sentiment when she remarked that only Jean was able to understand how she felt about having a child with a hearing loss. The theme of isolation and need for social interaction has been addressed in several studies (Durieux-Smith et al., 2001; Gregory, 1995; Robinshaw & Evans, 2001;). In contrast, Lederberg and Golbach (2002) observed that the majority of the mothers in their study were satisfied with the support they obtained from their social networks, despite the fact that these were small. Meadow-Orlans and Steinberg (1993) noted that mothers who were satisfied with their social support had more positive interactions with their children.

Kyla and Jared were the only parents in this study who referred to the support of friends during their transition. Morgan-Redshaw et al. (1990) indicated that the mothers of adolescents in their study did not appear to be isolated either, however this may be due to the fact that the children in their study were older. Therefore, the prevalence of social isolation in the parents of children with hearing loss is inconclusive and further research is needed in this area.

Interactions with Professionals

The new interactions associated with this transition included those with the auditory-verbal therapist and the audiologist. Most parents in this study commented favourably on their

relationships with these professionals. Lederberg and Golbach (2002) indicated that the mothers of young preschool children in their study had more interactions with professionals than the mothers of normally hearing children. Robinshaw and Evans (2001) reported positive parent-professional relationships among parents who attended centres that met best practice criteria, but less satisfying interactions at other centres. Bodner-Johnson (2001) suggested that professionals consider an adult learning perspective when assisting parents as “they make a transition to a new life role: being parents of a deaf child” (p. 268). The professional-parent interaction will be discussed further when answering the next research question.

In summary, all the parents in this study indicated that they had enjoyed routine activities with their families prior to the detection of the hearing loss. Similar to previous findings, they reported that they had experienced grief and shock when informed of the diagnosis. The quest for information was a major activity in which they engaged following the detection, as has been noted by other researchers. Most of the roles described by the mothers in this study were similar to those that had been reported by mothers in previous research. They included attendance at therapy, more often than fathers, serving as advocates for their children, and teacher. Other roles that had not been reported previously included administrator and equipment manager. Most parents observed that this was a lonely process and that there was a decrease in their social interactions following the detection of the hearing loss, however two parents did note the importance of friendships. As seen in the literature, the change in social interactions after the detection of hearing loss seems to be variable. The parents appeared to be satisfied for the most part with their new interactions with the audiologist and auditory-verbal therapist.

Research Question 2 - What personal and family characteristics impede and/or facilitate this transition at the level of the microsystem?

Personal Characteristics

Parents' Personalities

In this section, the personality traits of the parents and children will be discussed. The word barrier is used to refer to personal challenges as perceived by the parents.

(1) Quiet Personalities.

Nancy, Evelyn and Susan described themselves as quiet and found the demands of auditory-verbal therapy for talking difficult to implement. Some of the participants in Gregory's (1995) study reported the same feelings. Evelyn reported that she could not change in this regard, and felt guilty that her lack of input may have been the cause of Allison's speech and language delay. This feeling of guilt due to lack of input to one's child was admitted by some of Gregory's (1995) participants as well.

(2) Patience.

Most of the mothers and fathers in this study either described themselves as being patient, or having become more patient as a result of the interactions required of auditory-verbal therapy. McNeil and Chabassol (1984) indicated that some of the fathers who used a total communication approach also reported this change.

(3) Optimism.

Kyla and Jared were the only ones who mentioned their optimism in the face of this crisis. Zach indicated that he had less optimism than previously, but that it was on the rise. One of the participants in Morgan-Redshaw et al.'s (1990) study observed this sentiment.

(4) Spirituality.

Although Nancy and Jared were the only ones who remarked on their religion and spirituality, Evelyn and Margaret referred to G-d as having provided them with the voice and temperament to carry on. Spirituality and religiosity are cited as one of five coping resources that form part of a model by Folkman et al. (as cited in Calderon and Greenberg, 1999) and are also mentioned anecdotally (Estabrooks, 1998).

(5) Guilt.

Both Evelyn and Jean remarked that they felt guilty about not having done enough therapy with their daughters. This finding was also reported by Durieux-Smith et al. (2001). Margaret and Jean both felt guilty that Melanie's hearing loss had been detected so late (at the age of 2 ½ years).

(6) Tenacity.

Zach commended himself and Susan for their tenacity and their desire to provide the best service possible for Peter. In fact, it appeared that all the parents in this study were prepared to go to great lengths and make sacrifices to provide the best opportunities for their children. This finding is also reported by Robinshaw and Evans (2001).

Champion (1983) noted that the mothers' personal style of interaction influenced the family's implementation of an intervention system with children who have Down syndrome. Yet, there has been little previous research regarding the parents of children with hearing loss and how their personalities impact on their adoption of therapeutic procedures. Further research in this area is needed.

Grief

The parents all acknowledged the profound grief they felt at the time of the detection. One of them mentioned that the grief and pain continue. This finding is supported in the literature (Kashyap, 1986; Luterman, 1999; Moses, 1985).

Stress

Although most parents in this study reported considerable stress at the time of the detection, they did not report high levels of stress at the time of the interviews, perhaps because by that time they had adapted to the diagnosis. Similarly, Lederberg and Golbach (2002) in a longitudinal study found that mothers of 3- and 4-year old children with hearing loss exhibited the same levels of stress as mothers of hearing children of the same age. They noted that satisfaction with social support and levels of stress remained stable during the two years during which they conducted their study. The authors hypothesized that this may be due to the support they perceived from the early intervention centre that they attended. They advised that mothers who felt competent in their parenting abilities and had accepted the changes in their lives resulting from being a parent had greater life satisfaction. The authors suggested that an important component of early intervention programmes is therefore to emphasize parents' strengths in parenting their children with hearing loss.

Contrary to this finding, Quittner et al. (1990, 1991) observed high levels of stress in their sample of Canadian mothers whose children were identified late and received less intensive intervention. The authors hypothesized that support may serve as a mediating factor, in that those who feel a high amount of stress may perceive that their social support is not adequate and may demonstrate psychological symptoms such as depression and anxiety. Crnic and Booth (1991)

noted high levels of stress, which was moderated for some outcomes by social support in parents of normally hearing preschoolers. While Quittner and her colleagues (1991) and Olds et al. (2004) observed high levels of stress among parents of children with cochlear implants, Horsch et al. (1997) and Chmiel et al. (2000) reported improved quality of life after implantation.

Several of the participants in the current study remarked that the initial period of detection seemed like a “long time ago”, and in fact for Allison’s, Melanie’s, Peter’s and Shelley’s families the detection had occurred at least three years earlier. In the case of Diane, her hearing loss had been confirmed about two years prior to the interview. Seligman and Darling (1997) indicated that after an initial period of “anomie”, most parents begin to feel more in control of their situation and are able to return to a “normalized” lifestyle. Although they did not express concern about stress, several of the parents stated that they were worried about their child’s entry into Grade 1. Both Zach and Dave stated that they were anxious about their children’s futures. McNeil and Chabassol (1984) also reported this finding for fathers, as did Lederberg and Golbach (2002) for mothers. Margaret and Jean reported that they felt a great deal of stress in dealing with this transition. It is important to recall that at the time this study took place, this couple was in the throes of a separation, which certainly must have added to their stress levels. In this regard, Patterson (1991) noted that amongst families with children who have chronic illness, the divorce rate was not higher, but the chronic stress tended to exaggerate the direction in which a family was heading and pushed them to the extreme of their current manner of functioning. This finding was corroborated in a study by Kashyap (1986).

Children’s Personalities

All the children, except Allison, were described as happy, outgoing, persistent and

determined. All but Allison seemed to have a desire to communicate with those in their environment. She reportedly balked at doing any activity that appeared to resemble a formal teaching situation. Interestingly, Easterbrooks and O'Rourke (2001) found that boys were more likely than girls to have difficulty with auditory-verbal therapy because of its demands for attention, organization and ability to engage in social activities.

Each child in this study seemed to have a warm relationship with both parents, except for Allison whose parents, Evelyn and Dave, reported that Evelyn was closer with Allison. Susan and Jared commented that they considered the child's disposition an important ingredient in performing auditory-verbal therapy and that if the child did not comply, it would be very difficult to carry out auditory-verbal therapy. Several parents have remarked anecdotally that their child's personality facilitated the therapy process (Estabrooks, 1998).

It has been observed that early intervention can positively influence parent-child personality mismatches, that is, ameliorate poor "fits" between parent and child (Karp, 2004). The practice of auditory-verbal therapy requires close interaction between parent and child, therefore it appears that compatibility between the personalities of the child and parent are very important to the implementation of this intervention method. This study adds to our understanding of the effect of the parent's and child's personalities on the transition to auditory-verbal therapy and has some implications for clinical practice.

In summary, the findings of this research have shown that the personalities of parents and children are important elements of the transition to auditory-verbal therapy and that they can impede or facilitate this process. Although Susan's taciturn nature may have been a challenge, her resourcefulness in finding a nanny who could perform auditory-verbal therapy proved to facilitate

this transition. Timely intervention can be a significant factor in coping with stress (Patterson, 1991) and personality mismatches (Karp, 2004). These findings have implications for clinical practice.

Family Interactions

In this section, the interactions between parents and child, between parents, between siblings and between grandparents and other family members will be discussed. The word barrier is defined as a challenge or obstacle confronted by parents.

Parent-Child Interaction

Most parents in this study reported satisfactory relationships with their child who has a hearing loss. Susan commented that it would be difficult to do auditory-verbal therapy if one did not have a close relationship with the child. The importance of a mother-child bond was previously noted by Morgan-Redshaw et al. (1990) and Gregory (1995). In fact, observations seemed to confirm that it was very important to these parents that they be able to communicate with their children. There were numerous examples of parents' interpreting their children's incomplete utterances to facilitate communication. Not only is this an auditory-verbal technique that is encouraged by their therapists, it is also a means of reassuring the child that he/she has been understood and reinforcing the parent-child bond.

Christiansen and Leigh (2002) indicated that the parents they interviewed generally valued communication with their child and sought ways to overcome barriers to communication between themselves and their child with hearing loss. In their sample, this often included some form of manual communication. Interestingly, Nancy and Evelyn indicated that they added lipreading to facilitate communication with their children.

Calderon (2000) found that parental involvement as well as maternal communication skills were important predictors of positive language and academic outcomes. She postulated that effective maternal communication skill indicated significant parental involvement as the parents in her study learned sign language in order to communicate with their children. She added that parents who converse orally with their children must also be very involved with their children's intervention as it requires a great deal of sensitivity and practice in order to make the message accessible.

Mother-Father Interaction

Most parents in this study felt supported by their spouse during this transition. The only mother who did not receive any emotional support from her spouse was Nancy. Seligman and Darling (1997) reported that single parents often feel that the demands on their time are too great, that they have significant financial problems and feelings of stress. Certainly, Nancy stated that she felt depressed initially and that she had little personal time. This has been reported by Freeman, Dieterich and Rak (2002) in their discussion of urban families of children with hearing loss, many of whom were single parents. Although Margaret and Jean separated, Margaret still reported that Jean understood best how she felt about Melanie's hearing loss. Jean, however, felt the transition to auditory-verbal therapy had added stress to their marriage. Although Evelyn sensed that Dave blamed her for not working more with Allison, he did indicate that he was proud of the way he and Evelyn had weathered hard times together. Therefore, similar to Gregory (1995), the mothers with spouses in this study did feel supported by their husbands. Meadow-Orlans and Steinberg (1993) cited the importance of spousal support in addition to that of extended family and friends.

Relationship with Siblings

In three of the families, those of Diane, Melanie and Allison, the siblings exhibited resentment of their sister with hearing loss, as has been noted by Kashyap (1986). In Peter's family, Susan described the two older siblings as distant from their brother and attributed that distance to the age difference between them. Shelley's parents indicated that she and her sister, Sally, were close, however Kyla did report that Sally often inquired when Shelley would be more normal. These findings are supported by Morgan-Redshaw et al. (1990), who recounted that there was tension between the siblings in their study when they were younger. They added that this friction seemed to dissipate once the children reached adolescence and were more independent.

Bat-Chava and Martin (2002) noted generally satisfactory relationships between siblings. However, they did observe strained interactions when the child with the hearing loss was the younger sibling. In the present study, all five children were younger than their hearing sibling, as this had been one of the criteria for inclusion in the study. The intent had been to ensure that parents had had experience in the parenting role prior to the detection of the hearing loss and the transition to auditory-verbal therapy. However, this does not enable us to appreciate the varying effect of birth order. Bat-Chava and Martin (2002) postulated that when a child with hearing loss is born first into a family, the family may have normalized disability and when the hearing child arrives he/she accepts this as part of the family culture. These authors observed that parents' anxiety about deafness may affect sibling relationships. They cautioned that sibling interactions must be considered within the family context because environmental factors such as family characteristics, in addition to individual factors, may contribute to our understanding of

behaviour. Mark, who seemed very resentful of his sister, was dealing not only with a sibling who is hearing impaired, but also with the dissolution of his family as he had known it.

Seligman and Darling (1997) observed that older sisters seemed prone to taking on a caregiving role with their younger siblings who had a disability. Luterman noted the same phenomenon (as cited in Kisielewicz, 1999). Sally certainly seemed to adopt a teaching role with Shelley, as did Kate with Peter on occasion. However, Linda, who was 16 years older than Diane, resented the caregiving tasks she was asked to assume. Evelyn stated that the close spacing of her three children was a barrier to her transition. This finding was supported by Seligman and Darling (1997) who observed that sibling age, spacing and gender are factors that interact in complex ways and indicated that the effect of having a disabled sibling is dependent on many interrelated factors. In considering children with disabilities, these authors postulated that there are no definitive answers as yet, a conclusion supported by Israelite (1985) in her study of siblings of children with hearing loss.

Behaviour Management

Most parents in this study reported that they managed the behaviour of their children with hearing loss differently from that of their other children, citing the child's lack of comprehension and their feelings of pity as the rationale. Susan was the only parent who indicated that she felt that she treated each of her children according to their individual strengths and weaknesses. She did admit that when Peter was younger and understood less, this was more difficult.

Gregory (1995) remarked that there seemed to be a variety of behaviour management techniques among the parents she interviewed. There seemed to be more parents who indicated that they were strict with their hearing impaired child as he/she would have to be more

disciplined in order to cope in the hearing world. Those who were more lenient cited lack of comprehension on the part of the children as their reason. As her study was originally conducted in 1976 and was re-published in 1995, these views may reflect child-rearing practice at the time. Quittner (1991) reported that behaviour problems during language lessons were assigned the highest ranking type of problem by mothers of children with hearing loss and that behaviour problems at home were considered the most difficult type of problem by mothers of hearing children.

Relationship with Extended Family

Support from extended families was reported by all parents, although it varied in degree. In Melanie's case, her grandmother attended therapy sessions with her frequently. Although Margaret acknowledged the benefits of her in-laws' support, Jean felt that asking his parents for help was an imposition. Allison and her family lived with her maternal grandmother for several months while her father was working in Iqaluit. Shelley's maternal grandmother, living in India, offered weekly prayers and fasted to support her daughter and granddaughter. In each family, it appeared that it was not the amount of support, but the parents' perception of support that seemed to provide them strength. These findings are also cited by Nybo et al. (1998) and Seligman and Darling (1997). Nybo et al. (1998) reported that grandparents were prepared to assist their children's families and were instrumental in the family's adjustment. Seligman and Darling (1997) concurred with this view, but cautioned that grandparents may also represent a burden if they have not adequately dealt with their own feelings of guilt and mourning. Luterman (1999) advised the establishment of support groups for grandparents.

In summary, as has been reported in the literature, it was found that the parent-child

relationship and specifically, the communication between the parent and child, is crucial. Positive relationships with one's spouse and extended family, specifically grandparents, were also found to ease the transition, as has been previously noted. The relationship with siblings was observed to be generally negative in this study, but that may be because all the children were the youngest in their families. Hence, birth order may have a negative effect on the relationship between siblings, as has been noted by other researchers. Behaviour management was found to be different for the children with hearing loss for reasons based on communication difficulty and pity, as has been cited in earlier studies.

Research Question 3 - What elements of the auditory-verbal therapy model and workplace impede and/or facilitate this transition at the level of the mesosystem?

Auditory-Verbal Therapy Model

In this section, the elements of the auditory-verbal therapy model that will be considered are as follows: how parents choose the approach; their compliance with technology; their compliance with therapy in terms of the ways they carry it out and the frequency of its use; and the support provided by the hospital, the local education system, the local parent group, the community and the workplace.

Choice

Several investigators have advised that it is imperative that parents be well-informed about communication options before being required to choose one (Luterman, 1999; Steinberg & Bain, 2000). Despite this recommendation, it is very common for professionals to suggest to parents an intervention which they have seen to be beneficial for other families with whom they

have worked (Christiansen & Leigh, 2002). Although the parents and professionals in this study mentioned several options, it was the parents' perception that auditory-verbal therapy had been recommended. Five of the eight parents in this study indicated that it was their trust in the professionals' recommendations that led them to choose auditory-verbal therapy. This goal was associated with ease of function in the hearing world and with their wish for normalcy for their child with hearing loss, as well as for their other children, an aim previously reported by others (Gregory, 1995). Although most had had some exposure to Deaf culture either through neighbours or relatives, they all reported that they strongly desired that their child speak. In Ontario, statistics reported by the Infant Hearing Programme on February 25, 2004 indicated that as of December, 2003, 80 of 120 children receiving communication development, are enrolled in auditory-verbal therapy programmes (M. Bagatto, personal communication, August, 2004). One of the mothers in this study explained that while she felt auditory-verbal therapy was the best choice for her family, she was not sure whether it had been the best option for her child. She was the only parent who mentioned sign language on several occasions and also inquired whether there was an oral day school in the vicinity.

The participants in this study attended a centre where their child's hearing loss was detected, amplification provided and therapy administered until the age of 5 years, a setting unlike others that have been reported (Calderon et al., 1998; Estabrooks, 1998; Gregory, 1995; Hodges et al., 2000; Most & Zaidman-Zait, 2003; Robinshaw & Evans, 2001). The staff at this centre were characterized by one of the parents as "not just a bunch of professionals ... but like part of the extended family" (Jared, p. 36, l.17-19).

Although clinics that are housed in locations separate from early intervention centres and

educational settings, are more removed from the parents' decision-making, this logistical set-up is not wholly desirable according to parents (Most & Zaidman-Zait, 2003; Robinshaw & Evans, 2001) and professionals (Luterman, 1999). Testimonials (Estabrooks, 1998), as well as systematic investigations (Calderon et al., 1998; Elweke & Rodda, 2000) indicated that parents often feel confused and overwhelmed by the choices that confront them. It has been reported that parents are most satisfied with their decision-making process when they feel that they have received emotional support for their choice (Steinberg & Bain, 2000). While professionals at a comprehensive centre may be more involved in decision-making, they also can provide the much-needed emotional support recommended in the literature (Calderon & al., 1998). However, it is imperative that professionals at such a centre provide a diagnostic period of therapy during which the child's best learning mode is determined (Luterman, 1999; Rushmer, 1994).

It appears that the availability of auditory-verbal therapy at the hospital, the possibility for speech that it represented, in addition to the emotional support perceived by the participants seemed to influence the decision-making of these parents.

The parents in this study had to decide not only on a method of intervention, but also whether or not to seek a cochlear implant for their child. Kluwin and Stewart (2000) reported that parents' decision to seek a cochlear implant was motivated by three factors: a goal of normalcy, access to medical advice and the availability of insurance. Those whose first source of information was a medical professional who was part of a cochlear implant team were less likely to seek other sources (Kluwin & Stewart, 2000). Bat-Chava and Deignan (2002) indicated that the parents in their study were motivated by the wish for the broadest possible educational opportunities and a better life for their children. Most of the parents in this study relied on the

professionals with whom they had established a trusting relationship when the time came to make a decision about a cochlear implant. The goal of these parents was spoken language, and as the hearing aids were not providing enough amplification for their children to achieve that goal, the cochlear implant seemed to be the natural alternative. One parent reported that she viewed videotapes of children with cochlear implants and that helped her make her decision. She also recalled meeting another child who wore a cochlear implant and was speaking. All the parents reported that their children benefitted significantly more from the implant than they had from their hearing aids, as has been noted by Christiansen and Leigh (2002) and Kluwin and Stewart (2000).

Thus, the parents in this study chose auditory-verbal therapy because they wanted their children to be able to speak, and the professionals, with whom they consulted, recommended auditory-verbal therapy as a way of attaining that goal. This choice was facilitated by the availability of this option at the hospital. Moreover, pushed by poor results provided by hearing aids and pulled by proof that a cochlear implant could make a difference and the counsel of therapists, they opted for a cochlear implant with the hope of providing optimal hearing to their children and therefore the potential for spoken language.

Compliance with Technology

Susan and Evelyn reported that it had been difficult for them to keep the hearing aids on Peter and Allison because they constantly pulled them out. They surmised that this was because their hearing loss was so profound that the hearing aids provided little benefit. Gregory (1995) and Kashyap (1986) indicated that when the mothers in their studies did not view the hearing aid as helpful, they were less likely to encourage their child to wear it. These findings were refuted by

Christiansen and Leigh (2002), who indicated that although all their participating children used hearing aids prior to implantation, most parents indicated that they derived minimal or no benefit from these instruments. Kyla and Margaret indicated that compliance with the hearing aids had not been a problem. In Melanie's case, this may have been due to the fact that she had had some residual hearing prior to its deterioration and therefore derived benefit from amplification.

Christiansen and Leigh (2002) reported that approximately 76% of their respondents used their hearing aids all day every day, even when the hearing aids did not seem useful.

All parents reported that their children could hear better with the cochlear implant than with the hearing aids. This finding is corroborated by Archbold et al. (2002) who reported that the children in their study derived significant benefit from the implant. All the children in this study, except Allison, were reportedly happier since they received the implant. This finding is supported by other investigators (Beadle et al., 2000; Chmiel et al., 2000). Christiansen and Leigh (2002) indicated that about one quarter of the participants they interviewed reported improved confidence in social situations with the implant. Although Evelyn commented that Allison's speech and language had improved immensely since receiving the implant, she added that her daughter did not seem happier. She conjectured that perhaps Allison was not happier because she sensed that more demands for spoken language were being made of her. However, Christiansen and Leigh (2002) posited that some of the children in their study were self-conscious because of the visibility of the implant.

In summary, two of the parents reported that their children rejected the hearing aids, as had been noted previously. All concurred that the cochlear implant significantly facilitated their transition.

Compliance with Auditory-Verbal Therapy

Techniques of Auditory-Verbal Therapy.

Zach and Dave commented that the transition to auditory-verbal therapy entailed a change in the way they did things, not what they did. My observations seemed to corroborate this perception. Most parents modified the way they spoke to their children with hearing loss, employing auditory-verbal techniques that they had learned during their sessions at the hospital. Some of the techniques included: repetition; a slower rate of speech; highlighting, which involved placing emphasis on a key word in the sentence; using a varied intonation pattern when speaking to the child; moving closer to the child to enable him/her to hear better; standing behind or beside the child to discourage lipreading and encourage listening; interpreting the child's utterances and expanding them, that is when the child refers to an object with a sound or word, the parent acknowledges this by repeating the child's utterance and adding a word or two to it; and following the child's lead in terms of interests. The aforementioned techniques are very useful for developing the child's understanding of language (Kurzer-White, 1999). Yet there have been no previous studies that have documented the use of auditory-verbal techniques in a naturalistic setting. Although it is important to encourage the child's use of spoken language, techniques used to develop this function were less evident during the observations. Only on a few occasions were parents observed to ask the child to imitate an expanded phrase, thereby encouraging expressive language development. The discrepancy between parents' reinforcement of understanding and use of language has not been reported before and merits further study.

Barriers- Hospital

(1) Second Language.

Most parents reported that the transition to auditory-verbal therapy required changes in their way of talking. They mentioned slowing down their rate of speech and repeating more. Melanie's family chose to speak English rather than using both English and French with the children. Shelley's family decided to speak English to the children, rather than encouraging the use of their native language, Tamil. This choice of English rather than use of the native language has been reported by Luterman (1999) and in testimonials (Estabrooks, 1998).

(2) Time.

Although they did not specify the amount of time, all the parents in this study indicated that implementation of auditory-verbal therapy is time-consuming and a lot of work. This is similar to the conclusions of Quittner (1991) who also stated that parents of children with hearing loss reported that therapy is very time-consuming and contributes to stress. Christiansen and Leigh (2002) supported this finding based on their interviews with parents who used a variety of communication methods with their children. Most parents remarked that it was difficult for them to implement the therapy, and in two cases they expressed guilt about their perceived lack of compliance, similar to reports by Durieux-Smith et al. (2001).

(3) Formal vs. Informal Therapy.

Formal auditory-verbal therapy conducted at home resembles the sessions at the hospital. The child and parent are seated at a table and the parent organizes toys that reinforce objectives assigned by the therapist. The duration of such sessions varies according to the attention span of the child. These sessions are in contrast to informal therapy which consists of the reinforcement

of language in a variety of contexts throughout the child's waking hours. While Susan, Evelyn and Kyla differentiated between formal and informal techniques, most of the other parents felt they should be doing formal lessons similar to the ones they experienced at the hospital with their auditory-verbal therapist. They deemed the informal interactions with their child as inadequate. This finding was also observed by Gregory (1995).

Evelyn and Kyla commented that the techniques were not difficult, but Evelyn felt that Allison's uncooperative behaviour prevented her from doing formal lessons. Quittner (1991) observed that behaviour problems during language lessons were ranked highly as sources of stress by mothers of children with hearing loss. She did not specify whether they were referring to lessons at home or at the clinic. Evelyn added that Allison seemed to enjoy informal play with her mother, but she was too busy with housework and caring for her other children to play with Allison, a finding also cited by Gregory (1995).

Three of the parents indicated that the techniques had become part of their lifestyle and Kyla added that the use of the techniques had become so habitual that she found herself using them with young children who did not have hearing loss, when they did not seem to understand her. Evelyn, Susan and Margaret suggested that the provision of structured materials based on the language targets would have facilitated their transition. Although these techniques are well-known to practitioners of auditory-verbal therapy and have been described anecdotally, their use by parents has not been documented in a systematic way until now.

(4) Slow Progress.

Most parents expressed concern about the slow progress with auditory-verbal therapy initially, although Margaret commented that the longer she did it the more encouraged she felt.

This finding has also been noted by Lloyd (1994). Most also stated that they would like to know how their child is progressing compared to others at the same stage, in order to know whether they are “on track”. Luterman (1999) indicated that one of the advantages of the parent groups offered by his centre is that parents have the opportunity to observe their child interacting with nursery staff and to compare their child’s progress with that of others.

Christiansen and Leigh (2002) reported that the children in their study, who experienced a variety of interventions, also exhibited slow progress. They specified that although the progress of each child was dependent on a multitude of factors, such as age at implant, presence of speech and auditory therapy, years of implantation, and amount of time the implant is worn, generally at least one or two years of implant use were required before the child was able to communicate with family and close friends. This seems to correspond to the “breakthrough phase”, described by Perold (2001).

(5) Transportation.

For Nancy, transportation to the therapy sessions at the hospital presented a significant hardship. Simone, her auditory-verbal therapist, attempted to overcome this barrier by occasionally doing home visits. Home-visiting is common in other centres (Gregory, 1995). Difficulty with transportation, particularly in inner-city settings, has been reported by other researchers (Freeman et al., 2002).

(6) Cost.

Zach and Susan were the only parents in this study who mentioned the high cost of doing therapy. As they had chosen to hire a nanny to implement auditory-verbal therapy, this proved to be very expensive for them. In addition, expertise was cited as a barrier by them because they had

found it difficult to locate a nanny who would be interested in carrying out auditory-verbal therapy with their son, Peter. Christiansen and Leigh (2002) also mentioned the costs associated with educating a child who has a cochlear implant, including the equipment costs as well as the cost of the mother leaving the work force to stay home and teach the child.

(7) Related Services.

Two parents stated that they had had to wait a long time for psychological assessments after the initial pre-implant evaluation. One of these evaluations had been requested for the sibling of a child with an implant and the other had been recommended as follow-up for a child with an implant. Pre-operative assessments have been described previously (Durieux-Smith, Angus, et al., 2000; Filipo, Bosco, Barchetta & Mancini, 1999).

Facilitators- Hospital

(1) Support from Auditory-Verbal Therapist.

All the parents were quite effusive in their praise of the service they received from their auditory-verbal therapist. Beadle et al. (2000) noted that when parents perceived high social support from formal sources such as the cochlear implant team and educators, their quality of life was better and there was lower parental stress. In previous research, Robinshaw and Evans (2001) noted that in centres that met best practice criteria, parents reported satisfactory relationships with professionals. These parents indicated that they were involved in the programmes of care for their children, were committed to carrying out targets that they had helped to develop and felt empowered. Desjardin (2003) noted that more empowered parents are also more involved. Duquette et al. (2002) observed that because of the positive experiences their participants had had they felt better able to advocate for their children throughout their school years. Turnbull et al.

(2000) concluded that when there is reciprocal appreciation between parents and professionals, a synergy occurs that results in enhanced capacity for all participants.

(2) Support from Audiologist.

The parents in this study lauded the audiology services at the hospital as well. Only one parent indicated that she felt there could be more audiologists. Zach indicated that they would have moved if the services at the hospital were not considered excellent. In the case of Allison's and Melanie's families, they did move to obtain better service.

These findings are supported by Robinshaw and Evans (2001) who found that parents were willing to travel great distances and endure inconvenience to access service that would benefit their child. The parents in their study preferred access to a facility where there was close liaison between professionals of different disciplines including an audiologist, Ear, Nose and Throat physician, therapist and hearing aid dealer. They also sought coordinated appointments at a shared location and prompt response to parental concerns from the various disciplines involved. The participants in this study had access to such a shared facility and Sarah indicated that the close liaison between therapist and audiologist facilitated the management of Melanie's progressive hearing loss. Archbold et al. (2002) and Most and Zaidman-Zait (2003) also reported that their participants favoured collaboration between the medical implant centre and the educational centre and indicated that cooperation amongst varied professionals would benefit them. Archbold et al. (2002) added that continuing support from the implant centre particularly for the management of technical difficulties is recommended.

(3) Support from the Ear, Nose and Throat Surgeon.

Three parents remarked on their appreciation of the accessibility they had to the surgeon.

One of them recalled words of encouragement regarding benchmarks of language progress, specifically that she would notice marked improvement after her daughter had been wearing the cochlear implant for 18 months. Zach reported that his access to the surgeon to discuss his research about the treatment of meningitis was very beneficial. Several parents remembered encouraging words spoken to them at the beginning of their journeys several years previously. It appears that the events and feelings surrounding parents initially may contribute to their sense of well-being at later phases. Most and Zaidman-Zait (2003) also indicated that the surgeon is one of three professionals favoured by parents to provide information. The others included the audiologist and the speech therapist.

Barriers- Local Education System

(1) Lack of Itinerant Teachers - Private Sector.

Susan lamented the fact that there were no itinerant teachers of the hearing impaired in the private school system, as she felt that limited her choice. Sarah concurred with this opinion. Christiansen and Leigh (2002) mentioned the presence of therapy offered either privately or by the implant centre for students who are enrolled in private preschools, but did not comment on services for school-aged children. Rubin (personal communication, May, 2004) noted that there are speech therapy services offered to children in private schools in New Brunswick, Canada. Nicholas and Geers (2003) reported that parent ratings of their child's adjustment seemed better for children enrolled in private as opposed to public schools. Clearly, there is a need to examine this issue further.

(2) Lack of Self-Contained Oral Class.

The lack of this option was considered a barrier by Evelyn. Indeed, in the literature the

presence of such an option has been frequently mentioned (Calderon & Greenberg, 1999; Gregory, 1995)

Facilitators- Local Education System

(1) Itinerant Teacher Support.

Four of the children were enrolled in inclusive school settings and all the families were very satisfied with the service they were receiving from their itinerant teacher of the hearing impaired. This finding is supported by Durieux-Smith et al., (2001) who described the seamless transition between preschool and school age services. Contrary to this finding, Calderon et al. (1998) lamented the fact that often in the United States children “graduate” from early intervention programmes at the age of 3 years and must attend public school systems that do not always offer the support that is still needed by parents. They suggested that research that examines service delivery models and efficacy outcomes is required.

(2) Educational Assistants.

Two children benefitted from the service of educational assistants, as has been previously reported by Christiansen and Leigh (2002).

Barriers- Local Chapter of Voice

While most parents in this study had attended at least one meeting of the local chapter of Voice, some of them felt that it did not meet their needs. Gregory (1995) cited some examples of parents who did not wish to meet others in the same situation, however this is unusual. One parent recommended that a buddy system should be established for newly identified families, a recommendation made by Durieux-Smith et al. (2001). The same parent suggested that Voice should be more knowledgeable about services in western Quebec, where some of their members

reside.

Facilitators- Local Chapter of Voice

All the parents who had attended meetings where other children were present indicated that this had been very encouraging for them. Kyla and Jared added that it was beneficial for Sally to meet other children who have siblings with cochlear implants. Nancy, who was the only parent who had not attended a Voice meeting, did benefit from the service of a tutor whose daughter had a cochlear implant and who was a member of Voice. Luterman (1999) suggested that parent tutors can be very beneficial. Although it has been noted in the literature on children with disabilities that some parents do not want to be pressured into attending parent groups (Krauss et al. 1993), the research on children with hearing loss tends to be in favour of parent groups (Dromi & Ingber, 1999; Feigin & Peled, 2000; Koester & Meadow-Orlans, 1990; Most and Zaidman-Zait, 2003; Robinshaw & Evans, 2001). The camp, funded by Voice for one month during the summer, was mentioned by the six parents whose children attended. Their one suggestion was that it take place on an all-day basis, rather than just for one or two hours each week. No references to such a summer programme were found in the literature. Durieux-Smith et al. (2001) observed that the parents in their study deemed the interaction with other parents through Voice was essential. It should be noted that their study was a retrospective one in which parents whose children were preschoolers in the 1970's and 1980's participated. Clearly, Voice has a role to play in facilitating interaction among parents and in providing tutorial and teaching opportunities for children. It may be that due to changing demographics this organization must re-examine its methods for recruiting members.

Barriers - Local Community Resources

Simone indicated that Diane's exposure to Arabic for most of the day was a barrier to her developing English. However, Nancy thought that this arrangement facilitated her transition because of its convenience. References to the need to speak one language to a child with hearing impairment have been found in books by Estabrooks (1998) and Luterman (1999).

Facilitators- Local Community Resources

The following services offered by the community facilitated the transition according to parents in this study: tutors, who provided speech and language stimulation in the home under the supervision of an auditory-verbal therapist for a minimum of three hours each week; infant development workers, who visited the home and supported the child in the areas of language and fine and gross motor development; and special integration support workers, who consulted with preschool teachers regarding classroom accommodations that could be made for the child. In addition, Well Baby clinics and on-line contacts with other parents of children with cochlear implants were found to be helpful.

Although this study has noted considerable community resources, Cebe (1996) found that the parents in her study lacked community support. Yet, Seligman and Darling (1997) indicated that access to community resources such as financial assistance and respite care can help immeasurably in the parents' normalization process.

Barriers - Workplace

Barriers to the transition included inflexible employers and the lack of babysitters who would care for children with special needs. Difficulty finding babysitters has been reported by parents of children with chronic illness (Martin, Brady & Kotarba, 1992).

Facilitators - Workplace

In most cases, however, employers were very receptive to participants who needed to adapt their schedules due to attendance at therapy. McNeil and Chabassol (1984) reported that the fathers in their Canadian study were all able to make arrangements to attend appointments with their children when necessary.

In summary, most parents used some auditory-verbal techniques with their children in the course of their day. Interestingly, some of them felt that doing auditory-verbal therapy meant primarily formal lessons. They did not perceive the use of informal techniques as effective.

As described in other studies, most parents felt that the time commitment and the initial slow progress were barriers to the implementation of auditory-verbal therapy. Cost, transportation and delayed access to psychological services for siblings were also mentioned as challenges. Facilitators of the transition included the support of the auditory-verbal therapist, the audiologist and the surgeon.

Obstacles presented by the local education system included the lack of itinerant teachers in private schools. The presence of itinerant teachers of the hearing impaired in public schools facilitated the transition. Although the parents felt that the local chapter of Voice targeted the school-aged population more than the preschool population, they did acknowledge the summer camp and meeting other children with cochlear implants as facilitating features of Voice.

Several resources in the community facilitated the transition for these parents: tutors, infant development and integration support workers, Well Baby clinics and cochlear implant companies. When there was a delay in access to these services, parents perceived this as a barrier. The need for greater parental access to community resources has been previously mentioned in

the literature.

Research Question 4 - What elements of the public policies impede and/or facilitate this transition at the level of the exosystem ?

In this section, the barriers and facilitators presented by the policies of the Ministries of Health, Education and Community and Social Services will be discussed.

Barriers - Provincial Health

Melanie's and Allison's families moved to the province of Ontario in order to access the auditory-verbal therapy services. Although both had received audiology services from the hospital because of an interprovincial agreement, the therapy services would not have been available on a regular basis and therefore these families decided to move. Robinshaw and Evans (2001) and Christiansen and Leigh (2002) also found that parents will move in order to obtain services that they feel are beneficial for their children. Melanie had a limited choice of hearing aids in Quebec, a finding that has been reported by Gregory (1995) in England where the National Health Service also limited the types of hearing aids that children could receive.

Facilitators - Provincial Health

All the parents indicated that they were very grateful that the Ontario Ministry of Health funded cochlear implants. This finding is dissimilar to that noted in previous studies of different health systems which have indicated that the high cost of implantation may discourage some families from considering one (Meadow-Orlans, Mertens & Sass-Lehrer, 2003). Christiansen and Leigh (2002) found that one out of every five or six families they interviewed reported that they had significant difficulty obtaining full coverage for the surgery and device, a sum of

approximately \$40,000 (US). This can have devastating consequences on a family as a father who must work longer hours to pay for equipment can become alienated from his family (Allegretti, 2002). Francis, Koch, Wyatt and Niparko (1999) found however, that children with cochlear implants were more likely to enter regular school and require less special education support, representing a savings of \$30,000 to \$200,000 (U.S.) per pupil over the course of the years from Kindergarten to Grade 12. In a Canadian pilot study, Durieux-Smith, Angus et al. (2000) found that post-implant follow-up over a three year period, including audiological assessment and therapy would cost \$56,241.44 per child. These medical costs are covered by the health care system. The authors suggested that increased integration of children with cochlear implants and reduced need for support services in the schools would offset the medical costs of implantation.

All the participants acknowledged the provincial funding provided for therapy, which is estimated to be \$20,000 (U.S.) per year (Marschark et al, 2002). In a previous study, Christiansen and Leigh (2002) reported that less than half of the families they interviewed in the United States received full coverage of programming and therapy costs. They also found that those parents in their study whose children received auditory-verbal therapy services often had to pay for it themselves.

Barriers - Provincial Education

In western Quebec, itinerant teachers of the hearing impaired do not provide service to children with hearing loss in the school system, and in Ontario these specialists are not present in the private school system. These barriers, cited by parents in this study, have not been previously cited in the literature. The fact that children with hearing loss are placed in large classes was considered a barrier by one of the parents in this study and was similar to a finding noted by

Christiansen and Leigh (2002). There is no provincial legislation in place in Ontario that mandates reduced class size, but there is an obligation on the part of the school and the school board to accommodate a student acoustically and with support (personal communication, N. McIntyre, July, 2004).

Facilitators - Provincial Education

The three families whose children attended school lauded the service of the itinerant teachers of the hearing impaired, the provision of FM systems, as well as the support of educational assistants. Funding for all these services is provided by the Ministry of Education, a finding noted by Durieux-Smith et al. (2001) but refuted by other research (Konstantareas & Lampropoulou, 1995) and in testimonials by parents (Estabrooks, 1998). Evelyn felt that the Identification, Placement, Review Committee (IPRC) process (see Appendix H for details of this process) in which she was involved, facilitated the delivery of essential services for her daughter. The availability of the aforementioned services in schools is also cited by others (Durieux-Smith et al., 2001; Estabrooks, 1998).

Barriers - Provincial Responsibility for Community Resources

The only barrier cited by the parents was the delay in accessing these services earlier in the process, a finding that has not been reported before. In Margaret's case, the family's move to this province after the detection meant that she had to research resources. Evelyn too regretted that she had not been informed earlier about community resources, although she did benefit from Well Baby Clinics, as well as Multiple Births Canada, a finding that has not been reported previously.

Facilitators - Provincial Responsibility for Community Resources

Four of the children received service from a tutor who was funded by the Ministry of Community and Social Services (see Appendix I for details of this programme). All the parents extolled the virtues of this programme. In addition, three of the children had received service from Infant Development and two had had an Integration Support Worker visit their preschool. The availability of community resources was found to be invaluable by the parents in this study, but these resources are not available in other contexts (Freeman et al., 2002). Seligman and Darling (1997) indicated that regardless of the nature of the disability or the parents' coping ability, supportive community resources are essential for families to be able to normalize.

Barriers - Provincial Voice

Most parents seemed unaware of the role of the provincial organization of Voice.

Facilitators- Provincial Voice

One parent mentioned that he read the provincial newsletter and found it informative. Durieux-Smith et al. (2001) indicated that Voice played a strong role in supporting parents.

In summary, the provincial Ministry of Health facilitated the transition by providing surgical, audiological and therapy services, a finding that is not supported in the literature. As has been reported in previous literature, the Ministry of Education facilitated the transition by providing funding for teachers of the hearing impaired, educational assistants, FM technology and the Identification, Placement and Review Committee (IPRC). The Ministry of Community and Social Services facilitated the transition by providing funding for tutors, infant development and integration support workers. These findings have not been reported until now. The provincial chapter of Voice did not seem to impact on these parents, a finding that is contrary to that of a

previous study.

Research Question 5 - What elements of the culture and belief system about hearing loss impede and/or facilitate this transition at the level of the macrosystem?

Barriers - Economy

The only barrier cited by two fathers was the poor state of the economy which prevented one of them in the high tech sector from attending therapy as often as he might have liked. The other was concerned that he might have to support his child longer than he might have envisaged and therefore, because of the economic recession, he would have to work longer before retiring than he had planned. These findings are supported by Bronfenbrenner (1995) who indicated, in a revised version of his model, that an individual's developmental life course is influenced by the historical events and circumstances during which he/she lives. Martin et al. (1992) also noted that the vagaries of economics and societal currents can be challenges to families of children with chronic illness, although they remain secondary to the life and death issues these children face daily.

Facilitators - Accessibility

(1) Accessibility of the Cochlear Implant.

In Ontario, cochlear implant programmes have received funding from the Ministry of Health since 1993 (Durieux-Smith, Angus et al., 2000). All the parents were very grateful for their access to the cochlear implant to which two of them referred as a miracle. Both Nancy and Kyla indicated that their daughters would not have had implants in their native countries. Susan considered the availability of the implant to Peter after his meningitis as a facilitator, however

both she and Zach felt the process could have been faster. This universal access is not reported in previous literature. (Meadow-Orlans et al., 2003).

(2) Accessibility of Role Models.

All parents were very encouraged when they met other children who spoke and wore cochlear implants. Access to these children in the waiting room at the hospital and at Voice meetings was considered a facilitator by all. This finding has been observed by other investigators (Christiansen & Leigh, 2002).

(3) Accessibility of Auditory-Verbal Therapy.

The prevalence of auditory-verbal therapy services in this area clearly facilitated the transition of these parents and motivated two families to relocate to access what they considered to be ideal services for their child. Auditory-verbal therapy is usually obtained privately in the United States (Christiansen and Leigh, 2002). Robinshaw and Evans (2001) noted that there were three centres in England that offered such service, which was paid for by their National Health service.

(4) Awareness of Deaf Culture.

All parents were aware of the Deaf culture but felt they wanted to give their children the opportunity to learn to speak. One of them mentioned that if his daughter wanted to learn to sign later that was fine with him. This finding has been previously reported by Christiansen and Leigh (2002).

Facilitators - Inclusion

(1) Inclusion in Neighbourhood Schools.

All the parents were very pleased that local schools enrolled their children and

encouraged the acceptance of their hearing peers. Christiansen and Leigh (2002) reported that a little more than half of the approximately 40 children in their study who were past preschool age, were in inclusive public or private settings, all or almost all of the time. Only one parent in this study questioned whether a self-contained oral class would have been a better option for her daughter. Other authors cite the availability of self-contained classes that offer a variety of approaches for teaching speech and language (Calderon & Greenberg, 1999; Estabrooks, 1998; Gregory, 1995).

(2) Potential for Normalcy.

All parents mentioned their desire for normalcy for their children and their families. This finding is supported by Meadow-Orlans et al (2003). Associated with this was their feeling that their children were not aware that they were different and thus felt no sense of stigma. This finding may be more applicable for younger children than adolescents (Capelli, Daniels, Durieux-Smith, McGrath, & Neuss, 1995; Meadow-Orlans et al., 2003).

In summary, the only barrier cited by two fathers at the level of the macrosystem was the unstable economy. The facilitators included access to technology, therapy and speaking role models, as well as the inclusive nature of the education system and the society in which they lived.

Current Perceptions of the Transition

When asked how they are feeling about the transition at this point, most parents indicated that they are pleased with their child's progress and are hopeful about the future. Dave and Evelyn continued to worry about Allison's progress, and Susan wondered whether Peter was at the level that he should be. Evelyn remarked that the grief over the hearing loss will always be

with her, but that she is relieved the twins do not have additional problems. Luterman (1999) indicated that grief is the recognition that one must adopt a new identity and coping is the process of assuming that new identity. Dave added that he had not thought Allison would be able to hear and talk when they were first told about the hearing loss, and he was grateful that she was now able to do both. Dave, Zach and Jared commented that they did not consider the experience (meaning the transition to auditory-verbal therapy) to be a negative one. Jared was proud of the way he and Kyla handled the transition and added that he thought life was “pretty normal” now. Luterman (1999) described integration or acceptance as that time when a parent realizes that “‘beating’ deafness is not a matter of reaching normalcy, but rather of living life more fully and authentically with the hearing impairment” (p. 205). In short, the parents have come to reframe their experience. They have discovered “a new version of normal” (Atkins, 1987, p. 33). Luterman (1999) suggested that we give meaning to our lives and that “events that happen to us are mediated by our perceptions of them” (p. 209).

In summary, this chapter answered the five research questions by situating the findings in the context of pertinent literature. This is the first time qualitative methodology has been applied to auditory-verbal therapy. It is also the first time Bronfenbrenner’s model has been used as a theoretical framework for examining auditory-verbal therapy. Many of the findings lend support to previous results obtained with quantitative research designs that examined various other therapeutic interventions. Following are the findings that have not been reported in previous literature conducted using quantitative measures with diverse communication approaches. These are: the new role of administrator and equipment manager adopted primarily by mothers; the significance of parental and child personality traits in implementing auditory-verbal therapy; the

techniques used by parents as they adopt auditory-verbal therapy and the discrepancy between their ability to encourage the child's understanding and use of language; the pivotal role played by a centre-based delivery of service model; the importance of funding from the Ministries of Health, Education and Community and Social Services; and the essential roles played by accessibility to technology, therapy, speaking role models, as well as inclusion.

CHAPTER SIX - CONCLUSIONS, IMPLICATIONS AND EPILOGUE

In referring to Bronfenbrenner's theory of the ecology of human development, Konstantareas and Lampropoulou (1995) indicated that "we cannot understand a family's adaptation to a child who is deaf unless these broader social structures (referring to the four nested levels) and institutions are taken into account as well" (p. 265). In considering the variable outcomes obtained with children who are hearing impaired, Calderon and Naidu (2000) concluded "that it is not deafness per se that inevitably leads to poor academic and social outcomes but rather an interaction between the child and his or her family and educational environment" (p. 54).

Bronfenbrenner's theory has been useful in exploring the multiple variables that are involved when a family embarks on intervention with a child who wears a cochlear implant. The findings of this study are similar to those of others who have employed this model with children who have delayed development (Champion, 1983; Mitchell, 1983). Both these investigators found the model useful in examining multiple variables within each environmental level. Champion (1983) found that the network of supports and services at the more distal levels strengthened the primary caregiver's role at the microsystem level. Although the studies by Konstantareas and Lampropoulou (1995) and Lampropoulou and Konstantareas (1998) also used Bronfenbrenner's model to study a group of parents of children with hearing loss, they limited their study to one dimension, that of stress. Their observation regarding the barriers that exist in Greece at the level of the exosystem and macrosystem are in sharp contrast to the findings of the present study.

Seligman and Darling (1997) noted that parents' ability to achieve a normalized lifestyle may depend less on the severity of a child's disability and the coping skills of parents and more on the "opportunity structures" or resources, available to them. This section will describe a model of the findings obtained in this study (see Figure 6) which demonstrate the appropriateness of Bronfenbrenner's theory for answering the research questions.

Model of Factors Facilitating the Transition to Auditory-Verbal Therapy

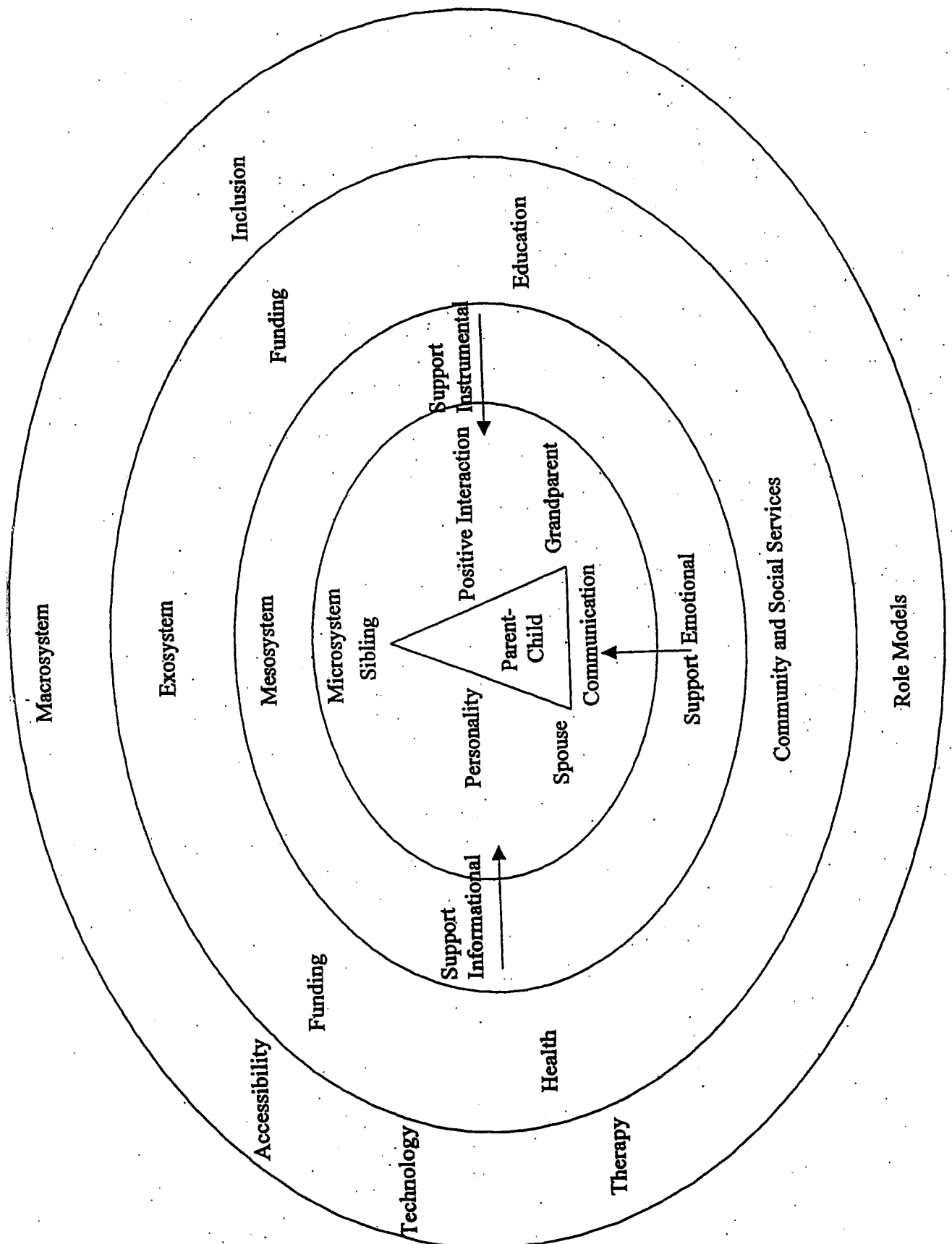
Microsystem

When the personalities of the child and parents are compatible and there is a "good fit" between them, this facilitates the transition. Birth order and adequate spacing between the siblings may assist the transition. Positive relationships between the spouses, the siblings and the extended family, principally the grandparents, also appear to enhance the transition.

Mesosystem

The availability of an interdisciplinary team, in one location, is a facilitating condition. An informative, encouraging, empathic manner at the time of initial diagnosis is appreciated and remembered by parents. An appropriate blend of informal and formal therapy techniques that foster both understanding and use of language is another facilitator. Professional-parent relationships, including those with the auditory-verbal therapist, the audiologist, the surgeon, the psychologist and social worker are crucial. It is essential that these professionals provide emotional, informational and utilitarian/instrumental (resource) support. One-on-one parent interaction, in addition to group meetings assist in the transition.

Figure 6- A Model of Factors Facilitating the Ecological Transition to Auditory-Verbal Therapy at the Preschool Level



Exosystem

Utilitarian support in the form of funding of technology, audiology and therapy services supports a smooth transition, as does access to community resources.

Macrosystem

A culture and belief system, that favours access to technology, therapy and speaking role models, as well as inclusion in regular classrooms and community activities, facilitates the transition.

Theoretical Contributions of the Study

The findings of this study contribute to theory in several ways. The research contributions will be outlined in relation to the theoretical model.

This study was guided by Turnbull and Turnbull's family systems theory (1990, 1997) and by Bronfenbrenner's theory of the ecology of human development (1979, 1995). Turnbull and Turnbull consider that a change in one member of the family system has consequences for the interactions and functions of all the members. Bronfenbrenner's model addresses the reciprocal relationship between the individual and her environment in the presence of an ecological transition. His taxonomy includes four nested levels: the microsystem, which is the most proximal to the individual, the mesosystem, the exosystem and the macrosystem, which is the most distal from the individual.

Bronfenbrenner (1995) himself has stated that his theory has been accused of emphasizing laboratory settings at the expense of more naturalistic settings. Thus, this study extends his model by using a methodology anchored in naturalistic settings. In fact, McMillan (1990) remarked that qualitative approaches may provide more ecologically valid data. This is the first time that this

model has been used to study the transition to auditory-verbal therapy. It is also the first time that the process of auditory-verbal therapy has been studied using a theoretical framework. It has the advantage of regarding this process from both mothers' and fathers' viewpoints and is well-timed, as it is early enough that families can recall the diagnostic period and late enough that they have some perspective on the events and their feelings at that time. From a Canadian perspective, it is also the first to provide recommendations for those practicing auditory-verbal therapy.

Using this model, it has been found that mothers adopt new roles as administrators and equipment managers. This may be related to the provision of funding from the Ministries of Health and Community and Social Services who offer resources for tutors and developmental workers. The significance of parent and child personalities in implementing auditory-verbal therapy is an important contribution of this study, as is the manner in which parents carry out this intervention approach. The utilitarian support offered by the provincial Ministries has been shown to be pivotal to the transition of these parents. The accessibility of technology, therapy and role models and inclusion in mainstream settings has also facilitated their adoption of this approach.

Practical Contributions of the Study

At the microsystem level, this investigation has provided some reasons for behaviour management problems arising from communication difficulties and feelings of pity. At the mesosystem level, findings include the lack of understanding of the difference between formal and informal therapy, a need for more structured materials and the difficulty parents experience in encouraging expressive language, as opposed to receptive language. It has indicated the importance of community resources. At the exosystem level, the critical role of funding of

services was demonstrated. At the macrosystem level, the importance of accessibility to technology, therapy and speaking role models was emphasized.

One outcome of the transition that was not included in the theoretical model but emerged from the findings and contributes to theory and practice, is that of personal growth. Most parents commented that the transition had changed them in a positive way. Margaret, Kyla and Susan felt that it was a learning experience. Margaret indicated that she had learned about parenting, specifically parenting a child with hearing loss. Kyla referred to the knowledge about hearing impairment and technology that she had gained. Susan commented that she had learned about communication and language development and that knowledge would have been useful with her other children. Evelyn and Jared both stated that they felt they had matured. Jared added that his spirituality had helped him deal successfully with this unanticipated life event and that he felt strengthened by it and better able to cope with future adversity. He also felt that he spends more time with his family than he had previously. Dave stated that his patience had increased and Nancy described herself as more independent. This finding supports that of Morgan-Redshaw et al. (1990) whose participating mothers of adolescents also reported personal growth in their ability to make decisions and assume a variety of roles. One mother in their study commented that she had been stretched emotionally, physically, spiritually and intellectually. Seligman and Darling (1997) also commented on the increase in personal growth as a result of having a child with disabilities.

Study Limitations

Although qualitative research is considered to be a valuable means to investigate parents' experiences with children who have disabilities and case study methodology in particular enables the researcher to understand perceptions through the lens of the participants, this research design does have limitations. The narratives are my interpretation of the information provided to me by the participants, and therefore I used my own past experiences as a frame of reference for this interpretation.

In addition, the interactions I experienced with the participants reflect a snapshot of their thoughts about events that occurred in their lives at a specific point in time. As our lives are dynamic, our perceptions of reality may change. Thus, the parents may have new insights regarding the research questions. In an attempt to provide an opportunity to the participants to have a "final say", an epilogue is presented at the end of this chapter.

Although this study involved observations which provided direct information about the microsystem, knowledge of the mesosystem, exosystem and macrosystem came from interviews, not from multiple settings. Interviews also provided data concerning the microsystem. This may explain why the data at the microsystem level are more detailed than that at the other levels.

Interviews with Peter's nanny and with the itinerant teachers of the hearing impaired may have provided more information about the mesosystem. It was decided not to include these as I wanted the sources of information for each family to be equitable. This may be an area to explore in future research.

Despite these limitations, the findings of this multiple case study should provide information that will be useful to other parents of children with hearing loss and to the

professionals who practice auditory-verbal therapy with them and their children.

Future Research

Although Bronfenbrenner's theory of the ecology of human development (1979, 1995) has been employed widely, it has not before been used to guide a study of parents who have chosen auditory-verbal therapy to develop the communication skills of their children with hearing loss. Therefore, there are several implications for further research.

It has been observed that at the level of the microsystem there are more barriers than facilitators for some families (Table 4) than for others. It is important to understand the factors contributing to this disparity and how the facilitators can be more equitably distributed.

Several researchers (Most and Zaidman-Zait, 2003; Robinshaw and Evans, 2001) in other countries have observed that it is desirable to deliver service to the families of children with hearing loss in one location which features a team of professionals whose specialty relates to hearing impairment. This finding was supported by this study, whose participants lauded the model of service delivery provided by one hospital. As there are in Ontario several models of service delivery, it would be interesting to investigate the experiences of parents enrolled in these different models in order to determine their satisfaction.

The personalities of both parent and child have been seen to affect the transition to auditory-verbal therapy and may affect parents' perceptions of this transition. Further investigation of this relationship is warranted.

Robinshaw and Evans (2001) noted that there were significant gaps perceived by parents in information provision. It would be important to know whether the parents in this jurisdiction experience the same lacunae and ascertain whether the timing of information provision is

satisfactory to parents.

Mitchell (1983) investigated the perceptions of parents regarding their children with Down syndrome across the life span. The present study could be replicated with the parents of school-aged children and adolescents, as well as young adults with hearing loss, and thus follow their development across the life span.

Parents in this study seemed very concerned about their child's progress and this was also cited as a concern by Christiansen and Leigh (2002). It would be interesting to investigate further the concept of a "breakthrough phase", as described by Perold (2001), from a Canadian perspective. Specifically the following questions could be addressed: When does such a phase occur? What are the characteristics of this phase? What supports need to be put in place until such a phase is attained? What supports are required after such a phase has been reached?

Two of the families in this study were not originally from Canada. It would be interesting to do a follow-up study with other families of varying ethnic groups to determine whether their perceptions of the transition are similar. As the clinical population includes more and more diverse groups, such information would have theoretical as well as clinical applications.

This study has not addressed the transition that parents with hearing loss must make when their children are detected with hearing impairment. It behooves the professional community to investigate this topic.

Bodner-Johnson (2001) suggested the application of adult learning theory to parents of children with hearing loss. It would be interesting to apply this theory to parents who have chosen auditory-verbal therapy.

In this study, it was observed that a feeling of social isolation was common among

participants. While this has been noted previously by other investigators, findings have been inconclusive. It would be interesting to conduct further inquiry in this area.

This study raised issues from the perspective of parents who chose auditory-verbal therapy as the form of intervention with their children who wear cochlear implants. A study that examines this transition from the perspective of parents who have chosen another form of intervention is warranted.

Summary and Recommendations for Practice

In this section, I will review research findings as they relate to the theoretical model and include recommendations for practice. Although funding would be required to implement most of these recommendations, they will be made without considering financial limitations.

Microsystem

The parent-child relationship seemed to be crucial to the transition to auditory-verbal therapy. Compatible personalities appeared to be an essential feature of a positive relationship. It appears that the support of a psychologist for those families where this relationship is difficult would facilitate the transition. Karp (2004) indicated that favourable outcomes can be attained with intervention. Another area that emerged as pivotal to the transition is the issue of behaviour management. This seemed to be confounded by the parents' feelings of pity for their child, their insecurity with how much the child's lack of comprehension is the source of behavioural problems, as well as their feelings of grief.

This research and other studies have demonstrated that fathers' support is important to the mother-infant relationship (Meadow-Orlans and Steinberg, 1993) and that fathers' needs are different with regard to their children with hearing loss. Support for fathers in the form of groups

or individual counselling would address this issue.

Siblings of children with special needs often feel isolated (Seligman and Darling, 1997) and may feel resentful of the time that their parents must allot to their sibling with hearing loss. Support for siblings would be beneficial.

Grandparents have been observed to be instrumental in providing support to grieving parents, however their own mourning must be acknowledged (Nybo et al., 1998). Support for grandparents would be useful.

Recommendation 1- The pre and post-implant meeting with a mental health professional (either a psychologist or social worker) should address the issue of personality, and counseling should be available to those whom the mental health professional, the parents and the auditory-verbal therapist feel would benefit from such intervention.

Recommendation 2- The mental health professional should hold additional meetings with the parents during the first and second years post-implant and, in consultation with the therapist and the parents, determine whether counseling regarding behaviour management and grief would be beneficial for the family.

Recommendation 3- A social worker, in combination with a parent, should hold a group meeting for fathers on a regular basis.

Recommendation 4- A group for siblings should be organized by the social worker.

Recommendation 5- A group for grandparents should be organized by the social worker.

Mesosystem

As some parents in this study indicated that there was a delay in their access to resources and as the therapists were not always aware of the family support available to the children and parents to whom they provide service, it seems that a parent needs survey or family resource inventory would be an asset. Such documentation would assess the families' strengths and needs and mobilize resources already present in the family's personal network as well as resources available through the community to help meet their needs (Dunst et al., 1994).

Some parents remarked on the difficulty they experienced in creating their own materials to do therapy at home and in determining how to use the toys they own. They requested that structured materials be provided by the therapist with specific suggestions for their use.

Most parents were concerned about whether their children's language was at the level that it should be. One parent stated that even though tests indicated that his child was performing at levels equivalent to those of normal hearing children of his age, he doubted these findings. The significance of test results, as well as their range and predictive value for future development must be explained to parents.

Most parents appreciated Voice's summer programme and the opportunity it provided for meeting other children with cochlear implants. They did not feel that Voice met their emotional support needs. One mother mentioned that she enjoyed an on-line buddy system established by one of the cochlear implant companies. Perhaps there is a need for more individual support as mentioned by Most and Zaidman-Zait (2003). Such a buddy system set up by Voice might be useful.

It appeared that the parents in this study were not aware of the auditory-verbal strategies they were using and did not always differentiate between formal and informal techniques. They also had more difficulty implementing techniques that promote expressive language, compared to those that foster comprehension of language. Videotaping sessions at the parents' home, as well as at the hospital and discussing these videotapes with the parents would be instructional and empowering for them. Luterman (1999) referred to the use of videotapes at his centre.

As parents seemed to find progress slow, especially until their children were able to have some form of verbal interchange with them, it appears that close liaison with the psychologist and/or social worker in conjunction with the therapist until the "breakthrough phase" is attained would be beneficial. Most and Zaidman-Zait (2003) suggested that the ideal cochlear implant team consists of: a surgeon, a psychologist, an audiologist, a social worker, a speech clinician, and a teacher of the hearing impaired. The parents in their study requested emotional and informational support during the first year post-implant.

Recommendation 6- When a child is first diagnosed with hearing loss, a protocol that inquires about the family's resources and needs should be completed. In this document, there should be some way of determining when parents want to receive information and with what frequency. This form should be updated on a regular basis.

Recommendation 7- Structured materials based on a theme should be provided. Scaffolding techniques, that would take a parent and child from their current level of functioning and move them forward according to established goals would be beneficial.

Recommendation 8- Test materials should be explained and their predictive range thoroughly discussed with parents.

Recommendation 9- A one-on-one buddy system should be established through Voice, with the possibility of the buddy being involved in therapy sessions if the parents so choose. This individual buddy system would complement parent groups to be held on a regular basis.

Recommendation 10- Regular videotaping of parents doing therapy at home and at the hospital and analysis of these videotapes should be performed.

Recommendation 11- Close liaison with the social worker and psychologist should be maintained at least until the child is able to carry on some verbal interaction with the parent, that is until the “breakthrough phase” is achieved.

Exosystem

One parent mentioned that she thought her daughter could have benefitted from a self-contained oral classroom for children with hearing loss. Another parent mentioned the possibility of a self-contained class for half-days when the children are in Kindergarten. Criteria for admission into such a class, as well as for eventual partial and full inclusion as appropriate, would have to be established in consultation with the hospital and school specialists.

Most parents felt that Voice Ontario had little impact on their transition. It is important to increase the relevance of this provincial organization to local parents, perhaps by encouraging attendance at conferences and inviting provincial members to speak to the local chapter.

Recommendation 12- Consideration should be given to the establishment of a self-contained oral classroom for those children who require more intensive intervention than the home and hospital/school model can provide.

Recommendation 13- The relevance of the provincial level of Voice could be increased by encouraging and financially supporting attendance at conferences and inviting speakers to local meetings.

Summary

In this chapter, the theoretical implications of the investigation and its limitations were outlined. Ideas for future research were suggested and the chapter concluded with recommendations for practice.

This is the first time qualitative methodology has been applied to auditory-verbal therapy. It is also the first time that Bronfenbrenner's model has been used as a theoretical framework for examining auditory-verbal therapy. Many of the findings lend support to previous results obtained with quantitative research designs that examined various other therapeutic interventions.

The detection of hearing loss in a child may have devastating effects not only on the child's speech, language and cognition, but also on the whole family constellation including parents, siblings and grandparents. This thesis has explored parents' experiences after the detection of hearing loss in their children and the adoption of auditory-verbal therapy, as well as the environmental factors that may impede or facilitate this transition. It has been seen that a society that offers access to technology and support can have a salutary effect on parents who are struggling with these changes. Such environmental assistance can aid parents in attaining

fulfillment for themselves and their families. In so doing, society can reap the benefits that will accrue from productive, reciprocal relationships with each of these family members.

Epilogue

As a period of approximately one to one and a half years elapsed from the time of the first interviews until this point and in view of the dynamic nature of our lives, I have provided a brief update on each family and I have asked those participants who were available at my last visit to provide their closing thoughts on the transition. These are recorded below.

Nancy Wood and Family

When I arrived at the Woods' apartment, I was greeted at the door by Nancy. Diane was seated on a couch and did not respond to my questions. Nancy informed me that Diane was about to go for a nap and she was not wearing her cochlear implant. Nancy's only comment about her story was that I had mentioned Jamaica a lot. I replied that was because it seemed to me that she really liked it there and wanted to return one day and she agreed. When I asked how she is feeling now, she said she feels better. The court case with her ex-husband is over. She indicated that she wants to change jobs and is planning to train as a personal support worker. She reported that Linda is working and taking courses at adult high school at night. She stated that Diane is doing well. She attends an English daycare nearby, where she is the only child who wears a cochlear implant. Nancy stated that she will likely stay at that daycare next year instead of attending Junior Kindergarten because it is full days and this suits Nancy's schedule. Diane's tutor, Frances, sees her five hours each week. When asked her opinion of the breakthrough phase, or when she felt that Diane was doing better, she responded, "Now". She reported that Diane is able to talk, to ask for what she wants and she can count. Nancy reported that she and Diane had visited her sisters in Toronto last summer and that she is planning to take a vacation this summer, perhaps to the United States. She would like to take a trip to Jamaica, but would prefer to go there in the winter.

When I said she seems to be doing well, she replied that she has to “go on”.

Margaret Briggs and Jean Dupuis and Family

When I called Margaret to arrange a time to deliver her story, she was in the midst of moving house. She met me that day and introduced me to her new partner, Allan. When I returned to pick up the story I was given a tour of the house. Melanie was present but did not interact with me. Margaret reported that Melanie lives with her full-time, while Mark lives with Jean. The children visit the other parent on weekends. This arrangement seems to be satisfactory to all the family members. Margaret stated that Melanie will be changing schools in the fall and will likely spend part of her day in a language class. When asked if she had any concluding thoughts she would like to share, she remarked that she feels the hospital should more actively participate in organizing support for parents in conjunction with Voice. She suggested that the model employed by one of the cochlear implant companies could be implemented. Margaret advised the therapists to counsel parents regarding expectations for language development. She reiterated her satisfaction that the Ear, Nose and Throat surgeon had indicated that there would be a turning point 18 months post-implant. When asked about the breakthrough phase, she stated that the surgeon had been quite accurate, in that she estimated that the breakthrough phase did occur at the 18 month mark. It was at that time that Melanie started to talk.

Susan and Zach Owen and Family

When I arrived at the Owen home, Susan was outside talking to a neighbour. We entered the house and she explained that she was taking care of her nephew, who is the same age as Peter. I discussed the issue of expressive language and the concept of a breakthrough phase with Susan. She remarked that she finds it easier to expand Peter’s language now that he is older and

his language is more advanced, than she did at earlier stages. She opined that the breakthrough phase occurred for her when Peter was able to tell her about events at which she had not been present, for example at school. She defined it as that time when the child can participate in more abstract conversations. After we discussed some changes to her story, I asked Susan if there were some final words she would like to add. She remarked that she is feeling better now but there are still some worries related to the possibility of a need for reinsertion of the implant in the future. Due to the ossification of Peter's cochlea, it is not known how successful such a reinsertion might be. She added that during the fall they spent a lot of time at the hospital dealing with technology issues. She concluded by saying that this is an exciting period because Peter is starting to integrate more with other children. She cited the example of a new neighbour with whom he plays. Peter and his cousin joined us in the kitchen at the end of our visit and he conversed quite naturally with me, his mother and his cousin.

Evelyn and Dave Wright and Family

When I delivered the Wright's story to them, three of their four children greeted me at the door with Evelyn. The baby, Reid, 7 months old, was sleeping upstairs. Allison smiled at me and informed me that she and her brother and sister all go to school. She seemed very pleased to share this information with me. When Evelyn was ready to return the story to me, she suggested that I meet her at the florist where she works part-time, as it is closer to my home. She informed me that she is planning to be trained as a school bus driver so that she can be home with her children longer and still earn some income. She added that Dave was about to begin a nine-week paternity leave so that he could spend time with the children. She reported that Allison, who is turning 7, will be entering grade 2 in the fall. Evelyn had inquired about additional testing for

Allison because she appears to be struggling with some areas of learning. While she demonstrates strengths in speech pronunciation and art, her comprehension in other areas is weak. Evelyn indicated that Allison seems happier, as she is better able to express her needs. She is involved in swimming and soccer and has one good friend. When asked about the breakthrough phase, Evelyn commented that she did not feel Allison was there yet. While Allison is able to use long sentences now, she does not produce these consistently. Evelyn feels she will have reached the breakthrough phase when she is consistently able to talk in sentences and can “put her point across”.

Kyla and Jared Jones

When I picked up the Jones family’s story, they were not home, therefore I did not see Shelley. As it was difficult to find a convenient time for me to return to their home, we decided to have our last meeting in the coffee shop at the hospital. Shelley accompanied her mother, as they had just completed a therapy session, at which the itinerant teacher, who will be providing service for Shelley next fall, had observed. Kyla had informed me during a telephone conversation that she had returned to school to take some prerequisite courses before beginning a two year business accounting course at a local community college next fall. She had just returned from a trip to India for one month on her own and reported that the families of children who receive cochlear implants in that country must pay for them privately. She added that therapy is rarely recommended there because it too is paid for privately. When asked about the breakthrough phase, she commented that Shelley had recently reached it, as she was using full sentences with all grammatical parts. She seemed proud of the fact that her expectations for Shelley were high.

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Appendix A

Definition of Terms

Appendix A

Definition of Terms

Audition.

In the practice of auditory-verbal therapy, listening, rather than watching is encouraged. The children are taught to use their hearing to the maximum. The best listening conditions are established in teaching situations as well as in the home environment. Parents and/or therapists sit beside the child on the side of his/her better ear. They speak close to the microphone of the child's hearing aid or cochlear implant. They speak in a quiet voice or at a regular volume. Background noise is minimized. They use melody, rhythm, expression and repetition in their speech to maximize the child's ability to hear and understand the message. They use techniques which highlight their speech in order that it be heard better.

Auditory-Verbal Therapy.

This is a mode of intervention used to develop spoken language in the child with hearing loss through the use of audition (Estabrooks, 2000). The goals of auditory-verbal practice as adopted by the Board of Directors of Auditory-Verbal International, Inc. include: early detection of hearing impairment, the prompt pursuit of medical and audiological management including selection, modification and maintenance of appropriate technology (hearing aids, cochlear implants), the guidance of parents and caregivers as the primary models for spoken language development, the support of children in integrating listening into the development of communication and listening skills, the fostering of children's auditory-verbal development through one-to-one teaching, the training of children to monitor their own voices and those of others to enhance spoken language, the stimulation of natural communication by following

normal developmental patterns of listening, speech, language and cognition, the ongoing evaluation of the child's development in the aforementioned domains and the modification of the programme when necessary, and the provision of support services to encourage the child's inclusion in regular classes at school (Auditory-Verbal International, 1991).

Cochlear Implant.

This is a biomedical prosthesis, which provides the sensation of hearing to those who cannot derive benefit from conventional amplification (Estabrooks, 2000). The cochlear implant consists of internal and external components. The internal components consist of a receiver/stimulator, which is surgically placed under the skin behind the ear and an electrode array, usually consisting of multichannel electrodes placed near or within the cochlea. The external components consist of a microphone, a transmitter and a speech processor (Staller, 1996). Sound is picked up by the small directional microphone and is then transmitted to the speech processor via a thin cable. The speech processor is a miniaturized computer, which analyzes the sound into coded signals. Cables then carry the coded signals from the speech processor to the transmitting coil, which sends the signals across the skin to the implanted receiver/stimulator via an FM radio wave. The electrical signal is transmitted to the appropriate electrodes on the array, which then stimulate the auditory nerve fibres. The signal is thereafter transmitted to the brain for interpretation (Sheppard, 1994).

Deaf Culture.

"The term Deaf culture is used to identify a set of beliefs and practices shared by a group of deaf people who also share a common signed language" (Padden & Ramsey, 1993, p. 97).

"Members of the Deaf culture emphasize the mode and language of communication, rather than

the extent of hearing loss, in self-identification and view themselves as having a different, rather than deviant, way of life” (Jamieson, 1995, p. 111).

Hearing Impairment.

This is an umbrella term used to refer to all degrees of hearing loss, from mild to profound and to different kinds of hearing loss including conductive and sensorineural.

Language.

This term encompasses the understanding and production of vocabulary, grammar, concepts and pragmatics (Robbins, 2000).

Speech Perception.

This term includes measures of awareness of sounds and recognition of sounds in the context of syllables and words (Spencer, 2002).

Speech Production.

This includes measures of speech intelligibility, phonology (the production of consonants, vowels and suprasegmentals, such as pitch intensity and rhythm), the acoustics and the physiology of speech.

Appendix B

Letter of Invitation to the Study

Consent Forms

Appendix C

Areas of Focus for Observations

1. Setting of play
2. Participants involved in the observed activity
3. Activities taking place in the setting:
 - what is the nature of the linguistic input of the parent?
 - what accommodation is made for the hearing loss?
 - how is behaviour managed?
 - what is the role of each of the participants?
 - is there nonverbal communication?
 - are there informal or unplanned activities?
 - are there unexpected occurrences?
4. Frequency and duration of play

Appendix D

Questions for the Semi-structured Interviews

Appendix D

Questions for the Semi-structured Interview with Parents

Questions related to the Microsystem.

- (1) Describe your daily activities with your child prior to detection of the hearing loss.
- (2) How did these activities change after the detection of the hearing loss and the introduction of amplification and auditory-verbal therapy?
- (3) Why did you choose to adopt auditory-verbal therapy?
- (4) What obstacles to the delivery of auditory-verbal therapy did you have to overcome along the way?
- (5) How have you changed through this process?
- (6) How has your child changed?
- (7) What are the effects on the family?
- (8) Is your parenting of the child with hearing impairment different from that with the normal hearing child? What additional roles have you had to assume?
- (9) What personal characteristics do you possess that helped or hindered the transition to auditory-verbal therapy?
- (10) What characteristics of your child with hearing impairment helped or hindered the transition to auditory-verbal therapy?
- (11) How has the relationship between you and your child helped or hindered the transition to auditory-verbal therapy?
- (12) How has your relationship with your husband/wife helped or hindered this transition?

(13) How has the relationship between your children helped or hindered this transition?

(14) What characteristics of your family helped or hindered your transition to auditory-verbal therapy?

(15) How are you feeling about this transition?

Questions Related to the Mesosystem.

(16) What strategies have you learned at [the hospital]? Are there any that are easy to implement at home? Why? Are there some that are hard to do? Why?

(17) What effect does going to [the hospital] once a week and doing auditory-verbal therapy have on your family?

(18) How does the availability of audiology services at [the hospital] impact on your family?

(19) How do you think the local chapter of Voice helped your transition? Did it impede your transition in any way?

(20) How have personal supports such as family, friends, babysitters helped your transition?

(21) Describe the impact of the adoption of auditory-verbal therapy on your work life.

Questions Related to the Exosystem.

(22) What kinds of community supports are available to you? How did these help or hinder your adoption of auditory-verbal therapy?

(23) How does Voice Ontario impact on your family life? How has it helped your transition to auditory-verbal therapy?

(24) How have Voice Ontario and community supports been a barrier?

(25) Describe the support services available to you through the provincial health and education systems. How did these assist your transition to auditory-verbal therapy? What are the barriers presented by these systems?

Questions Related to the Macrosystem.

(26) How did your cultural/societal values and beliefs about hearing loss help or hinder your adoption and transition to auditory-verbal therapy?

Questions for the Semi-structured Interview with Auditory-Verbal Therapists

Questions Related to the Microsystem.

- (1) How do you think the family's daily routine is affected by the introduction of amplification and auditory-verbal therapy ?
- (2) What characteristics of the family do you think facilitated or presented obstacles to their transition to auditory-verbal therapy?
- (3) What personal characteristics of the family served as facilitators or barriers to their transition to auditory-verbal therapy?
- (4) What characteristics of the marital interaction facilitated and/or impeded the transition to auditory-verbal therapy?
- (5) What characteristics of the sibling interaction facilitated and/or impeded the transition to auditory-verbal therapy?

Questions Related to the Mesosystem.

- (6) Describe the family's visits to [the hospital] for auditory-verbal therapy.
What kinds of strategies do you teach with this approach?
- (7) How do you think the availability of audiological services at [the hospital] impacted on the parent's transition to auditory-verbal therapy?
- (8) How do you think the local chapter of Voice facilitated and/or impeded the transition to auditory-verbal therapy?
- (9) Describe the impact of the adoption of the auditory-verbal approach on the work life of the parent.

Questions Related to the Exosystem.

(10) How does the family benefit from supports offered in the community?

How does the family benefit from support offered by Voice Ontario?

(11) What barriers did the family encounter at the level of the community?

(12) How did provincial health and education policies facilitate and/or impede the transition to auditory-verbal therapy?

Questions Related to the Macrosystem.

(13) How did the prevailing societal/cultural beliefs and values about hearing loss facilitate and/or impede the transition to auditory-verbal therapy?

Appendix E

As questions to be addressed during the focus groups may vary depending on emerging themes and findings, specific questions will not be listed. Rather, discussion topics will be stated.

Topics Related to the Microsystem

Discussion will focus on how the parents' daily activities and roles have changed since the introduction of amplification and auditory-verbal therapy. As well, the challenges and facilitators presented by personal and family characteristics will be addressed. They will be asked to comment on the barriers and/or facilitators provided by the marital relationship, the sibling interaction and the relationship with the extended family.

Topics Related to the Mesosystem

The elements within the hospital setting and Voice Ottawa which have impeded and/or facilitated this transition to auditory-verbal therapy will be discussed.

Topics Related to the Exosystem

Public policies and elements within the workplace and Voice Ontario which have impeded and/or facilitated this transition will be discussed.

Topics Related to the Macrosystem

The elements of the belief system and culture that have impeded and/or facilitated this transition will be discussed.

Appendix F

Family Information Questionnaire

Who is completing this questionnaire?

☐ Mother ☐ Father ☐ Both ☐ Other (please specify) _____

☐	Single parent (sole custody)	☐	Single parent (shared custody)
☐	Two parent (both biological parents)	☐	Two parent (one biological parent and one step parent)
☐	Adoptive parent(s)	☐	Foster parent(s)

[illegible]

Mom	Dad		Mom	Dad		Mom	Dad	
		English			Signed English			Portuguese
		French			Greek			Vietnamese
		Arabic			Hungarian			Ukrainian
		Chinese			Italian			Punjabi
		Cree			Korean			Spanish
		German			Persian (Farsi)			Tagalog (Filipino)
		ASL			Polish			
		Other (please specify)						

How many years of elementary and high school have you completed?

	Mom	Dad
no schooling		
less than 6 years		
7 years		
8 years		
9 years		
10 years		
11 years		
12 years		
13 years		

Have you ever attended any other kind of school such as a university, community college, business school, trade or vocational school, CEGEP or other post-secondary institution?

	Mom	Dad
Yes		
No		

If yes, for how many years? _____

If yes, for how many years? _____

What certificates, diplomas or degrees have you obtained? (Please check all that apply)

Mom	Dad	
☐	☐	None
☐	☐	Secondary (high) school graduation certificate or equivalent
☐	☐	Diploma or certificate from at a trade, technical or vocational school
☐	☐	Diploma or certificate from at a business school
☐	☐	Diploma or certificate from at a community college, a nursing school or CEGEP
☐	☐	Bachelor's or undergraduate degree(s) (e.g., B.A., B.Sc., LL.B.)
☐	☐	Master's degree(s) (e.g. M.A., M.Sc., M.Ed.)
☐	☐	Degree in medicine, dentistry, veterinary medicine or optometry
☐	☐	Doctorate (e.g., Ph.D., D.Sc., D.Ed.)
☐	☐	Other _____

Who cares for your child during the day?

☐	Mom	
☐	Dad	
☐	Other family member	Please specify _____
☐	In-home daycare	How many children share this daycare _____
☐	Outside daycare	How many children share this daycare _____
☐	Other	Please specify _____

What is the main language used with your child during the day?

☐	English	☐	ASL	☐	Polish	☐	Ukrainian
☐	French	☐	Signed English	☐	Portugese	☐	Vietnamese
☐	Arabic	☐	Hungarian	☐	Punjabi		
☐	Chinese	☐	Italian	☐	Spanish		
☐	Cree	☐	Korean	☐	Tagalog (Filipino)		
☐	German	☐	Persian (Farsi)	☐	Greek		
☐	Other (please specify) _____						

To what ethnic or cultural group(s) does your family belong? (please mark all that apply)

Mom	Dad		Mom	Dad	
☐	☐	Canadian	☐	☐	Chinese
☐	☐	French	☐	☐	Jewish
☐	☐	English	☐	☐	Polish
☐	☐	German	☐	☐	Portugese
☐	☐	Scottish	☐	☐	Black
☐	☐	Irish	☐	☐	Filipino
☐	☐	Italian	☐	☐	Latin American
☐	☐	Ukrainian	☐	☐	Japanese
☐	☐	Dutch (Netherlands)	☐	☐	Korean
☐	☐	Aboriginal (North American Indian, Metis, Inuit, Eskimo)	☐	☐	Arab / West Asian (Armenian, Egyptian, Iranian, Lebanese, Moroccan)
☐	☐	South East Asian (Cambodian, Indonesian, Laotian, Vietnamese)	☐	☐	South Asian (East Indian, Pakistani, Punjabi, Sri Lankan)
☐	☐	Other (please specify) _____			

Are you currently working at a job or business? (Please include part-time jobs, seasonal work, contract work, self-employment, baby-sitting or any other paid work)

Mother ☐ Yes ☐ No ☐ Permanently unable to work ☐ At home with children
 Father ☐ Yes ☐ No ☐ Permanently unable to work ☐ At home with children

What kind of work are you doing (for example, janitor, medical lab technician, accounting clerk, manager of engineering department, supervisor of data entry unit, secondary school teacher, fishing guide, etc)?

Mother _____

Father _____

For whom do you work? (For example, name of business, government department or agency, person)

Mother _____

Father _____

What is your combined family income from all sources before taxes (for example, wages and salaries, income from self-employment, employment insurance, pensions, child support, alimony etc.)?

☐	Below \$20,000
☐	\$20,000 to less than \$30,000
☐	\$30,000 to less than \$40,000
☐	\$40,000 to less than \$50,000
☐	\$50,000 to less than \$60,000
☐	\$60,000 to less than \$70,000
☐	\$70,000 to less than \$80,000
☐	more than \$80,000

THANK YOU VERY MUCH FOR YOUR HELP

Appendix G

Summary Tables of Data

The Ecological Transition to Auditory-Verbal Therapy

Table G1

Nancy - Summary of Data

	Microsystem		Mesosystem		Exosystem		Macrosystem	
	Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Mother Interview	p. 11, l.15 p. 2, l.9-11 p. 4, l.16-18 p. 11, l.2 p. 4, l.3-5 p. 10, l.21-24 p. 11, l.15	p. 10, l.5-11 p. 13, l.8 p. 7, l.8-9, l.17 p. 13, l.4	p. 3, l.8 p. 26, l.21 p. 25, l.19-22	p. 3, l.1-3 p. 3, l.12-17 p. 18, l.9-12	p. 24, l.16 p. 22, l.2-3 p. 3, l.25 p. 8, l.13 p. 9, l.5-17	p. 1, l.21-23	p. 25, l.4-5	p. 12, l.3-4
Therapist Interview				p. 4, l.1-2 p. 4, l.12-14	p. 12, l.1-2, l.8-9 p. 13, l.19 p. 14, l.1 p. 18, l.19-23	p. 17, l.6-8 p. 17, l.10 p. 16, l.24	p. 18, l.16-19	p. 18, l.8-11
Observation	Observations 1-3	Observation 3		Observations 1-3				

The Ecological Transition to Auditory-Verbal Therapy

Table G2

Margaret - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem	
Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Mother Interview	p. 1, l.7-9 p. 9, l.5-7 p. 9, l.33-38 p. 14, l.12-13 p. 2, l.26	p. 16, l.41-42 p. 13, l.15-17, l.22-23	p. 7, l.27, l.33-35 p. 6, l.19 p. 16, l.14-15, l.17-21, l.22-24, l.27-28, l.31-32	p. 21, l.22-23 p. 9, l.19-22 p. 25, l.23-25	p. 25, l.34	p. 32, l.12-17	
Therapist Interview		p. 21, l.7-8	p. 2, l.4 p. 9, l.1-2	p. 17, l.17 p. 15, l.28-29 p. 5, l.22-25 p. 11, l.18-19, l.28-29	p. 20, l.2-3	p. 7, l.11-12	
Observation.	Observations 1 - 3		Observations 1 - 3				

Table G3

Jean - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem	
Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Father Interview	p. 1, 1.10-11 p. 2, 1.26-27	p. 2, 1.6-10 p. 2, 1.3-4 p. 3, 1.16-18 p. 5, 1.2-3	p. 1, 1.25-26 p. 1, 1.19-20 p. 1, 1.29 p. 2, 1.21-23	p. 4, 1.23 p. 4, 1.2-7 p. 4, 1.20-21	p. 5, 1.31-33	p. 6, 1.26	
Therapist Interview		p. 21, 1.10	p. 2, 1.4	p. 17, 1.17 p. 15, 1.28-29 p. 5, 1.22-25 p. 11, 1.18-19, 1.28-29	p. 20, 1.2-3	p. 7, 1.11-12	
Observation	Observation 2	Observation 2	Observation 2				

Table G4

Susan - Summary of Data

	Microsystem		Mesosystem		Exosystem		Macrosystem	
	Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Mother Interview	p. 20, l.8 p. 20, l.13-14 p.15, l.17-18 p. 23, l.1	p. 23, l.16 p. 23, l.8-12 p. 24, l.4 p. 28, l.12 p. 38, l.20	p. 55, l.13-18	p. 7, l.20 p. 33, l.10-12 p. 13, l.15-17 p. 20, l.18-19	p. 55, l.6 p. 44, l.1 9	p. 56, l.21 p. 53, l.8-9, l.11-14 p. 53, l.18-20		p. 57, l.5-6
Therapist Interview			p. 1, l.17-21	p. 4, l.17-18 p. 2, l.15-19	p. 21, l.15-23 p. 22, l.2-5 p. 26, l.11-12, l.19-21			
Observation				Observations 1- 3				
Discussion Group	D.G.- Personality	D.G.- Behaviour Fathers' Role		D. G.- Structured Therapy	D.G.- Employer, Isolation			

The Ecological Transition to Auditory-Verbal Therapy

Table G5

Zach - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem	
Personal Characteristics		Family Interactions	Choice	Compliance	Support	Support	Inclusion
Father Interview	p. 42, l.8-11	p. 33, l.18-21	p. 8, l.5	p. 4, l.6-16	p. 49, l.11-14	p. 65, l.9	p. 76, l.7-8
	p. 27, l.6-7	p. 37, l.9-13	p. 8, l.7-8	p. 10, l.2	p. 14, l.6-9	p. 65, l.11	p. 13, l.12-14, l.18
	p. 26, l.14	p. 19, l.4		p. 45, l.21	p. 50, l.6-9		
	p. 25, l.22-23	p. 22, l.21-23		p. 28, l.11-12	p. 50, l.21		
	p. 12, l.6-9	p. 23, l.2-5		p. 28, l.13-14			
Therapist Interview	p. 16, l.1-2						
			p. 1, l.17-21	p. 3, l.9-13	p. 26, l.11-12, l.19-21		
Observation 2					p. 22, l.5		
Observation 1				Observation 1			

The Ecological Transition to Auditory-Verbal Therapy

Table G6

Evelyn - Summary of Data

	Microsystem		Mesosystem		Exosystem		Macrosystem	
	Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Mother Interview	p. 15, 1.26-27 p. 21, 1.3-5 p. 16, 1.3-4 p. 21, 1.8-9 p. 22, 1.10	p. 18, 1.22 p. 18, 1.27 p. 43, 1.2-5	p. 15, 1.8-9 p. 15, 1.13-14 p. 42, 1.15-17 p. 18, 1.19-20	p. 10, 1.1 p. 30, 1.8-11 p. 43, 1.10-12 p. 7, 1.21	p. 35, 1.5 p. 44, 1.7-9 p. 32, 1.23-25 p. 33, 1.17	p. 33, 1.8		
Therapist Interview			p. 13, 1.15-16	p. 2, 1.16-18 p. 2, 1.21-22 p. 4, 1.34-35	p. 3, 1.32-33 p. 10, 1.9-11 p. 12, 1.14-15	p. 12, 1.24-27		
Observation	Observation 1			Observations 1-3				
Discussion Group	D.G.- Personality	D.G.- Sibling Relationship		D.G.- Cochlear Implant, Guilt	D.G.- School's Role			

The Ecological Transition to Auditory-Verbal Therapy

Table G7

Dave - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem	
	Personal Characteristics	Family Interactions	Choice	Compliance	Support	Accessability	Inclusion
Father Interview	p. 7, l.33-35 p. 1, l.4-5	p. 14, l.5-6 p. 13, l.4-5 p. 15, l.2-3 p. 10, l.9 p. 19, l.6		p. 4, l.22-23 p. 6, l.9-10 p. 8, l.1-3	p. 18, l.20-22 p. 17, l.13-14 p. 17, l.29-30 p. 5, l.37-38 p. 17, l.1-2 p. 19, l.26	p. 20, l.9-12	
Therapist Interview			p. 13, l.15-16	p. 2, l.16-18 p. 2, l.21-22 p. 4, l.34-35	p. 12, l.14-15	p. 12, l.24-27	
Observation		Observation 3					

Table G8

Kyla - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem		
	Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Mother Interview	p. 20, l.5-6 p. 13, l.10 p. 13, l.5-6 p. 19, l.4 p. 8, l.6 p. 23, l.4-6 p. 21, l.7	p. 25, l.11-15 p. 26, l.8 p. 18, l.19-21 p. 16, l.20-22 p. 34, l.7-9	p. 12, l.4-5 p. 12, l.7	p. 15, l.4 p. 37, l.18 p. 41, l.5 p. 36, l.15, l. 20	p. 42, l.5, l.16 p. 42, l.12 p. 15, l.20	p. 53, l.17-20	p. 68, l.12 p. 67, l.23-24 p. 70, l.3-7	p. 14, l.21 p.15, l.9
Therapist Interview				p. 3, l.9-10 p. 2, l.7-8 p. 5, l.11-15 p. 6, l.4-9	p. 6, l.19-22 p. 6, l.29- p.7, l.1	p. 9, l.17-18 p. 10, l.2-3 p. 8, l.3-4		p. 10, l.15
Observation		Observations 1 - 3		Observations 1 - 3				

The Ecological Transition to Auditory-Verbal Therapy

Table G9

Jared - Summary of Data

Microsystem		Mesosystem		Exosystem		Macrosystem	
Personal Characteristics	Family Interactions	Choice	Compliance	Support	Support	Accessibility	Inclusion
Father Interview	p. 19, l.10 p. 16, l.2, l.8-11 p. 19, l.12-16 p. 19, l.22-23 p. 11, l.9 p. 22, l.4-5	p. 24, l.13 p. 25, l.1-3 p. 27, l.16-17 p. 17, l.6-8 p. 50, l.18-19 p. 43, l.4-6	p. 34, l.22-23 p. 34, l.8-11 p. 32, l.12-13	p. 36, l.9 p. 36, l.17-19 p. 40, l.23- p. 41, l.2 p. 43, l.10-13	p. 46, l.3	p. 50, l.2-6	p. 31, l.6-7
Therapist Interview				p. 6, l.19-22 p. 6, l.29-p. 7, l.1 p. 9, l.17-18 p. 10, l.2-3 p. 8, l.3-4			p. 10, l.15
Observation	Observation 2		Observations 2 - 3				

Appendix H

Information about Ministry of Education Programmes

District School Board Name
Mission Statement of the Board [optional]
Philosophy of the Board [optional]

Notes:

1. If you wish to receive this parents' guide in Braille, large print, or audio-cassette format, please contact the board at the address or telephone number shown on the last page of this guide.
2. When used in this guide, the word "parent" includes guardian.

The Education Act requires that school boards provide, or purchase from another board, special education programs and services for their exceptional pupils. The purpose of this parents' guide is to provide you with information about the Identification, Placement and Review Committee (IPRC), and to set out for you the procedures involved in identifying a pupil as "exceptional", deciding the pupil's placement, or appealing such decisions if you do not agree with the IPRC.

If, after reading this guide, you require more information, please see the board's list of contacts at the end of the document.

What is an IPRC?

Regulation 181/98 requires that all school boards set up IPRCs. An IPRC is composed of at least 3 people, one of whom must be a principal or a supervisory officer of the board.

[School boards may list the members, identifying the member who is a principal or a supervisory officer.]

- 1.
- 2.
- 3.

Parents are invited and encouraged to attend the meeting.

What is the role of the IPRC?

The IPRC will:

- decide whether or not your child should be identified as exceptional;
- identify the areas of your child's exceptionality, according to the categories and definitions of exceptionalities provided by the Ministry of Education;
- decide an appropriate placement for your child *[here the board should list the full range of placement options offered by the board]*; and
- review the identification and placement at least once in each school year.

Who is identified as an exceptional pupil?

The Education Act defines an exceptional pupil as "a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program...." Students are identified according to the categories and definitions of exceptionalities provided by the Ministry of Education.

What is a special education program?

A special education program is defined in the Education Act as an educational program that:

- is based on and modified by the results of continuous assessment and evaluation; and
- includes a plan (called an Individual Education Plan or IEP) containing specific objectives and an outline of special education services that meet the needs of the exceptional pupil.

What are special education services?

Special education services are defined in the Education Act as the facilities and resources, including support personnel and equipment, necessary for developing and implementing a special education program.

What is an IEP?

The IEP must be developed for your child – if he or she has been identified as an exceptional student – in consultation with you. It must include:

- specific educational expectations;
- an outline of the special education program and services that will be received;
- a statement about the methods by which your child's progress will be reviewed; and
- for students 14 years and older (except those identified as exceptional solely on the basis of giftedness), a plan for transition to appropriate postsecondary school activities, such as work, further education, and community living.

The IEP must be completed within 30 days after your child has been placed in the program, and the principal must ensure that you receive a copy of it.

How is an IPRC meeting requested?

The principal of your child's school:

- must request an IPRC meeting for your child, upon receiving your written request;
- may, with written notice to you, refer your child to an IPRC when the principal and the child's teacher or teachers believe that your child may benefit from a special education program.

Within 15 days of receiving your request, or giving you notice, the principal must provide you with a copy of this guide and a written statement of approximately when the IPRC will meet.

May parents attend the IPRC meeting?

Regulation 181/98 entitles parents and pupils 16 years of age or older:

- to be present at and participate in all committee discussions about your child; and
- to be present when the committee's identification and placement decision is made.

Who else may attend an IPRC meeting?

- the principal of your child's school;
- other resource people such as your child's teacher, special education staff, board support staff, or other professionals, who may provide further information or clarification;
- your representative – that is, a person who may support you or speak on behalf of you or your child; and
- an interpreter, if one is required. (You may request the services of an interpreter through the principal of your child's school.) *[Boards may wish to list the types of interpreters available, e.g., sign language, oral, specific language.]*

Who may request that they attend?

Either you or the principal of your child's school may make a request for the attendance of others at the IPRC meeting.

What information will parents receive about the IPRC meeting?

At least 10 days in advance of the meeting, the chair of the IPRC will provide you with written notification of the meeting and an invitation to attend as an important partner in considering your child's placement. This letter will notify you of the date, time, and place of the meeting, and it will ask you to indicate whether you will attend.

Before the IPRC meeting occurs, you will receive a written copy of any information about your child that the chair of the IPRC has received. This may include the results of assessments or a summary of information.

What if parents are unable to make the scheduled meeting?

If you are unable to make the scheduled meeting, you may:

- contact the school principal to arrange an alternative date or time; or
- let the school principal know you will not be attending. As soon as possible after the meeting, the principal will forward to you, for your consideration and signature, the IPRC's written statement of decision noting the decision about identification and placement and any recommendations regarding special education programs and services.

What happens at an IPRC meeting?

- The chair introduces everyone and explains the purpose of the meeting.
- The IPRC will review all available information about your child. The members will:
 - consider an educational assessment of your child;
 - consider, subject to the provisions of the Health Care Consent Act, 1996, a health or psychological assessment of your child conducted by a qualified practitioner, if they feel that such an assessment is required to make a correct identification or placement decision;
 - interview your child, with your consent if your child is less than 16 years of age, if they feel it would be useful to do so; and
 - consider any information that you submit about your child or that your child submits if he or she is 16 years of age or older.
- The committee may discuss any proposal that has been made about a special education program or special education services for the child. Committee members will discuss any such proposal at your request or at the request of your child, if the child is 16 years of age or older.
- You are encouraged to ask questions and join in the discussion.
- Following the discussion, after all the information has been presented and considered, the committee will make its decision.

What will the IPRC consider in making its placement decision?

Before the IPRC can consider placing your child in a special education class, it must consider whether placement in a regular class with appropriate special education services will:

- meet your child's needs; and
- be consistent with your preferences.

If, after considering all of the information presented to it, the IPRC is satisfied that placement in a regular class will meet your child's needs and that such a decision is consistent with your preferences, the committee will decide in favour of placement in a regular class with appropriate special education services.

If the committee decides that your child should be placed in a special education class, it must state the reasons for that decision in its written statement of decision.

What will the IPRC's written statement of decision include?

The IPRC's written statement of decision will state:

- whether the IPRC has identified your child as exceptional;
- where the IPRC has identified your child as exceptional,
 - the categories and definitions of any exceptionalities identified, as they are defined by the Ministry of Education;
 - the IPRC's description of your child's strengths and needs;
 - the IPRC's placement decision; and
 - the IPRC's recommendations regarding a special education program and special education services;
- where the IPRC has decided that your child should be placed in a special education class, the reasons for that decision.

What happens after the IPRC has made its decision?

- If you agree with the IPRC decision, you will be asked to indicate, by signing your name, that you agree with the identification and placement decisions made by the IPRC.
- If the IPRC has identified your child as an exceptional pupil and if you agree with the IPRC identification and placement decisions, the board will promptly notify the principal of the school at which the special education program is to be provided of the need to develop an Individual Education Plan (IEP) for your child.

Once a child has been placed in a special education program, can the placement be reviewed?

- A review IPRC meeting will be held at least once in each school year, unless the principal of the school at which the special education program is being provided receives written notice from you, the parent, dispensing with the annual review.
- You may request a review IPRC meeting any time after your child has been in a special education program for 3 months.

What does a review IPRC consider and decide?

- With your written permission, the IPRC conducting the review will consider the progress your child has made in relation to the IEP. It will consider the same type of information that was originally considered by the IPRC, as well as any new information.
- The IPRC will review the placement and identification decisions and decide whether they should be continued or whether a different decision should now be made.

What can parents do if they disagree with the IPRC decision?

- If you do not agree with either the identification or the placement decision made by the IPRC, you may:
 - within 15 days of receipt of the decision, request that the IPRC hold a second meeting to discuss your concerns; or
 - within 30 days of receipt of the decision, file a notice of appeal with *[boards should fill in the name and address of the secretary of the board]*.
- If you do not agree with the decision after the second meeting, you may file a notice of appeal within 15 days of your receipt of the decision.

If you do not consent to the IPRC decision but you do not appeal it, the board will instruct the principal to implement the IPRC decision.

How do I appeal an IPRC decision?

If you disagree with the IPRC's identification of your child as exceptional or with the placement decision of the IPRC, you may, within 30 days of receipt of the original decision or within 15 days of receipt of the decision from the second meeting described above, give written notification of your intention to appeal the decision to *[boards should fill in the name and address of the secretary of the board]*.

The notice of appeal must:

- indicate the decision with which you disagree; and
- include a statement that sets out your reasons for disagreeing.

What happens in the appeal process?

The appeal process involves the following steps:

- The board will establish a special education appeal board to hear your appeal. The appeal board will be composed of three persons who have no prior knowledge of the matter under appeal, one of whom is to be selected by you, the parent.
- The chair of the appeal board will arrange a meeting to take place at a convenient time and place, but no later than 30 days after he or she has been selected (unless parents and board provide written consent to a later date).
- The appeal board will receive the material reviewed by the IPRC and may interview any persons who may be able to contribute information about the matter under appeal.
- You, the parent, and your child, if he or she is 16 years old or over, are entitled to be present at, and to participate in, all discussions.
- The appeal board must make its recommendations within 3 days of the meeting's ending. It may:
 - agree with the IPRC and recommend that the decision be implemented; or
 - disagree with the IPRC and make a recommendation to the board about your child's identification or placement or both.

Appendix I

Information about Ministry of Community and Social Services Programmes

Note

The Special Services at Home program (Ministry of Community and Social Services) and the Assistive Devices Program (Ministry of Health) might also be applicable. Your worker should be consulted for further details and advice.

Some situations that may affect the allowance

When Assistance for Children with Severe Disabilities is being received, changes in circumstances such as those listed below, may alter the allowance and should be reported immediately to your worker.

- your child enters a hospital, residence or institution;
- your income decreases or increases significantly;
- your address or marital status changes;
- your family size changes.

Should I apply?

Yes, if you believe that:

- your child is severely handicapped under the descriptions stated;
- your child has special (extraordinary) needs and costs associated with his or her handicap;
- your family income is within the low-or middle-income range (for family size).

How do I apply?

- Obtain an application form from your nearest ministry office. After filling in all details return the form to the office. On receipt of this completed form a ministry staff member will arrange a home interview to verify income and costs. You may also be asked for medical documentation respecting your child's handicap.
- If you require the help of a ministry staff member to complete the application form, please contact the office which sent the form.
- Your completed application is then submitted to an area review group, consisting of people familiar with the needs of handicapped persons.

Ministry offices

For the nearest office of the ministry, please see Community and Social Services in the Government of Ontario Section of the blue pages of your telephone directory.

What is entitlement?

Special needs - basic entitlement

Basic entitlement varies between the minimum of \$25, with \$25 increments to an established maximum. The amount granted will most closely represent the additional monthly costs associated with the handicapped child's special needs. Consequently, documentation of special needs and their costs will be the key factor in determining the amount of the benefit which will be paid.

Total income (gross)

Total income of the family is the gross sum of that reported by both parents for income tax purposes during the previous calendar year, together with any income reported for income tax purposes as having been received by the child. (The calculation of total income appears on the bottom of page 1 of the appropriate income tax return.)

Net entitlement

This is the actual amount you receive as determined according to your total income. If your total income is below certain specified limits, the monthly cheque will be the same as the basic entitlement previously discussed. If your total family income is over the specified limits, the basic entitlement is reduced according to income scale tables. These tables are revised periodically and adjusted to reflect changes in economic conditions, etc. Details of the rate tables are available from your nearest ministry office.

Note

For those families with more than one severely handicapped child, allowable income levels are adjusted accordingly.

Additional benefits

When Assistance for Children with Severe Disabilities are approved there are additional benefits which will automatically be made available to your child. Please note that these benefits are for your handicapped child and are in his/her name. They are not transferable to other family members.

- **Drug Benefits** - a drug benefit card in your child's name will automatically be issued. This card provides free a number of prescription drugs which are listed in Ontario's Drug Formulary. Your physician should be made aware of your child's entitlement to such drugs. The card must be presented at the pharmacy when a prescription is ordered.
- **Dental Card** - a dental card in your child's name will automatically be issued. This card provides free, regular (maintenance) dental work. It does not cover special dental requirements such as braces.
- **Eye glasses and/or hearing aids** are supplied where necessary. The worker assigned to your case would provide details of procedures.

Assistance for Children with Severe Disabilities

Ministry of Community and Social Services

The Assistance for Children with Severe Disabilities program helps the parents of severely handicapped children meet the ongoing extraordinary costs arising from their child's handicap. It takes into account the family's financial circumstances and the resources such as special schools and volunteer organizations available in the community in which the child's family lives.

The purpose of Assistance for Children with Severe Disabilities is to help severely handicapped children live as normal a life as possible at home, in the community.

How does the program operate?

The needs of each handicapped child are different. The nature of these special needs determines the basic allowance. To be eligible for Assistance for Children with Severe Disabilities the following basic requirements must be met:

- the child must be 17 years old or less, and
- the child must have a severe handicap which results in a functional loss as described below, and
- extraordinary costs, incurred because of the handicap, must be present.

The amount granted depends on:

- size of family (including parents),
- total family income (gross),
- extraordinary costs of the handicapped child.

What is a severe handicap which results in a functional loss?

This means an ongoing mental or physical condition which results in a major loss of ability to engage in any activity considered necessary to normal daily living (i.e. walking, self-feeding, dressing, personal hygiene, communication, etc.)

The above definition is not intended to specifically include or exclude any particular type of disability. It is intended, however, to clarify that a handicap must constrain normal daily living and to provide a standard by which the severity of that handicap may be judged.

How is the benefit determined?

Your child's special needs are the key factor. Certain special needs which may not be provided currently, due to limited family income, will also be considered in determining the benefit amount. If you request assistance, a ministry representative will help you document the special needs. These may include diets, clothing, drugs, transportation, nursing care or the cost of short-term parental relief. Ministry staff at the local level will then consider those needs and make a recommendation, taking into account recent expenditures, potential costs and other factors which make your child's situation unique.

GUIDELINES

The first time a word defined in the glossary appears in the text, it will be in UPPER CASE letters.

INTRODUCTION

Special Services at Home (SSAH) is intended to provide supports to:

- a) Individuals living at home with their FAMILIES
- and
- b) Families caring for family members

who have a disability and as a result have special needs which require services beyond care normally provided by family. When this is the case, the government has a commitment to assist with the costs and required services by supplying a range of family support services. SSAH is one of this range of community services for families and is based on the belief that families are primary caregivers for individuals with disabilities. As a result, SSAH focuses on the provision of funds to assist families to purchase supports which are not otherwise available in the community.

The Special Services at Home Program has developed as one model of individualized consumer-directed funding which has the potential for much broader application in the service system for people who are disabled.

Special Services at Home was initiated in 1982 to help CHILDREN with DEVELOPMENTAL DISABILITIES to live at home with their families and to prevent their institutionalization. Families welcomed the new program because it tailored services to the individual and considered the needs of the family as a whole. Although the Ministry of Community and Social Services (MCSS) has committed additional funds on several occasions since 1982, the program faces the continuing challenge of responding appropriately to a growing demand while managing with the funds available.

There is an ongoing effort on the part of MCSS and other ministries to clarify respective roles and responsibilities and to modify MAINSTREAM SERVICES for individuals with disabilities.

Special Services at Home has successfully supported children to live as independently as possible with their own families in their own communities. This experience, as well as the program's popularity with families, are the reasons for extending the program to new groups. ADULTS with developmental disabilities and children with PHYSICAL DISABILITIES, who are living at home with their families, are now eligible for Special Services at Home. These revised guidelines apply to all eligible groups.

PURPOSE

The goal of the SSAH Program is to help individuals with disabilities to live at home with their families. It helps them by providing INDIVIDUALIZED FUNDING, on a time-limited basis, to purchase supports and services not available elsewhere in the community.

WHO IS ELIGIBLE FOR SSAH

Children who have a developmental disability or a physical disability, and adults who have a developmental disability, are eligible for Special Services at Home if they:

- are residents of Ontario,
- have ONGOING FUNCTIONAL LIMITATIONS as a result of a disability,
- require support beyond that which is a normal family responsibility and
- are living at home with their families.

The ongoing functional limitation must be documented by a professional, such as a physician, audiologist or psychologist.

Applications will be reviewed based on the criteria outlined in the decision-making process on page 8. Anyone concerned with the needs of an individual with a disability who may be eligible for SSAH should contact the local AREA OFFICE of The Ministry of Community and Social Services for applications and for information and assistance with the program.

NEEDS RECOGNIZED AND SERVICES FUNDED

Individuals with disabilities and their families may identify a broad variety of needs. These could include needs for housing, specialized equipment, education and training, employment, attendant care; and the opportunity to learn new skills, to maintain or recover old ones, to socialize, to develop personal relationships, and so on.

The Special Services at Home program recognizes that it cannot meet all human needs. As a result, its resources are focused on meeting needs broadly described as:

- personal development and growth
and/or
- family relief and support.

These needs are described on pages 3, 4 and 5.

In addition, the needs which can be funded under SSAH are ones that:

- cannot be met by a service available elsewhere in the local community, for example the Handicapped Children's Benefits Program.

Special Services at Home values the participation of individuals with disabilities in their communities. Services funded should promote the involvement of the individual in everyday community life.

The following services may be considered for funding under Special Services at Home.

1) Personal Development and Growth

Personal development and growth services focus on the needs of individuals to acquire new skills and capacities. The purpose of the program is to help the individual achieve a specific goal.

Family members may benefit indirectly from Personal Development and Growth services because of the assistance made available or the skills learned. However, the overall goal is to enable the individual to learn and develop.

Funding can be used to provide the human resources necessary to carry out programs. Usually a special services worker provides direct assistance to the individual with a disability. Direct assistance will:

- address specific personal development and growth needs,
- focus on a goal (outcome expected) within a projected time frame,
- follow a plan for delivery of programming (method) and
- periodically review the progress made and the continuing appropriateness of the goals and plans.

A broad range of individual needs can be addressed with this type of programming. Some examples are activities of daily living, behavioral programming, mobility, communication, social skills, developmental programming, etc.

The family and the individual should develop the goals and delivery plans, either by themselves, or in conjunction with a professional or community agency. Some goals and plans may be left broadly defined.

However, in specialized areas of programming, goals and delivery plans should be more closely defined. The assistance of a professional may be required to provide expertise. Some examples of specialized areas are sign language, programs targeting self-injurious behaviour, carry-over of programs designed by a professional, etc.

The professional may, via the MEDIATOR MODEL, assist in identifying the goals, intervention techniques or activities, initial training of those providing direct service, and ongoing monitoring of the program.

Where a service is delivered depends on the appropriateness of the setting to the goals established, and on the needs of the family and the individual. A variety of locations may be used, e.g. home, community settings (shops, parks), vehicles while in transit, community services/programs (scouting groups, recreation programs).

Services to Infants. Special Services at Home recognizes that INFANCY is one of the crucial periods in the healthy development of an individual, and services to infants are best provided within a family context. For these reasons, infants can also receive Personal Development and Growth services through Special Services at Home. The service should be provided within a mediator model approach, using the expertise of qualified professionals in the field of infancy.

2) Family Relief and Support

Family Relief and Support services recognize the additional responsibilities of families caring for a family member with a disability. The purpose of the service is to assist families by providing respite/parent relief, and related home support services.

The individual with a disability will, in many cases, directly benefit from these services. However, the overall goal is to assist the family to meet their identified needs.

Funding can be used to provide the services or human resources required for Family Relief and Support. The most common type of service delivery uses special services workers to provide direct assistance to the individual. Direct assistance to the individual with a disability should:

- allow for the continuation of his/her established programmes (e.g. behavioral programming, use of sign language) and routines,
- ensure appropriate care, guidance, and personal safety and
- provide opportunities for participation in community life and functional learning.

Special services workers may, therefore, require closer involvement with the individual, and a greater skill level, than that expected in babysitting or adult companion sitting service.

Where the service is delivered will depend on the needs of the family and the individual, and the appropriateness of the setting. A variety of locations may be used, e.g. home, community settings (shops, parks), vehicles while in transit, community services or programs (scouting groups, recreation programs), or while on vacation.

Special Services at Home may consider time-limited requests for INDIRECT ASSISTANCE to families, instead of the direct service, if the assistance:

- enables the family to play a greater role in meeting the needs of the individual with a disability, e.g. care of sibling so parent can work with individual,
- maintains the individual's skills and capacities and

- provides opportunities for more effective service delivery.

Nursing Respite. Where indicated by a professional assessment of the need, and where all alternative resources, including Home Care, have been exhausted, respite may be provided by an individual holding a certificate of competency as a registered nurse or registered nursing assistant under Part IV of the Health Disciplines Act.

Notes on Services Funded

Specific supports and services may be a critical factor in the delivery of Personal Development and Growth, or Family Relief and Support Services. In some situations, requests for these supports and services listed below may be considered for funding if they cannot be provided in any other way.

- a) Training: Family members or special services workers may need training to understand and respond to the needs of the individual. Funding may be considered on a time-limited basis, if the training -
 - reflects specialized needs over and above initial orientation requirements,
 - provides opportunities for more effective service delivery and
 - maintains the individual's skills and capacities.
- b) Reimbursement of out-of-pocket expenses: Area Offices have discretion to establish local policy on authorization of the following types of expenses, and under what circumstances -
 - advertising for recruitment of special services workers,
 - travel costs,
 - supplies required to implement the programme,
 - additional liability insurance required to cover the services provided.
- c) Exceptional Circumstances: The following services, although not normally funded through Special Services at Home, may receive exceptional need consideration for funding under Personal Development and Growth and/or Family Relief and Support.
 - **Child care:** Where the Area Office determines that the cost of child care exceeds regular costs because of the needs of the child as a result of the disability, the Area Office may consider funding the portion of the fee over and above regular costs. Consideration may also be given to child care costs not normally met by families.

- Camp and recreation fees: Where the Area Office determines that the cost of camp or recreation services exceeds regular costs because of the disability of the individual, the Area Office may consider funding costs over and above the regular fee.
 - Professional services: Consideration may be given to funding professional consultation when it is required to provide service under a mediator model, but is not available in the community.
- d) Services Outside Ontario: Services authorized by Special Services at Home for Ontario residents are generally purchased in Ontario. In exceptional circumstances, such as a service outside Ontario being more economical and accessible than a similar service inside Ontario, Special Services at Home may fund service outside Ontario with the approval of the Area Manager.

SERVICES NOT FUNDED

The following services are not funded under SSAH:

- 1) Basic Care - Costs related to caring for the basic needs of children or dependent family members. Examples of these costs include food, clothing, diapers, baby sitting, child care, dental care, ROUTINE MEDICAL COSTS and MEDICAL FEES IN EXCESS OF THE OHIP FEE SCHEDULE.
- 2) Child Care Fees - Regular costs of centre-based, family or informal child care or nursery school services which a family normally meets.
- 3) Basic Camp and Recreation Fees - Regular recreation costs which a family normally covers, such as overnight/day camp programs and swimming programs.
- 4) Education and Employment - Costs related to education, supported employment and vocational activities.
- 5) ASSISTIVE DEVICES, specialized equipment and dental service.
- 6) Home Modifications.
- 7) Professional Services - With two exceptions, the services of speech and language pathologists, physiotherapists, nurses, nursing assistants, occupational therapists, psychologists and other similar professionals are not eligible for funding through the SSAH program. These services should be obtained from an established community resource. The two exceptions are nursing services required for respite care and a professional to monitor the mediator model, if not available otherwise.