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Parental Reactions to Deafnes	s in Chi	idren: A Gro	ounded The	eory Investigation
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by

Brenda Tracy Poon



A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

in

Special Education (Deafness Studies)

Department of Educational Psychology

Edmonton, Alberta

Spring 1999



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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled PARENTAL REACTIONS TO DEAFNESS IN CHILDREN: A GROUNDED THEORY INVESTIGATION submitted by BRENDA TRACY POON in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in SPECIAL EDUCATION (DEAFNESS STUDIES).

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#### Abstract

The purpose of this qualitative investigation was to develop a substantive theory representative of the experiences and feelings of 7 hearing parents of deaf children. Four mothers and 3 fathers, each with a severely to profoundly deaf child, were interviewed using an open-ended, semi-structured approach. Each interview was audio-taped and transcribed then analyzed utilizing grounded theory techniques. Grounded theory techniques included constant comparison of incidents and concepts in order to determine the main concern of the participants and, moreover, the core conceptual variable. The main concern for each parent was choosing an appropriate educational program and communication mode conducive to each child's present and future well-being. The core conceptual variable that emerged was "parental appraisal of a child's deafness." The relationships between the core category and various contextual factors, intervening variables, strategies, and consequences were incorporated into a theory representative of the experiences of the participants interviewed.

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#### CHAPTER I - INTRODUCTION

### Statement of the Problem and Purpose of Study

Ninety percent of deaf children have hearing parents (Marschark, 1997; Moores, 1987). This creates an interesting context for child development and also presents specific issues for hearing parents of deaf children to contend with. Not only are parents coping with their own emotional reactions associated with the diagnosis of deafness in their child, but often also with inexperience and uncertainty with regard to the implications of deafness for themselves and for their deaf child. Parents try to gather information about deafness, make choices about the child's education, learn about communication options, and learn about services available amidst a context of a multitude of professional opinions, diverse and often conflicting information, as well as a complex interplay of personal feelings and emotions.

The feelings that parents experience following diagnosis have been compared to a grieving process including feelings of shock, frustration, guilt, denial, anger, stress, depression, and acceptance (Carver, 1988; Crowley, Keane, & Needham, 1982; Hadadian & Rose, 1991; Luterman, 1987; Ryan, 1992; Sharkey, 1987; Vernon & Wallrabenstein, 1984). A common consequence of this grieving process is that parents eventually cope with the realization that their child is deaf and that their child's deafness is irreversible. Parents resolve feelings of anger, frustration, depression, and denial to reach what Sharkey refers to as a "focusing outward stage" (p.16) and eventually a "closure stage" (p.16). According to Sharkey, the "focusing outward" stage involves parents seeking information and help about deafness, expressing feelings of relief and confidence, and an increased awareness of reality. The closure stage is described as a period where the child's needs are beginning to be met, and the child's condition is accepted. According to Luterman, this stage of acceptance is not without feelings of sadness and grief. This sadness, however, is characterized as no longer immobilizing to the parent.

While stage models were prevalent in the literature pertaining to parents' reactions to deafness in their children, little research existed to support either the nature of these stages or their progression. The conceptual difficulties of this were twofold. First, were there concrete stages of emotion representative of the experiences of hearing parents of deaf children? Second, if stages of emotions were indicated, what were the conditions or strategies associated with transitions between stages? The purpose of this investigation, then, was to discover the feelings and emotions experienced by hearing parents of deaf children following diagnosis over time as well as to discover any precursory conditions associated with these emotions. Before providing an overview of the investigation, the genesis for this area of study is briefly described.

# Personal Perspective

My interest in the experiences of deaf individuals and their families culminated during practica in community adult living programs, school-age programs, preschool programs, and early intervention programs. While my initial focus was on interaction with deaf individuals, my interest in parent-child relationships grew with each new practicum placement. I met parents of children who were newly diagnosed with hearing loss as well as parents many years post-diagnosis.

One placement involved participation in a parent group for parents of deaf children. During these group meetings, parents were given the opportunity to share with each other their experiences and feelings of raising a deaf child. I was intrigued by the feelings and experiences described and, moreover, by the intensity of expression. Interestingly, many parents expressed similar feelings and shared common experiences following diagnosis of the child's deafness. These similarities in feeling and experience as well as the apparent progressive nature of these emotions encouraged me to explore other practicum placements involving deaf individuals and their parents. My interest in the parent-child relationship also stemmed from talking to professionals about their role in

providing services for families with deaf children. Professionals also referred to the intensity of emotion in parental reactions following diagnosis of a child's hearing loss. Some professionals suggested that there existed a need to provide emotional support to parents of deaf children supplemental to the provision of developmental support to the child who was deaf.

During my practicum placements, I was interested in deaf children and how or if their parents' reactions to the diagnosis of hearing loss influenced the children's social and emotional well-being. I found through casual observation that each child's social and emotional behavior did appear to be influenced by a parent's particular reaction to the child's deafness and did appear to be a factor in how the parent interacted with the child. The nature of this influence was very uncertain, however, and led me to peruse the literature for more information pertaining to parents' experiences post-diagnosis. After my initial literature search, I was disappointed to find limited research concerning parents' emotional responses following diagnosis or the progression of these responses over time.

This combination of practical experiences with deaf children and their parents, discussions with professionals, and the results of my literature search led to my interest in discovering more about hearing parents of deaf children and, moreover, was the impetus for focusing upon the feelings and experiences of parents of deaf children post-diagnosis in this investigation.

# Overview of the Study

Seven hearing mothers and fathers of deaf children were selected for this investigation. Each parent was interviewed and asked to describe her/his experiences and feelings following diagnosis of her/his child's hearing loss. A review of the literature pertaining to hearing parents' reactions following diagnosis of a child's hearing loss is presented in Chapter II.

The data acquired were analyzed by using grounded theory techniques described by Glaser and Strauss (1967) and Glaser (1978, 1992). Grounded theory techniques allowed for grounding in the data. That is, the conceptual

categories or the findings of the study emerged from the data. Emphasis was placed on what was occurring for the seven parents interviewed rather than on preconceived hypotheses. The grounded theory techniques used in the present study are described in Chapter III.

Part of grounded theory methodology is the discovery of the main concern or social problem experienced by all the participants. In this study, the primary concern for each participant was choosing the most appropriate communication mode and educational program for her/his child socially, emotionally, and intellectually. The primary concern for the participants in this study is described in greater detail in Chapter IV. Various conditions or intervening variables influencing this concern for choosing an appropriate option for her/his deaf child emerged while analyzing the data.

The extent and nature of "parental appraisal of a child's deafness" emerged as the core conceptual category in this study. That is, the way that parents assessed the meaning of deafness, the variable roles present, the resources available to them, and the diverse reactions to deafness influenced each parent's pattern of behavior in trying to make the "right" choice for her/his deaf child. The part of each parent's pattern of behavior that was focused upon in this study was the participant's emotions or feelings at various points in time following diagnosis of her/his child's hearing loss. In Chapter IV, we will see how varying degrees and types of appraisal influenced the progression of feelings and experiences of the seven participants interviewed.

Chapter IV includes a description of the emerged substantive theory or, in other words, description of the core category and its relationship to other subcategories and properties. The substantive theory is presented as a set of integrated concepts or hypotheses that can explain the varying pattern of behavior described by each of the seven participants. Each conceptual category is described with reference to the theoretical codes described by Glaser (1978).

Illustrations of each core category are presented in Chapter IV in the form of quotes by various participants. In this way, the theoretical concepts are complemented by the richness and depth of each participant's own words and,

thus, provide readers with a sense of the lived experience. The core variable and, moreover, the substantive theory is described with reference to the existing literature in Chapter V. Chapter V also includes sections pertaining to implications for the findings, limitations of the present study, and suggestions for future research.

#### CHAPTER II -- REVIEW OF THE LITERATURE

Reviewing the literature in grounded theory investigations occurs throughout data collection and data analysis. In this way, those areas that emerge during the course of the investigation are reviewed as well as those areas deemed initially to be directly related to the area of study. Literature inherently related to the area of study pertained to hearing parents' emotional responses to a child's diagnosis of hearing loss and, more generally, parental reactions to diagnosis of a child's disability. Another less obvious area of review that emerged from both reading the literature and from interviews with parents pertained to loss and grieving. It became evident, however, that loss could not be discussed without at least some understanding of what was lost and grieved for, which frequently was the loss of an attachment relationship or bond. Thus, the literature reviewed can be categorized into three areas: a) attachment and loss, b) parental reactions following diagnosis of a child's disability, and c) reactions of hearing parents of deaf children following diagnosis.

# **Attachment and Loss**

According to Bowlby (1980), attachment involved behavior that resulted in a person "attaining or retaining proximity to some other differentiated and preferred individual" (p. 39). This behavior led to the formation of emotional bonds between individuals over the entire life-span. According to Hazan and Shavor (1990; as cited by Baron & Byrne, 1994), the nature of affectional bonds that may form include avoidant (discomfort with getting close), anxious-ambivalent (discomfort in belief that a lack of or minimal affectional bond would result in another's departure), and secure (desire to get close with no anxiety concerning another's departure).

Behavior affecting the formation of affectional bonds was influenced by representational models of self and of the environment (Bowlby, 1980).

Homeostatic systems were posited to provide a continuing management system whereby discrepancies between representational models and behavior were first identified then modified. Intense emotions experienced by individuals were the result of changes in the attachment relationships, whether its formation, maintenance, or loss (Bowlby, 1980).

Bowlby (1980) proposed that the loss of an attachment relationship resulted in either pathological or healthy mourning. Five factors influenced the nature of mourning: identity and role of person lost, age and sex of the mourner, causes and conditions of the loss, social and psychological conditions of the mourner (e.g., living arrangements, socio-economic status), and personality of the person mourning loss. Bowlby suggested that personality was the most influential factor determining the nature of mourning, whether disordered or healthy. Disordered mourning and psychological difficulties were suggested to be particularly associated with those mourning the loss of an immediate family member.

Since the goal of attachment behavior was to maintain proximity in order to create emotional bonds with others, any situation viewed as threatening that bond was shifting the balance of the homeostatic system (Bowlby, 1980). The higher the threats to homeostasis or loss of affectional bond, the greater the intensity of reaction to preserve the bond. Environmental conditions related to this shift in homeostasis were labeled stressors while the personal experience related to these stressors was termed distress. Reactions to the stressor included determining the cause of the situation and planning future actions (Bowlby, 1980).

Information related to the stressor may be difficult for an individual to process, for example, when the information about the stressor was discrepant with one's representational models. Those situations deemed as unfamiliar and severely endangering the affectional bond might be so difficult to process that individuals postpone evaluating the situation. One key determinant of responses to loss of the affectional bond include an individual's cognitive biases (Bowlby, 1980). Cognitive biases determine the effects of cognitive structures on

information processing. Cognitive biases were closely aligned with the representational models of self and of those to whom an individual has attached over the life span. Bowlby suggested that representational models formed from childhood experiences were particularly influential on the nature of responses to loss because of their establishment of patterns of affectional relationships and link to the cognitive biases associated with loss.

### Grieving

Numerous models of grieving have been proposed. While it is beyond the scope of this study to review all the previous models of grieving and loss, presentation of two models in this review will indicate two major trends of research in grieving: a) stage models and implications for psychological distress, and b) process models and implications for individuality in experience. Presented below is a brief overview, first, of one of the most pervasive stage models of grieving proposed by Kübler-Ross (1969) followed by a process model of grieving proposed by Martin and Elder (1993).

Kübler-Ross (1969) described five stages of grieving based upon interviews with over two hundred terminally ill patients. The stages of grieving included denial and isolation, anger, bargaining, depression, and acceptance. Denial was described as a temporary defense that was not usually maintained, rather, interspersed with periods of realizing the extent of the situation or, in other words, partial acceptance. Anger and resentment were described to follow this period of denial representing the period of confronting the reality of a situation. Anger was described as being random and multi-directed. Bargaining was a stage characterized by patients making agreements in hopes of stopping or delaying the undesirable event from occurring. Feelings of anger were to be replaced by a depression. Two types of depression were identified: reactive depression and preparatory depression. Reactive depression involved feelings of sadness associated with a sense of loss, while preparatory depression involved intense expressions of sorrow viewed as necessary steps to accepting and

preparing for the loss of all that was loved. A final stage described by Kübler-Ross was acceptance. The acceptance stage involved neither anger, sadness, nor struggle, it was "almost void of feelings" (p. 113) and characterized by a patient's quiet, restful, and peaceful state.

Another model of grieving was proposed by Martin and Elder (1993). Grief was defined as "the emotional, physical, intellectual, behavioral, and spiritual process of adjusting to the loss of someone or something of personal value" (p. 73). This model emphasized the dynamic and continual nature of the grieving process. Grieving by an individual was influenced by the context of her/his present and past life or, more specifically, by the assumptions made about the meaningfulness and significance of events and relationships in our lives. The grieving process included inward and outward journeys within an all-encompassing circle of influence. This circle of influence included such factors as time, support network, prior life experiences, gender, culture, and religious beliefs. The inward (e.g., protest, despair, detach) and outward (e.g., explore, hope, invest) journeys were represented by an "infinity" symbol. This reflected the continuity of the process between inward and outward journeys as well as the lack of a concrete starting point. Overall, this theory emphasized the individual and dynamic nature of the grieving process.

#### Coping

Coping involves efforts made to manage loss or any other stress perceived as demanding and taxing to the system (Lazarus & Folkman, 1984; Schilling, Gilchrist, & Schinke, 1984). Strategies used to cope with loss are distinctive from the actual outcomes of loss which include responses to loss and emotional reactions. The coping strategies themselves are neither positive nor negative. Coping occurs regardless of the outcome, whether viewed as adaptive or maladaptive (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus, 1993).

Both emotion-focused and problem-focused coping strategies have been identified in the literature (Lazarus & Folkman, 1984). Emotion-focused coping,

also referred to as cognitive coping, include efforts made to manage emotional responses to the stressor (Lazarus, 1991b). Examples include avoidance, distancing, selective attention, and self-blame. Problem-focused coping includes ways to manage the stressor itself such as use of particular problem-solving strategies.

Mikulincer and Florian (1996) proposed that there were two requirements for coping with loss: maintenance of attachment ties to the person lost as well as redistribution of energy and affectional needs to other attachment figures. Generally, adaptation was facilitated by a gradual reorganization of the attachment system. Maintenance of ties to the lost person was significant because it allowed individuals to incorporate "the past into the present without splitting important segments of their personal and social identity related to the lost attachment" (p. 279). At the same time, establishment of new attachment bonds allowed the individual to satisfy affectional and interpersonal needs. In this way, the bereaved individual could "work through the lost relationship not at the expense of the formation of present and future ties" (p. 279).

### Summary

The previous literature on attachment, loss, grieving, and coping were reviewed briefly. Each of these processes has been proposed in literature pertaining to hearing parents of deaf children. Overviews of each process indicated that attachment and loss were mutually influencing and, moreover, that the nature of attachment influenced responses to loss. As well, the review of the literature on grieving indicated that grieving might be viewed as a sequence of discrete stages or as a continuous and fluid process. Finally the coping literature indicated that emotion-focused and problem-focused ways of coping exist and that these ways of coping are influenced by the pattern of attachment relationships established. Next, a brief overview of the literature pertaining to the experiences of parents of children with disabilities will be provided followed by a review of the literature specifically regarding hearing parents' reactions to a

child's hearing loss.

# Parents of Children who were Disabled

This literature review includes presentation of previous research pertaining to parents of children with disabilities. Similarities between emotional reactions of parents of children who were deaf and parents of children with other physical, behavioral, and mental conditions have been proposed. This suggests that reviewing studies involving parents of children with various types of disabilities may yield important insights into the experiences of parents of children who were deaf. Another reason for the inclusion of literature on families with children with various disabilities was because of the relative abundance of literature pertaining to "disability" compared with that pertaining specifically to parents of children who were deaf. Two focus areas identified from the review of the literature on disability were a) grieving and b) stress and coping.

## Grieving

As indicated in the previous section, stage models of grieving were proposed to represent the experiences of those mourning the loss of a loved one. Stage models were also suggested to represent the experiences of parents with children who were disabled. The grieving process related to the loss of a loved one through death and the grieving process related to parental reactions to a child's disability may share similarities. Both may arise from a discrepancy between "what is" and "what should be" (Martin & Elder, 1993). That is, individuals may be struggling with "assumptions and expectations they had of themselves, others, and their world" (Martin & Elder, 1993, p. 74). The birth of a child who is disabled is often a great shock for parents who have probably idealized the expected baby. This idealized image of the baby is compared with the actual image of the baby. For parents of children with disabilities, a great discrepancy may exist between the idealized or expected baby and the baby

born (Bristor, 1984; Ellis, 1989). Parents, then, may grieve for the loss of the expected baby.

Previous literature indicated various phases of emotion associated with the grieving process of parents of children with disabilities. Some emotional reactions included intense and recurring feelings of sadness or, in other words, chronic sorrow (Fraley, 1986; Olshansky, 1962). Schneider (1983) described five stages to a holistic model of grieving for parents of children with disabilities: initial awareness, strategies to overcome loss, awareness of loss, completions, resolution and reformulations, and transcending loss (as cited by Ellis, 1989). Stages could be overlapping or simultaneously occurring and did not necessarily follow any prescribed sequence. Initial awareness included feelings of being overwhelmed, guilt, and stress. Strategies to overcome loss constituted a stage involving parents' struggle to retain the image of the expected child but also letting go of that image in order to deal with the loss. Completions referred to acceptance of the loss, while resolution and reformulations involved a sense of increase power and control. Finally, transcending loss involved energy being freed from grief and allocated to new areas. Parents at this stage often experienced feelings of growth and enhanced self-trust.

Another model proposed by Fortier and Wanlass (1984) also included five stages: impact, denial, grief, focusing outward, and closure. The impact stage was associated with the awareness of the existence of a threat to personal well-being or life goals. Denial occurred often immediately following diagnosis and involved wishful thinking, while grief was a period of adjustment in which individuals felt great sadness and sense of loss. Focusing outward marked the end of wishful thinking and the beginning of accepting the reality of the situation. The final stage of closure involved the awareness of the significance of the situation and the implications for personal well-being. This awareness contributed to adaptation and a "realistic sense of hope" (Fortier & Wanlass, 1984, p. 20).

The grieving stages proposed to describe the experiences of parents of children with disabilities did share similarities to those proposed with reference to

the loss of a loved one, particularly in referring to the sadness and sense of loss experienced. Distinctions could be made, however, from Kübler-Ross's (1969) stage model. The primary distinction was the inclusion of the adaptive stages such as transcending loss, focusing outward, and closure. These adaptive stages, however, did appear to be associated with the outward journey proposed by Martin and Elder (1993) including the phases explore, hope, and invest. This suggests that parents of children who were disabled were believed to eventually be able to work through their feelings of intense sadness and grief and reach phases of growth and acceptance.

Interestingly, though, the grieving and crisis stages proposed have primarily stemmed from theoretical commentaries and anecdotal (e.g., Heller Miller, 1995) literature. Few empirical investigations have explored the reactions by parents to a child's disability and determined the relevancy of grieving stages to actual parental reactions. Future research is needed to examine the reactions of parents following diagnosis of a child's disability and, moreover, to discover how parents of children who were disabled were able to adapt in a context of potential stress and adversity.

### Stress and Coping

Much of the research involving families with a child who was disabled involved cross-sectional studies that compared the distress, coping, and difficulties of parents of children who were disabled with that of parents of children without any identifiable disability. Previous research often included self-report measures of such variables as stress, social support, adjustment, stress-related psychopathology, and depressive symptomatology. Some previous research, although very limited, also included longitudinal investigation (Goldberg, Morris, Simmons, Fowler, & Levison , 1990; Hanson & Hanline, 1990), observation (Hanson & Hanline, 1990), or interviews with parents of children who were disabled (Hancock, Wilgosh, & McDonald, 1990; Hanson & Hanline, 1990; Kazak & Marvin, 1984, Scorgie, 1996).

Research indicated that parents of children who were disabled tended to have higher stress levels than parents of children who were not disabled (Breslau, Staruch, Edward, & Mortimer, 1982; Kazak & Marvin, 1984), mothers tended to be particularly subject to stress (Hanson & Hanline, 1990; Kazak & Marvin, 1984), parents of children who were disabled had small but dense support networks (Kazak & Marvin, 1984), and parents of children with disabilities did not indicate difficulties in marital satisfaction (Abbott & Meredith, 1986; Kazak & Marvin, 1984). Generally, studies have indicated that the birth of a child who was disabled represented a transition where parents did experience higher levels of stress than parents of children who were not disabled and often needed to restructure family roles. Stress levels, however, were not related to the type of disability of the child (Breslau et al., 1982; Hanson & Hanline, 1990). That is, contrary to some hypotheses of stress levels being strongly influenced by type of disabling condition, the critical factor influencing parental stress levels was not related to the medical classification of the disability. In other words, "diagnostic category alone does not define the level of disability" (Breslau et al., 1982, p. 685).

The stress experienced by parents of children who were disabled was often associated with parenting issues or, more specifically, pertaining to the day-to-day demands of being the parent of a child with specialized needs (Breslau et al., 1982; Goldberg et al., 1990; Kazak & Marvin, 1984). Other researchers (Hanson & Hanline, 1990) suggested that factors other than the demands associated with parenting a child with a disability, such as socioeconomic status or presence of personal problems experienced by the parent, may have contributed to higher stress levels found in parents of children with disabilities.

Although parents were reported to experience stress, parents were still found to adapt in functional ways. One study, for example, including parents of children with spina bifida indicated that the presence of a spousal subsystem involving specialized roles was a factor influencing adaptation (Kazak & Marvin,

1984). In relation, another study, conducted by Trute and Hauch (1988), indicated that high spousal cohesion was associated with parental adjustment. Interestingly, degree of spousal consensus was found not to be a strong influencing factor on adaptation. That is, the bond and closeness within a couple had greater influence on positive adaptation than degree of agreement or disagreement between marital partners. Another study (Abbott & Meredith, 1986) comparing the marital and family strengths of parents of mentally retarded children and those of parents of intellectually average children indicated that spousal support was particularly influential to adaptation.

Other factors found to influence adaptation included high family integration or family unity, assigning positive meaning to the situation, accepting children like other children in the family, willing to work with the child's limitations, and focus upon the child's unique skills and strengths (Abbott & Meredith, 1986) The child's attitude was also found to be a coping resource for parents of children with disabilities whereby a child's positive attitude was associated with greater optimism by the parent (Hancock et al., 1990). Personality qualities of the parent such as nurturing and affiliative characteristics (Abbott & Meredith, 1986) as well as inner strength, optimism, and self-confidence (Hancock et al., 1990) were associated with adaptation. Provision of social support to the parent as well as parent's maintenance of social support networks were also found to influence parents' adaptation to the demands associated with being the parent of a child who was disabled (Barakat & Linney, 1992; Hancock et al., 1990; Hanson & Hanline, 1990; Kazak & Marvin, 1984; Trute & Hauch, 1988)

Overall, previous researchers (Hanson & Hanline, 1990; Lillie, 1994; Trute & Hauch, 1988) emphasized that being the parent of a child who was disabled did not necessarily predispose them to psychopathology, depressive symptomatology, or less functional parent-child relationships as some research had indicated in the past. Rather, parents of children who were disabled were found to adapt in functional ways and to identify life-enhancing aspects of being parents of children who were disabled. One study (Scorgie, 1996), for example, indicated that positive personal (e.g., enhanced sense of personal strength),

relational (e.g., new friendships), and perspectival (e.g., valuing each day) transformational outcomes were associated with parenting a child with a disability. Further research is needed examining transformational outcomes as well as parental coping strategies, particularly, those associated with successful, adaptive functioning (Abbott & Meredith, 1986; Hancock et al., 1990; Hanson & Hanline, 1990; Kazak & Marvin, 1984).

## **Hearing Parents of Deaf Children**

Deafness has been referred to as the "unseen handicap" (Styles, 1986) because hearing loss is unlike most other physical disabilities in that it is not detectable from simple observation. This "invisible" nature of deafness contributes to the ambiguity associated with the birth of a child who is deaf (Rodda & Grove, 1987). Because congenital hearing loss is often not detected at birth, parents continue to have expectations of a normal, healthy child well after the child's birth. The diagnosis of a child's hearing loss, then, can be a source of great shock to some parents who did not suspect hearing loss or, alternately, a sense of relief for other parents who suspected a problem but were unable to specify the precise nature of the problem (Rodda & Grove, 1987). Therefore, the diagnosis of a child's hearing loss is associated with numerous, complex and variable emotional reactions. The nature of these reactions, as indicated by previous research, is described in the following section.

### Grieving Process

As alluded to previously, following diagnosis of a child's disability, parents may engage in a grieving process. Discrete emotional stages, however, such as those described by Kübler-Ross (1969), were perhaps too simplistic and linear to account for the complex, cyclical, and diverse emotional reactions of hearing parents of deaf children (Kampfe, 1989; Luterman, 1987, 1991). Variability in reaction was attributed to the influence of each parent's unique pattern of prior

expectations and experiences. These expectations and experiences shaped how each parent assigned meaning to an event and, moreover, determined an event's significance to personal well-being (Luterman, 1987).

Feelings of shock, anxiety, anger, sadness, regained confidence, acceptance, and renewed sense of confidence were present in literature related to parent's reactions to her/his child's deafness (Koester & Meadow-Orlans, 1990). Luterman (1987, 1991) also suggested many feelings as associated with parents' grief reactions including shock, anxiety, anger, depression, guilt, resentment, vulnerability, confusion, panic, and denial. Luterman (1991) suggested that negative feelings were bases to the establishment of positive behavior:

Thus, the grief can become the sadness that enables the clients to appreciate what they have, the anger can become the energy to make change, the guilt can become the commitment, the recognition of vulnerability can become the means by which clients reorder priorities, and the resolution of confusion can become the motivation for learning. (p. 65)

Kampfe (1989) described other emotional stages associated with parental responses to a child's hearing loss including recognition, where parents realized the severity and impact of the situation, and acknowledgement or constructive action, where parents began to confront reality, discussed deafness openly, and developed realistic hopes for their child. Kampfe noted the diversity and individuality in reactions owing to the effects of variable factors or intervening variables (e.g., degree of social support, personal resources, and availability of services). Interestingly, emotional reactions related to confrontation of reality and adaptation, such as the acknowledgement or constructive action stage described by Kampfe, have been allotted limited attention in previous literature. Greater attention has been placed on the immediate, intense feelings occurring near the time of diagnosis of hearing loss rather than the course of adaptive stages

occurring throughout the child's development from infancy to adulthood.

In fact, previous literature was predominately related to experiences of parents when the children were in infancy (Greenberg, 1983; Meadow-Orlans, 1994, 1995) or school age (Calderon & Greenberg, 1993; Kashyap, 1986). Two studies (Henggeler, Watson, Whelan, & Malone, 1990; Morgan-Redshaw, Wilgosh, & Bibby, 1990) pertained to the adaptation of families with youths who were deaf. Greenbaum and Markel (1990) suggested that the extent of parental crisis reactions were influenced by the nature of life-cycle events related to the age of the child. These life-cycle events included diagnosis, preschool years, school entry, late childhood, adolescence, adulthood, and aging parents. Future research, then, is needed in exploring not only the adaptive emotional reactions of parents of deaf children, but also the nature of these reactions throughout the child's development and, particularly, during late childhood, adolescence, and adulthood.

### Neglect of Fathers in the Literature

Traditionally, studies involving hearing parents focused on the treatment, programming, and education of mothers of deaf children. Little attention was placed on fathers of deaf children (Crowley et al., 1982; Greenberg, 1983; Hadadian & Rose, 1991; McNeil & Chabassol, 1984; Sharkey, 1987; Vernon & Wallrabenstein, 1984). Hadadian and Rose noted the significance of the triadic model of interaction in examining parent-child interactions. This model identified mothers, children, and *fathers* as key contributors to the overall adjustment and well-being of each individual in the family. Thus, the role of fathers needs to be more thoroughly addressed in studies involving parents of deaf children.

Only two studies (Crowley et al., 1982; McNeil & Chabassol, 1984) examined the specific needs of hearing fathers in coping with their child's deafness. McNeil and Chabassol investigated the involvement of fathers in the care and treatment of their deaf children. Both the fathers and mothers indicated that the fathers were very involved, attached, and accepting of their deaf

children. While fathers felt they were adequately involved in the lives of their child, approximately 40 percent of the fathers felt embarrassed when in public with their deaf child. Crowley et al. also examined the levels of involvement of hearing fathers of a deaf child. Fathers expressed greater feelings of involvement and understanding after participating in a series of parent-infant deaf intervention programs.

### Summary and Limitations of Past Research

Literature related to attachment, loss of a loved one, parents of children who were disabled, and parents of children who were deaf was reviewed in order to obtain a better understanding of the myriad of complex processes that were potentially associated with the reactions of parents of children who were deaf.

Attachment, loss, stress, grieving, adaptation, and coping all appear to be influential in shaping parental reactions. The review of the literature suggested that the nature of attachment formed and changes to attachment relationships influenced emotional reactions to loss and also ways of coping. Perceived loss of an attachment relationship could result in intense phases of grieving. Grieving models varied in nature, ranging from discrete stage models to fluid process models. The nature of grieving for parents of children with disabilities may pertain to grieving for the loss of an expected baby and expected way of life. Responses to loss for parents of children with disabilities and particularly for parents of children who were deaf involved phases of growth, hope, and constructive action in addition to those phases specifically related to grief and intense sadness. This suggested that many parents were able to adjust to periods of transition and reach adaptive levels of functioning.

The nature of adaptation and, moreover, the means by which parents achieved adaptation has been provided limited focus in previous literature particularly with regard to experiences of parents of deaf children. As well, previous research has included minimal study of experiences of parents throughout various stages of child development, particularly adolescence and

adulthood. Another limitation was the lack of inclusion of fathers in studies examining parental reactions to a child's hearing loss. These limitations in previous research indicated the need to explore the nature of parents' reactions to deafness in children and, more specifically, to investigate various phases of emotional response for mothers and fathers of children who were deaf and at varying stages of development.

## Statement of Research Questions and Aims of the Current Study

Given the limitations of past research, there exists a need to explore phases of reaction and adaptation experienced by parents of children who were deaf. The purpose of this study was to investigate the various phases of emotional response and, particularly, those emotions associated with coping and adaptation. A qualitative research design and, more specifically, grounded theory methodology was used to explore the feelings and experiences of seven hearing parents of children who were severely to profoundly deaf. The study examined the nature of parental experiences with respect to the following:

- 1. What types of thoughts, feelings, or emotional reactions were experienced by mothers and fathers at various points in time following diagnosis?
- 2. What factors were associated with varying responses?
- 3. How did mothers and fathers compare in their reactions? What similarities or differences existed?

These questions served as guides for exploration rather than rigidly set foci of investigation. They served to identify theoretical areas of inquiry and provided potential focal points for the interviews. The nature of the findings, however, is dependent on the concepts that have *emerged* from the data rather

than the need to answer preconceived research questions. This exemplifies the emergent nature of qualitative research and indicates the "fit" of a qualitative research design and, particularly, grounded theory methodology to this investigation. Chapter III provides further description of grounded theory methodology and, specifically, techniques associated with data collection and analysis.

#### **CHAPTER III -- METHOD**

# **Grounded Theory Methodology**

The grounded theory approach is a method that uses "a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss & Corbin, 1990, p. 24). Emphasis is on the generation of concepts that are "relevant theoretical abstractions about what is going on in the area studied" (Glaser & Strauss, 1967). Following various levels of coding and comparative analysis, which are described in further detail in the Data Analysis section, a theory emerges which is representative of one or more aspects of the main concern for the participants under study.

Fit and relevance of the theory to the participants' experiences are achieved through continually asking questions of the data such as "what category or concept does this incident indicate?" or "how does this incident compare with a previous incident?" Glaser (1978) emphasized the importance of generating concepts which have emerged from the data rather than any preconceived notions pertaining to the main concern or basic social problem for the participants.

While description of the meaning of grounded theory was consistent throughout the literature reviewed, the specific procedures and techniques used in grounded theory methodology varied depending upon the resource referenced. In order to better understand the ambiguities present in descriptions of grounded theory analysis, a brief description of the roots of grounded theory is necessary.

Two sociologists, Barney Glaser and Anselm Strauss, originally developed grounded theory methodology. Glaser and Strauss presented their method in 1967 in the book <u>The Discovery of Grounded Theory</u>. Glaser then elaborated upon the description of grounded theory methodology in his 1978 book <u>Theoretical Sensitivity</u>. Individually, Glaser and Strauss further developed

grounded theory methodology in two monographs. Strauss in collaboration with Juliet Corbin (1990) provided a description focused upon grounded theory analysis while Glaser's monograph (1992) was written in reaction to Strauss and Corbin's work. Glaser refuted Strauss and Corbin's description of grounded theory analysis because of its conduciveness to forcing and preconception rather than to emergence.

Because of the discrepancies between the monographs, each monograph was compared with the original publication by Glaser and Strauss in 1967. The description of grounded theory analysis in monographs written by Glaser in 1978 and 1992 were closest conceptually to the original 1967 description. Therefore, those procedures and techniques of grounded theory analysis described by Glaser and Strauss (1967) and Glaser in 1978 and 1992 were focused upon during data analysis for this study. Further description of grounded theory analysis techniques used in the present study is given in the section on data analysis.

# Implementation of the Study

## Selection of the Participants

Participants were selected through purposeful sampling techniques. According to Patton (1990), purposeful sampling is the process of selecting information-rich cases. That is, participants are chosen because of the belief that in-depth information pertaining to the research question can be acquired. Given that parental experiences were the focus of this investigation, hearing parents of deaf children were viewed to be information-rich informants.

Agencies and educational institutions within a Western Canadian metropolitan area that provide services to severe to profoundly deaf children were contacted following appropriate ethical clearance. Professionals at each of the agencies and institutions were informed of the study and asked to be key informants for the investigation. Professionals were asked to nominate parents of

deaf children who were or had been involved with their school or agency.

Nomination criteria were provided to each professional in order to assist nomination of potential participants for the study. Professionals were asked to nominate parents who met the following criteria: was the mother or father of an individual who is severely to profoundly deaf (i.e., with a minimum unamplified three-frequency (i.e., 500, 1000, and 2000 Hz) pure tone average of 70 decibels); was not deaf or hard of hearing; was able to speak and read English; was willing to communicate about this topic; was currently or previously involved with agency or school programs (e.g., parent, staff member).

The reason for the selection of participants who were parents of children with severe to profound hearing losses was that severe to profound hearing losses were usually associated with "deaf" children while lesser degrees of hearing losses were associated more with "hard of hearing" children (Moores, 1987). Parents of deaf children and parents of hard of hearing children may or may not have similar experiences or feelings. The focus here was on the parents of deaf children. As well, since the study involved an audio-taped interview, the nominee needed to feel comfortable talking about her/his feelings and experiences. Past or present involvement with the agency or school program was included as a criterion because it likely led to nominations of participants residing within or near the metropolitan area. It also allowed me to incorporate each professional's insights and experiences with parents in order to obtain information-rich cases.

Professionals were also asked to nominate mothers and fathers who expressed greater confidence in parenting a child who was severely to profoundly deaf; sought or were seeking information or help about deafness; began or continued to meet the child's needs; realized that the child was deaf and that deafness was irreversible. The behaviors indicated by the aforementioned criteria were theoretically associated with adaptation and positive coping outcomes. The goal of the nomination criteria was to identify parents who were believed to have experienced various and numerous phases of emotional reaction, the most recent of which were linked to adaptive

consequences for both the hearing parent and the child who was deaf. In this way, the inclusion of parents who had experienced a wide range of emotional reactions ranging from intense feelings of sadness and grief to feelings of increased confidence and optimism about the child's future could be identified.

After the eligibility of parents of deaf children was determined, professionals contacted potential participants initially in order to briefly describe the purpose of the study as well as to make an initial query as to their interest in participation. A parent invitation, which provided a brief introduction into the purpose and rationale for the study, was distributed to each nominee. Parents who showed interest in participating directly contacted the investigator or were contacted by the investigator.

### Description of the Participants

Seven participants representing six families (i.e., two participants were married and parents of the same child) were selected for this study: four mothers and three fathers (see Table 1 for participant descriptions). Five of the seven participants were married (i.e., two mothers and three fathers). Two participants were single mothers. Six of seven parents were employed full or part time during the time of the interviews. One parent was a homemaker and stayed at home to take care of the children. The total number of children who were deaf within these families was seven. Four of the children were males and three were females.

Hearing loss in the better ear ranged from severe to profound (i.e., minimum pure tone average of 70 decibels) for six of the seven children. One child had a profound hearing loss in one ear and a moderately severe hearing loss in the other ear. Six of the seven children had congenital hearing losses while one child had a progressive hearing loss. Five of the seven children possessed only a hearing loss, while two children possessed physical conditions in addition to hearing loss.

Modes of communication used with the children who were deaf included

speech, sign-assisted speech, or solely sign language. Six of seven parents used sign language consistently during interaction with their children while one parent reported only using sign language occasionally for clarity. Educational backgrounds for the children included aural-oral, bilingual-bicultural, total communication, and integrated programs. The child with both a profound and moderate hearing loss wore a hearing aid in one ear and received supplemental speech training as part of the educational program. At the time of the interviews, one child was in a preschool program, three were in elementary school, one was in senior high school, one in post-secondary studies, and one was seeking employment.

Table 1

<u>Participant Descriptions</u>

PARTICIPANT	AGE (YEARS)	NUMBER OF CHILDREN	AGE OF DEAF CHILD(REN) (YEARS)	BIRTH ORDER OF DEAF CHILD(REN)	AGE CHILD(REN) DIAGNOSED (YEARS)	DEGREE OF HEARING LOSS
Α	30-34	2	0-4	First	1-2	Profound
Mother						
В	55-59	2	30-34	Second	2-3	Profound
Mother						
С	40-44	2	20-24	First	1-2	Severe to
Mother						profound
D	30-34	2	0-4	First	1-2	Profound
Father						
E	50-54	2	15-19	First	2-3	Severe to
Father						profound
F	35-39	3	5-9	Second	1-2	Profound
Father			*5-9	*Third	*0-1	*Profound & moderately severe
G Mother	35-39	1	5-9	Only Child	1-2	Profound

<u>Note.</u> Asterisk (\*) designates a second child who was deaf in a family. Ages are presented as age ranges rather than specific ages in order to protect the anonymity of the participants.

### **Data Collection**

Professionals from four different agencies and educational institutions nominated parents for this study. Four parents were contacted by telephone, while the other parents contacted this investigator directly. The initial telephone conversation consisted of a description of the purpose of the investigation. Each parent was asked to be a participant in the study. If the parent agreed to participate, a brief meeting between the investigator and the participant was arranged in order to establish rapport, describe further aspects of the investigation, provide orienting instructions to help participants prepare for and understand what was desired in the interview, answer any questions, discuss and distribute the informed consent forms (see Appendix A), obtain participant descriptions in a brief background questionnaire, and to set up a time and place to conduct an interview.

Five of the initial meetings were conducted in the participants' homes while the other two were conducted in the participants' workplaces. The initial meetings were between 30 to 60 minutes in length. The initial meetings and interviews occurred in March and April of 1998.

### Interview Procedure

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Data were collected through open-ended semi-structured interviews. According to Patton (1990), understanding another's perspective is the primary purpose of interviewing. One can enter a person's world and try to discover what life is like for other individuals through their eyes. Individuals may reflect upon their experiences in their own words (Bogdan & Biklen, 1992). Patton described three basic approaches to open-ended interviewing: informal conversational, general interview guide, and standardized. For the purposes of this investigation, the general interview guide approach was selected. The general interview guide included topic areas or broad focus points for the interview. It allowed the interviewer to ask relevant questions; yet, at the same time, participants could

elaborate upon or clarify points and could also take the lead in initiating topic areas. A natural flow, spontaneity, and flexibility was achieved through this approach. It should be noted that an informal conversational approach was also viewed as an appropriate open-ended interview approach. Given the limited experience of this researcher in interviewing participants, however, a general interview guide was selected because it not only allowed flexibility in interviewing but also was conducive to feelings of preparedness and readiness in this researcher. This researcher was not yet comfortable in following the spontaneous and impromptu nature of the informal conversational approach.

Topics which were covered during each interview included each participant's descriptions of reactions to diagnosis, choice of educational program, involvement in child's activities, feelings towards her/his child and her/his child's deafness, and so forth. The questions allowed parents to tell their stories of what it was like to raise a deaf child. The questions varied slightly from interview to interview. As each participant was interviewed, the investigator wrote brief memos about the participant's experiences or about the interview itself; these memos were used to guide potential areas to explore for the next interview. New questions were added when a new area to explore was discovered, and other questions were withdrawn or modified if they were ambiguous or repetitive.

Emphasis was placed on encouraging each participant to share her/his feelings and experiences without asking questions that led the participant to specific types of responses. For example, parents were not asked if they felt grief or sadness following diagnosis of the child's hearing loss. Instead, parents were asked a question such as, "How did you feel when you learned about your child's hearing loss?" This type of open-ended question encouraged participants to share their experiences in their own words rather than in those introduced by the interviewer. In this way, specific topics could be introduced by the interviewer without imposing the interviewer's hypotheses or assumptions about parental reactions on participant responses.

Each interview was audio-taped and transcribed. The investigator

transcribed six of the seven interviews; one interview was transcribed by a medical secretary. The medical secretary signed an oath of confidentiality form in order to ensure that the content of the interview would remain confidential. The interviews were transcribed from March to June 1998. Each participant was contacted and asked to participate in a follow-up meeting in order to discuss the transcript. At this point, the participant clarified points, verified any ambiguities in the transcript, elaborated upon any responses, and asked any questions related to the interview or the study in general. Analysis began in May 1998 and continued through August 1998.

Following analysis, another follow-up meeting with the participants was set up so that interpretations could be shared and discussed. All participants resided in the metropolitan area at the time of the interviews, however, one participant moved to another area during the period of the follow-up interviews. Therefore, the last follow-up discussion of the study with this participant was conducted over the telephone. All other follow-up meetings occurred within the metropolitan area. The techniques and guidelines used for analysis are described in the next section.

### Data Analysis

Analysis in the grounded theory approach involves procedures that will build a theory which "closely approximates the reality it represents" (Strauss & Corbin, 1990, p. 57). Some general guidelines for analysis included the following: a) analysis occurred throughout the research process, b) the guidelines and their procedural order were not rigidly set; they changed throughout the course of the study, c) data collection and data analysis occurred alternately as each took turns in directing the other, and d) each aspect of analysis involved asking questions of the data and of oneself as well as making comparisons both within and between data.

Analysis in the field involved following the leads of each data-collection session. While looking through fieldnotes, new discoveries or observations

developed which helped to direct data-collection sessions to new or unexplored areas. Insights were recorded consistently. Memos were written so that discoveries and emerging patterns were reflected upon. Visual devices, such as diagrams and charts, were constructed to aid in organizing and visually representing a set of ideas or concepts.

Analysis after data collection involved using coding and categorization procedures. Three types of coding are characteristic of the grounded theory approach. They are open coding, selective coding, and theoretical coding. Each type of coding was used throughout this investigation.

Open Coding. Open coding involved line-by-line analysis of the data. It involved continually asking questions of the data such as "what concept or category does this incident represent?" and "how is this concept or category similar to or different from other concepts or categories?" By continually asking questions of the data and constantly comparing incident with incident as well as category with category, emergence of concepts from the data was facilitated. Each incident was assigned a conceptual title until no new categories were emerging, that is, until a point of theoretical saturation was reached.

Selective Coding. Selective coding involved focusing analysis on one core variable and using the core variable to guide analysis (Glaser, 1978). Each category and property was compared with the core category in order to determine if or how a relationship existed. Focus was on first identifying whether an incident represented a category or property of the core category and second on potential relationships between the category or property with the core category. The core category or variable was identified because of its relation to most of the other categories and properties and its frequency of reoccurrence while coding.

<u>Theoretical Coding.</u> Glaser (1978) described 18 theoretical codes. Each of the categories and properties that emerged from open and selective coding was

assigned a theoretical code. This occurred by comparing each category and its properties with the core category in order to determine the extent of the relationship between them. In this study some theoretical codes which emerged included cause, context, condition, strategy, and consequence.

### Overview of Coding Procedures

- Each interview was audio-taped and transcribed. Listening to audio-tapes following the interviews allowed memos to be written concerning the interview. These memos often stimulated questions to be created, edited, or deleted for the next interview with a participant. Questions, then, from the general interview guide were modified continually during data collection.
- Each of the transcripts was read repeatedly. With each read-through notes were written in the margin of the transcript regarding potential conceptual categories that came to mind. A line-by-line analysis occurred.
- 3. Each participant was given the opportunity to read over the interview transcripts and clarify or elaborate upon anything from the initial interview. Participant comments were written directly on the transcript. The investigator then retrieved the transcripts in order to incorporate the comments into the analysis process.
- 4. Each incident was compared with previous concepts. Incidents were compared for similarities and differences. If incidents appeared to refer to a similar concept, they were provided with a similar code. If incidents were different, then this incident would be provided with a new conceptual category title or compared with other incidents that appeared similar to it. Through this procedure, transcripts were coded

to result in various conceptual categories. Concepts that emerged from the data were then used to guide new areas to explore in the forthcoming interviews.

- 5. Memos were written during coding to determine new areas to explore in future interviews, to compare similarities and differences between incidents (constant comparison), to determine an apt conceptual category name, to determine category properties and sub-properties, and to determine potential connections between conceptual categories. Open coding and selective coding, thus, occurred interchangeably.
- Once all the interviews were completed, interviews continued to be transcribed and coded. Eventually, each incident had been assigned a conceptual title and no new categories were emerging, thus, theoretical saturation had occurred.
- 7. Relationships between categories were considered continually and recorded in memos. Categories were compared with one another resulting in some categories being merged while some were separated. Eventually, the category that emerged frequently and also had the most numerous categories related to it was identified as the core category.
- 8. The coding notes used to determine conceptual categories were read repeatedly along with the examples of data that led to the codes. Category names were transferred to color-coded index cards such that each participant was represented by a different color. Categories were then compared with one another across the different participants. In this way, incidents could be compared with one another once again to determine if each incident was relevant to the others and also if each

- incident fit with the conceptual category. What resulted was an ordering of all the conceptual categories which emerged and all the relevant examples in a set of piles.
- 9. Each of the conceptual category piles was read through with relevance to the core category as the primary focus. Additional memos were created to record potential relationships between categories and, moreover, relationships to the core category (i.e., theoretical coding). Those theoretical codes provided by Glaser (1978) were used to identify potential theoretical codes. Eventually, each category was assigned a theoretical code. In this way, selective coding and theoretical coding occurred interchangeably.
- 10. Once coding was completed, all the memos were gathered together. Each was then cut into different segments and sorted according to similarity in theoretical code. In other words, theoretical sorting occurred. Each sub-category of each theoretical code created by theoretical sorting was distinguished by using color-coded labels.
- 11. Diagrams were created throughout the theoretical sorting process to visually depict the relationships that emerged. The memos and the diagrams were then integrated to form a visual representation of the theory that emerged (see Figure 1 in Chapter IV)
- 12. Each participant was provided with an overview of the theory at a follow-up meeting. Parents had the opportunity to discuss my interpretations of the data, provide feedback, and modify in conjunction with this investigator. In this way, parents were involved in data analysis and, specifically, were able to describe whether concepts, such as those pertaining to the core category of reappraisal, corresponded with their own descriptions.

- 13. Following theory emergence, the findings including description of the core category and its associated theoretical codes and sub-categories were integrated into Chapter IV of the thesis.
- 14. Literature relevant to the theory that emerged was then reviewed.

  Comparisons between the substantive theory and the relevant literature reviewed are presented in Chapter V.

### **Bracketing: Personal Perspectives**

In qualitative research, researchers attempt to understand the realities of their participants or to "objectively study the subjective states of their subjects" (Bogdan & Biklen, 1992, p. 46). This understanding develops through the intuitiveness and insights of the researcher (Borg & Gall, 1989). Therefore, the key instrument for qualitative analysis is the researcher. Difficulties arise, however, in deciphering the point where objectivity ends for the researcher and subjectivity begins. Biases, prejudices, and presumptions may sway interpretations in one direction or another. As a result, researchers must constantly confront and acknowledge their preconceptions and foreunderstandings in order to successfully hold them in abeyance. This process of confronting biases, beliefs, prejudices, and preconceptions about a phenomenon under investigation is referred to as bracketing (Gall, Borg, & Gall, 1996; Patton, 1990). My preconceptions regarding parental reactions to deafness in children will be discussed initially from a theoretical perspective and then from a personal perspective.

### **Theoretical**

One theoretical presumption pertains to parental reactions following diagnosis of deafness. An assumption is that deafness may create grief and

stress for parents of deaf children, which, if not resolved, may have negative, enduring effects on the nature of the relationship between parent and child. These preconceptions of problems in coping or adaptation must not result in an expectation that every parent-child relationship involving a child who is deaf will experience difficulties. Every family must be viewed on its own and within its own context.

A second theoretical presumption is that parents' reactions to a child's hearing loss will have an effect on the socio-emotional adjustment of the entire family. It must be acknowledged that parental reactions may have a great impact, little impact, or perhaps, no impact at all on the parent-child relationship. For example, any child who may be perceived to have difficulties socio-emotionally should not be automatically assumed to have been rejected by her/his parents. Parental reactions may have no influence on the parent's or the child's adjustment. Other factors or intervening variables may influence coping and adaptation processes.

An additional assumption is related to mothers' and fathers' responses and reactions to children who are deaf. Given the negligible presence of fathers in the literature and in my own practical experiences, I have a preconception that fathers may be less involved in the lives of their deaf children. This perceived lack of involvement led to a presumption that fathers have more difficulties in coping and adjustment than mothers. While these presumptions are based on little empirical data, this personal expectancy must be identified. Recognition of these preconceptions will ensure that equal attention is given to fathers and mothers and that fathers are not presumed to be more or less accepting in their reactions than mothers.

### <u>Personal</u>

In addition to drawing upon the theoretical aspects of self-awareness, a researcher must also note any preconceptions related to personal experience that may influence interpretation. Through observation and practicum visits to

various agencies, I discovered that I have my own biases regarding parental reactions and deaf children. These biases are rooted in my view that sign language, deaf role models, and deaf peers can be important aspects in the socio-emotional adjustment of some deaf children. Thus, I realize that my advocacy for certain educational contexts and communication modes chosen for deaf children may influence my perceptions of what constitutes more or less positive reactions.

My hope is to discover the nature of parental reactions to deafness in children and, moreover, to better understand how parents' emotions are variably experienced and expressed. I realize that my conceptions may differ from others and moreover, that my own understandings should not be used as a yardstick upon which other perceptions are based. My goal is not to judge others as right or wrong, but rather to search and explore their varying perspectives.

### **Establishing Credibility**

According to Patton (1990), establishing credibility in qualitative research is dependent upon a) techniques and methods used to ensure integrity, validity, and accuracy of findings; and b) researcher qualifications, experience, and perspective.

### Valid Techniques

One set of techniques for establishing credibility is triangulation. Triangulation reduces systematic bias in the data because it involves checking findings against other sources and perspectives (Patton, 1990). There are four types of triangulation in qualitative inquiry: a) methods triangulation, b) data source triangulation, c) analyst triangulation, and d) theory or perspective triangulation. In this study, triangulation of data source, analysts, and theories occurred. Methods triangulation was not an aspect of this study as only one type of methodology, grounded theory, was utilized throughout data collection and

data analysis.

Triangulation of data sources enables examination of the consistency of different data sources within the qualitative method (Patton, 1990). One way to triangulate data sources is to compare perspectives of different people in order to better understand each point of view with reference to a single experience. Interest in this study was in both mothers and fathers of deaf children. By including both mothers and fathers, maternal and paternal points of view of the experience of raising a deaf child were investigated. As well, since some mothers and fathers were from the same family, two perspectives on raising the same child were obtained. Triangulation of data sources also occurred in that more than one experience was of interest; seven parent perspectives were examined.

Analyst triangulation involves two or more people independently analyzing the same qualitative data and then comparing their findings (Patton, 1990). One approach, according to Patton, is to have participants review the findings of a study. Participants in this study reviewed the findings and provided feedback as to the accuracy and interpretation of the data. As well, the thesis supervisory committee members were readers and reviewers of the report. By having multiple readers reacting to and commenting upon the accuracy, believability, and reasonability of the findings, face validity of the study will be tested (Patton, 1990). Face validity refers to the extent to which readers of a research report believe in its feasibility.

Theory or perspective triangulation involves using multiple perspectives or theories to interpret the data (Patton, 1990). The data will be discussed in terms of various theories in order to better understand the data from varying philosophical premises.

Patton (1990) discussed the importance of considering sampling errors. For example, findings may be distorted because of selectivity in the people, situations, or time periods sampled (Patton, 1990). To avoid such sampling errors, Patton suggested that conclusions be specific to "situations, time periods, persons, contexts, and purposes for which the data are applicable" (p. 471).

### Researcher Credibility

Because the researcher is the key instrument in qualitative inquiry, what the researcher brings in terms of experience, training, philosophies, and biases are of utmost importance (Patton, 1990). Any personal or professional information that may have an effect on data collection, analysis, or interpretation must be documented. One means of establishing researcher credibility is through bracketing one's own personal and theoretical presuppositions regarding the phenomenon of interest. Another means is by taking extensive field notes and memos throughout the research process. Field notes and memos allow qualitative researchers to document any perceived changes in themselves or in the participants during the course of the research project (Patton, 1990). It allows introspection and in-depth reflection upon not only the phenomenon, but also upon themselves as part of the research process.

Memoing, bracketing, field notes, and journalling were all included in this study. Any potentially confounding effects such as researcher subjectivity or loss of impartiality can be at best avoided or at least monitored to better understand the full extent of the effect. Patton (1990) argued that "subjectivity is inevitable" (p. 482), but that the most important thing was "to be aware of how one's perspective affects fieldwork, to carefully document all procedures so that others can overview the methods for bias, and to be open in describing the limitations of the perspective presented" (p. 482).

Researcher credibility was also established by ensuring that data were repeatedly referred to, examined, and interpreted with "making sense" of the experiences of hearing parents of deaf children as the primary goal. Continually going back to the data and trying to make sense of it with reference to the phenomena of interest will support greater intellectual rigor and professional integrity (Patton, 1990).

Another aspect of researcher credibility pertains to attempts to generalize the findings. The small sample size of this study and of many qualitative research projects produce findings which provide information specific to the contexts,

situations, and participants under study and are less contributive to generalizations about a target population. Any conclusion drawn may be viewed more as a working hypothesis than a generalization (Patton, 1990). Patton suggested that instead of generalizing, qualitative researchers could extrapolate or make "modest speculations on the likely applicability of the findings to other situations under similar, but not identical conditions" (p. 489). The focus in this study was, therefore, on discussing and interpreting the findings in terms of the specific experiences of each of the seven participants with her/his child in various situations and contexts.

### **Ethical Considerations**

Before proceeding with any formal research, an extensive research proposal was submitted to a thesis supervisory committee for review. Following committee reviews, the proposal underwent an ethical review process with the University of Alberta's Department of Educational Psychology ethical review committee. After obtaining clearance from this committee, the gatekeepers at each agency of interest were informed of the purpose of the study and of the agency's potential involvement. Professionals at the various agencies were asked to nominate potential participants or to suggest other agencies that could be of assistance. One program had its own ethical review board, and therefore, an additional ethical review of the proposal was required.

Bogdan and Biklen (1992) discussed the importance of two ethical guidelines when working with participants: informed consent and protection from harm. Informed consent forms (see Appendix A) including a description of the study, how findings would be used, and assurances of confidentiality and anonymity were provided to each participant. The consent forms also indicated to participants that data would be used for the present thesis investigation and might be used in other ways after data collection such as in a poster presentation, a published article, or in another investigation.

I ensured each participant that her/his identity would be protected. No

proper names or any other identifying information were used. With reference to any mothers and fathers from the same family who were involved, attempts to protect the identity of each participant was made. Each participant was assured that none of the information shared during the interview would be shared by the researcher with her/his spouse. In the final write-up of the thesis, contextual information and, in some cases, the description of the gender of the child was altered.

With reference to ethical issues during the interviews with each participant, permission to tape record the interview was requested both on the informed consent form as well as just prior to tape recording. Each participant was informed before the interview that s/he did not need to respond to a question if s/he did not want to and that the tape recorder could be turned off at any point in time during the interview.

This chapter provided an overview of the grounded theory techniques used to develop a theory representing the experiences of the seven participants. The theory emerged from simultaneously using three types of coding: open coding, selective coding, and theoretical coding. Coding enabled the core category to be identified. The core category identified in this study and, moreover, the theory that emerged from grounded theory analysis is presented in Chapter IV.

### **CHAPTER IV -- THE FINDINGS**

The intent of this study was to better understand the feelings and experiences of hearing parents of deaf children following diagnosis of the child's hearing loss and, more specifically, to develop a substantive theory representative of the experiences of the participants in this study. Grounded theory techniques and particularly the constant comparative method were used to develop a theory that fit with the experiences of the seven participants and described an aspect of the main concern or basic social problem for the participants. This chapter begins with a description of the main concern for the participants as well as an overview of its relationship to each of the emergent categories and their properties, each indicated in this section by underlined text (see Table 2 for a summary of the emergent codes and sub-categories).

Following this overview of the main concern for the participants, a detailed description of the core category "parental appraisal of a child's deafness" and its related categories and properties is provided.

### Main Concern for the Participants

The main concern for the participants in this study was to help their children to acquire knowledge and skills that would be conducive to each child's future as an independent adult. Participants were trying to determine such things as the best communication mode to use with their child, the most appropriate educational program, or a suitable career choice in the future. Each participant's actions and reactions following diagnosis of her/his child's hearing loss were influenced by how the individual was thinking and feeling at various points in time. In other words, it appeared participants were in varying points of a cycle or process pertaining to accepting the child's hearing loss and integrating it into their lives.

<u>Table 2</u>
Summary of Emergent Categories

1. Context									
Societal Context			Personal Context						
Societal barriers:         - societal pressures, perceived socie evaluation, social support     Familial experiences:         - spousal influence (involvement, congruence, support)			Parent's Personality:						
2.	2. Conditions influencing the main concern								
En	notion and Perspective	ŀ	formation hered	Pressure					
•	Sense of loss Feeling overwhelmed Sense of adequacy Feeling inadequate Sense of enrichment Sense of validation Sense of empowerment Deafness as integrated into life Adaptability and pragmatism Sense of parental responsibility: - feeling that there was no other choice, feeling committed to the child, feeling needed (belief in one's own skills and knowledge as significant to the child, belief in the impact a parent has on a child) Sense of shared responsibility			<ul> <li>Internal pressures:         <ul> <li>sense of parental responsibility</li> </ul> </li> <li>External pressures         <ul> <li>amount of information received, number of information providers, nature of the information provided</li> </ul> </li> </ul>					
3.	3. Strategies to Manage the Participant's Main Concern								
* *	Taking the lead Planning ahead Child-centered responsiveness Lessen the pressure on self Consequences Related to t								
<b>*</b>	Sense of connectedness with child Sense of increased confidence								

Note. Asterisk (\*) designates a conceptual category with no emergent sub-categories.

### Context

Each participant's actions with regard to the main concern of assisting her/his child occurred within both a social and a personal context. The social context included societal barriers, societal pressures, and familial experiences. The personal context included child and participant personalities, sense of internal pressure, and prior life experiences of each participant.

Personal context. The parent's personality emerged as an influence on each participant. For instance, those who were more optimistic and self-confident tended to have a positive outlook on the child's future and one's own abilities. As well, each participant's locus of control emerged as a personal contextual factor. Each participant's reactions to the diagnosis of the child's deafness and the actions they took were influenced by the degree to which s/he felt in control. One participant's internal locus of control influenced this parent's perspective of the available literature, of the role of the educational system, and of a parent's role.

... I strongly believe that individuals direct their fate if you like to a large extent. And this is something that I grew up with that you have to be responsible for what you do and you take the blame and you take the credit if you like. I just feel okay if I just don't do something well, there's a reason for it, and I can change it. And I rarely encounter situations where I just couldn't do something. And I feel the same is true for [my child]. Of course [my child] being younger, I feel if in the end he ends up not doing as well as I want him to do, it's because either he decided not to or I didn't help him sufficiently. (F)

The <u>child's personality</u> also emerged as a contextual factor influencing each parent's feelings about her/his child's future. The child's self-confidence, determination, and courage influenced how participants would view the child's

communication skills and future career options.

Other personal contextual factors that emerged pertained to those involving prior life experiences as in prior experiences as a parent, prior experiences with deafness, and prior life experiences in general (e.g., maturity level). These contextual factors influenced how participants felt following diagnosis of their child's deafness. For example, many participants commented on being "first-time parents" and having little or no experience with deafness. Inexperience emerged as a factor influencing each participant's initial shock and uncertainty of where to go and what to do following their child's diagnosis of deafness. As well, one participant commented upon being a young parent and how that may have influenced her uncertainties regarding what to do.

It could be I was a very young parent as well. But certainly there was a lot of hesitance on my part to be confident about who I was as a parent. Am I doing the right thing? ... And again inexperience. I mean if I had had three or four children, there were a lot of bells and whistles that would have gone off for me... I was a first time mom and young. I didn't have a repertoire to know any different. (B)

Social context. Participants also discussed the influence of societal pressures and perceived societal evaluation in their interviews. Many parents felt self-consciousness pertaining to their own communication skill level. Interestingly, this self-consciousness was most evident in contexts involving individuals who were fluent in using sign language. Parents commented upon feelings of self-consciousness in their communication skill level when evaluated by individuals who were fluent in sign language.

I'm so self-conscious in front of hearing people who can sign well. If a person didn't sign, it didn't bother me at all. Then it doesn't matter because they weren't judging my signing skills. That's why I think I felt like my

signing skills were being judged and it made me feel uncomfortable initially, just sort of at the beginning. (A)

So that's the idea. It's like being watched and not being watched. If you're in a public area where nobody signs, you're not being watched. You're being watched but you can't be judged. If you're in an environment where there are lots of other signers around, you're being watched and in my eyes being also judged. And that then could become embarrassing and frustrating if you like. (F)

Other parents also commented upon feelings of self-consciousness with regard to drawing attention to their child and themselves in a public context. For instance, one participant commented upon feelings of embarrassment when her child's hearing aids squealed because of the attention it drew to them. This participant commented upon feeling self-conscious because she felt different from everyone else in her neighborhood.

So I remember public events such as going to church and his hearing aids squealing and everybody turning around and a little church of a hundred people if it was really full ... And for me, we didn't have any seniors in our church so nobody wore a hearing aid. So these hearing aids squealing and everybody goes "whoosh" turns around and "what's that sound?" And you just wanted to melt, you know, sort of like I can't fix it. (C)

Another parent commented upon embarrassment and self-consciousness felt initially when using sign language in a public environment.

It was very self-conscious. You know, you kind of signed so that people would see you, but they wouldn't see you. You wanted [my child] to see you, but then you blocked out everybody else. And again it's acceptance of the situation. You don't say much when you're out at a restaurant with

[my child] because you don't want people to see or else you sign very small. And now we just sign the way we usually do. (D)

One parent commented upon the <u>societal pressures</u> felt to communicate with her child as well as to be an interpreter for others.

It's really, really hard to contemplate because in a way I'm there I can communicate with him. It's my moral responsibility to do that. And well there are times when you know people would say, "Tell him this, tell him that," and when he was little I did. (B)

This participant also felt pressure because of a feeling that others including professionals and other parents were judging her as a parent. This parent commented upon the pressure she felt to conform to the opinions of professionals educating her child.

But when I picked him up from school-whoa-there was a lot I suppose you might say subtle but to me it wasn't so subtle judgement on the part of the school, you know, that I was a bad parent. This kid needed this and I was denying him this or one thing or another. (B)

The degree of <u>social support</u> received from each participant's spouse, friends, family, other parents of deaf children, deaf adults, and professionals influenced how participants reacted to the child's deafness.

... it [parent groups] gave me a view of a variety of other parental situations, other situations with children and brought me to a place where I realized that I was the decision-maker here. (B)

There we were basically. We were seen as I think what it boils down to is we were seen as "wow, you're trying this. You're doing this. Good for you,

how difficult it must be." So that's where I think we came from, having very supportive friends. (F)

The degree of <u>spousal influence</u> also emerged as a condition for the main concern of the participants. This category included properties such as <u>involvement, congruency, and support</u>.

Participants commented upon spousal involvement, varying from very involved to non-involved. One participant described the lack of spousal support received immediately following diagnosis of their child's deafness.

I went through a lot of that alone. My mother lived out of the province and my husband didn't take care of things related to the baby, you know. So I was always doing the appointments by myself. (G)

Participants described difficulties in choosing a communication mode or educational program for their children when incongruencies existed between the participant and her/his spouse. One participant commented on the struggles associated with having differing perspectives from his spouse regarding the best communication mode for and with their child.

But the worst part for me was more how do my wife and I step in synch? Having to come to an agreement because if we disagreed on what needs to be done, what do we do? (F)

Some participants also described their spouses as a primary source of support in raising their deaf children.

One of the things that we've got going for us is that [my spouse] and I have an incredible marriage ... There's somebody that you can talk to.

There's somebody that you can say, tell the incredibly stupid thing that

you've just did and share that with them. So I'm really lucky that way, not really so much personality so much as we make a good team. (E)

### Conditions

Various conditions emerged from the data as being influential in each participant's reactions and actions following diagnosis of her/his child's hearing loss.

Emotion and perspective shift. Some conditions pertained to the emotional state and perspectives of the participants at varying points in diagnosis. Some participants indicated a shift in both emotional state and perspective. For example, some participants described feeling a sense of loss, feeling overwhelmed, and feeling inadequate at some points following diagnosis while feeling a sense of enrichment, sense of adequacy, sense of validation, and sense of empowerment at other points. Other conditions that emerged included the degree to which a participant felt deafness as integrated into life as well as the degree to which a participant focussed upon adaptability and pragmatism.

Other conditions that influenced participants' reactions to diagnosis of the child's hearing loss pertained to the sense of responsibility felt. For example, sense of parental responsibility emerged as a condition influencing some participants' attitudes and reactions regarding implications of deafness for their children. Properties of this category included feeling that there was no other choice, feeling committed to the child, and feeling needed. Some sub-properties of feeling needed included belief in one's own skills and knowledge as significant to the child as well as a belief in the impact a parent has on a child. Participants felt it was their responsibility to prepare the child for the future and to provide the child with skills. Many of the participants believed that what happened to their children depended a lot on what they did as parents.

But with [my child] I had to learn a whole new language—huge adjustment. I had to plan much more—huge. Again, there are just things that I've got to learn you know—how to speak slowly [and] more clearly, sign and talk. I have to make adjustments ... but hey I'm a dad so that's what I do. (F)

... I don't have a choice. I think that has been a real coping mechanism for whatever it is. It gets me through a hell of a lot. It gets me through a hell of a lot. I feel like it doesn't matter if I fail. I will try it again. Dust myself off, pick up my feet, do it again. Because I don't have a choice. (G)

Some participants also described <u>a sense of shared responsibility</u>. For example, some parents discussed the influence of the Deaf Community in the child's life. Some participants felt that the Deaf Community was a source of information and support for both themselves and for deaf children in the present as well as in the future. For many participants this sense of shared responsibility developed over time.

Pressure. Another factor influencing each participant's concern to assist her/his deaf child was the degree of pressure felt whether from internal sources or external sources. "Internal" and "external" refer to the source of the pressure. Internal pressures were the pressures that occurred from within each participant whether from a sense of parental responsibility to be a language interpreter or a sense of being the child's primary information source and communication partner.

... I'm there. I can communicate with him. It's my moral responsibility to do that and well there are times when you know people would say, "Tell him this, tell that," and when he was little I did. (B)

... I don't just mean sign language interpreter. I mean interpreter of the world. What other channel of information was available to him? (B)

One participant also described feeling pressure to improve upon his communication skills in order to ensure that his skills did not fall behind those of his deaf child.

... it was always the thought that maybe one day his communication skill in terms of signing would be so great that I can't keep up or understand ... if I don't make that effort, he will lose interest in communicating with me because it will be painful to him [because] he has got to slow down and everything else ... I am trying to ensure that I will be able to keep up with my communication ... (F)

External pressures experienced by participants stemmed primarily from information provided by program professionals. The information provided by professionals influenced how parents reacted and responded to the child's diagnosis of deafness. Properties of this category included the <u>amount of information received</u> by parents from external sources, the <u>number of information providers</u>, and <u>the nature of the information provided</u>. This condition was associated with the degree to which participants were <u>feeling overwhelmed</u> following diagnosis.

So I mean I really started to scramble around and find out what it [deafness] meant. [Being told] "well you need to give him hearing aids and this and that and the other thing." (B)

it was good that we were elsewhere because we were not surrounded by a multitude of professionals with all of their opinions bombarding us right away. So we didn't have to feel bad or limited or embarrassed about how little we did or did not do. (F)

Some participants commented upon pressure felt to conform to the

strategies and ideas described by the consultants working with their deaf children.

I suppose you might say subtle but to me it wasn't so subtle judgement on the part of the school, you know, that I was a bad parent. This kid needed this and I was denying him this or one thing or another. So it was a hard thing for me to do. (B)

We were doing it very wrong, if you would. We were doing it very against what the accepted norms were. We were doing it based on research that we had done rather than listening to all the "experts." (D)

Information gathered. This condition refers to the information that the participants sought after the child's diagnosis of deafness. Rather than the information provided by professionals, this category refers to the information gathered by each participant to learn more about hearing loss, Deaf Culture, communication options available, or services available for her/his child. The degree of information gathering emerged to be an influential factor in the parents' reactions and actions following diagnosis of each child's hearing loss.

You know, you feel terrible about things for the first little while. You feel confused, you feel angry and then slowly as you get more information or as we got more information, we felt more comfortable and more confident in what we're doing. (D)

Well the confidence usually came with experience or with some knowledge or responding to whatever this next issue was that came up. It's like a learning curve. You've got to learn about something and you think, "Oh now I've got it under control." (B)

### Strategies

Participants used various strategies to help their children develop knowledge and skills that they believed would be useful for their children in the future. These strategies included taking the lead, planning ahead, and child-centered responsiveness.

Another strategy that emerged pertained to participants trying to lessen the pressure on themselves by sharing responsibility with others. This strategy had less to do with assisting the child in her/his future and more to do with self-care. It allowed the participant to focus on aspects of her/his life other than her/his deaf child and was found to be related to the degree to which a participant was feeling overwhelmed by issues related to the child's deafness. In other words, the more participants were able to lessen the pressure off themselves by sharing responsibility with others, such as with the child or the Deaf Community, the less overwhelmed the participants felt.

### Consequences

Each participant was concerned with supporting her/his child's development of skills and knowledge to facilitate the child's independence in the future. Participants' actions and reactions were influenced by various contextual factors, conditions, and strategies. The interplay between these variables had two consequences: sense of connectedness with child and sense of increased confidence. Some participants described feeling closeness and interconnectedness with their children that developed over time. Many participants also expressed increased confidence with their own knowledge and skill development as well as that of the child.

### **Summary of the Main Concern**

The main concern for the participants was to help their children who were deaf develop skills and knowledge to manage successfully and independently in the future. The first section of this chapter was devoted to introducing the categories and properties that emerged from the participants' descriptions of their experiences and feelings following diagnosis of their children's deafness. The next section provides an overview of the core category that emerged following data analysis.

### **Emergence of the Core Category**

As described in Chapter III, selective coding facilitated identification of the core category. The core category was identified by its relevance to most or all of the categories and properties that had emerged as a result of open coding. These categories and properties were presented in the previous section. The core category that emerged in this study was "parental appraisal of a child's deafness." A summary of the theory of parental appraisal including the core category and related sub-categories is presented in Figure 1.

Figure 1. Core Category: Parental Appraisal of Child's Deafness

# Appraisal of Meaning of

### Deafness

- 1) For parent
- 2) For child

information provided, information gathered Conditions: prior experience with deafness, Consequence: sense of loss, sense of

enrichment, broadened perspective, Integration of deafness into life

## **Appraisal of Resources**

- 1) Parental
- 2) Interpersonal
- 3) Societal

Conditions: services available, information provided about deafness, information gathered about deafness

Inadequacy with personal, interpersonal, Consequence: feelings of adequacy or and/or societal resources

4) Child's resources

pragmatism, child centered responsiveness Consequence: sense of loss, sense of pride Strategy: focus upon adaptability and

Parental resources in comparison with

Conditions: services available, information

provided about deafness, information

societal resources

inadequacy, feeling overwhelmed, sense of Consequence: feelings of adequacy or gathered about deafness empowerment

Strategy: taking the lead, focus upon adaptability and pragmatism

### CHILD'S PERSONALITY PRIOR LIFE EXPENSIVE OPRENTAL CONTRA PARENTAL CONTER HEARING PERBONALITY CHILD'S **FOSS** CHILD'S STELLS SOCIAL SUPPOR

## Appraisal of Reactions to Deafness

- 1) For parent
- Condition: feedback from information gathered and provided.
  - Consequence: feelings of adequacy or inadequacy, sense of validation
    - Strategy: focus upon adaptability and pragmatism
- 2) For child Consequence: sense of pride in child's reaction, sense of validation

pragmatism, child-centered responsiveness Strategy: focus upon adaptability and

# Appraisal of Roles in Deafness

- 1) Parental
- Conditions: age of child, roles assigned to child

Consequence: sense of parental responsibility Strategy: taking the lead and society

- 2) Child
  Consequence: sense of parental responsibility,
  sense of shared responsibility with child, sense of child's responsibility

Strategy: taking the lead, lessening pressure on self

- 3) Societal
- Conditions: information provided about
- deafness, information gathered about deafness Consequence: sense of parental responsibility,
  - Strategy: taking the lead, lessening pressure on sense of shared responsibility with society self

### Core Category: Parental Appraisal of Child's Deafness

Theoretical coding and sorting allowed determination of the relationships between the core category, "parental appraisal of a child's deafness" and the other relevant conceptual categories and properties that emerged from the data. Glaser (1978) described 18 theoretical codes that most or all conceptual categories and their properties would fit into. For this study, the theoretical codes that emerged included cause, context, conditions, consequences, and strategies. Each theoretical code was integrated to form a substantive theory of the core variable. A diagram in Figure 1 represents the theory of parental appraisal.

Four types of parental appraisal emerged from the data: meaning of deafness, resources available, roles related to deafness, and reactions to child's deafness. Each type of appraisal was not mutually exclusive, rather, some appraisal components, for example, sense of loss and feelings of adequacy or inadequacy overlapped between appraisal types. As well, the types of appraisals did not emerge in any set sequence. Appraisal types occurred at varying points in time and some were likely occurring simultaneously.

### Cause

The cause associated with each parent's appraisal was the diagnosis of the child's hearing loss and the various day-to-day events thereafter that were associated with the hearing loss. These included events such as fitting the child with hearing aids, choosing the child's educational program, choosing communication mode, involving the child in family events and discussions, and observing the child interacting with other children. These events or situations were often assessed to varying degrees by parents, and this assessment would influence subsequent parent emotional reactions and responses.

### Context

According to Glaser (1978), context was a "condition of overriding scope" (p. 65). Several contextual factors emerged to influence the core category of parental appraisal. The parental context included parent's personality, parent's prior life experiences, child's personality, child's skills or capabilities, and degree of social support. Each of these factors influenced the manner and extent of parents' appraisal of the meaning of deafness, resources available, reactions to the child's deafness, and roles related to deafness.

For example, many parents described the influence that the degree of prior parenting experiences had on their appraisals following diagnosis of the child's hearing loss. Parents expressed the difficulties associated with being a first-time parent and how it was associated with appraisals of inadequate experiences and knowledge concerning children and levels of development. For example, one parent said, "And I'm a first time parent so I don't have a lot to compare it to except for a lot of advice from my other friends who are older and already have grown children." (G) Similarly, another parent expressed, "I mean had [my deaf child] not been our first [child] we might have known a lot more...Well [my deaf child] was our first born so I've got nothing to compare it to." (E)

Each parent's appraisal was continually influenced by contextual factors such as personality, prior life experiences, and degree of social support. That is contextual factors were prevalent in each type of parental appraisal. The four types of parental appraisal (i.e., meaning, resource, role, and reaction) and each appraisal type's own emergent set of intervening conditions, consequences, and strategies are the foci for the following sections of this chapter.

### Appraisal of the Meaning of the Child's Deafness

The significance or meaning of the child's deafness was appraised on two levels: meaning to the parent and meaning for the child. Each parent had

expectations of what her/his child would be like, the type of future the child would have in terms of career, and the type of interaction s/he had expected to share with that child. These personal expectations were compared against the perceived implications of the child's hearing loss. The consequences of assessing the meaning of the hearing loss varied. Initially, particularly in the time period immediately following diagnosis, parent appraisals were linked with a sense of loss. Over time, however, parent appraisals of the significance of deafness resulted in other consequences such as sense of enrichment and a broadened perspective of the meaning of deafness.

### Factors influencing appraisal of meaning

The meaning parents assigned to the child's hearing loss was influenced by numerous factors: a) information provided about deafness from professionals, b) information gathered or sought by the parent through reading or talking with deaf individuals or other hearing parents of deaf children, and c) the degree of prior experiences with deafness. Information acquired through professionals, research, or interaction with others contributed to each parent's store of knowledge and background experience. The more information acquired, the greater the depth and breadth of understanding. Each individual's level of understanding about concepts or events associated with being the parent of a deaf child influenced that parent's appraisal of the significance of a particular event to the parent's and child's well-being.

Prior experiences with hearing loss also influenced each parent's appraisal of the meaning of deafness. Parents in this study described minimal or no prior experience with deafness. Most parents had never interacted with a deaf individual before. The experience and knowledge about deafness that each parent did possess were used to assess the meaning of the child's hearing loss to her/himself, to the child, and to the parent-child relationship. For many parents, particularly immediately following diagnosis, the meaning associated with deafness was that of loss.

### Sense of loss

One consequence of this appraisal of what hearing loss meant to the parent was that many parents expressed a sense of loss for themselves. The expectations of what the child would be like and the child's anticipated future were discrepant from the images associated with a child who was deaf. As a result, parents expressed sadness for the loss of the expectation of the "perfect" or idealized child. One participant described his feelings immediately following diagnosis of his child's hearing loss.

I took the information and we went into the car, and the hospital wasn't very far from our place. But I remember putting [my child] in the car and he was sitting in the back. And as I drove, I turned up the radio all the way to the point where it was, you know, it would have hurt his ears, and he didn't notice, not at all.... This was right after on the way driving home. And it was really one of those frightening, sickening sort of feelings to realize that your child, your perfect child, isn't as perfect as you thought, And I remember crying essentially on the way home. I was very sad. (D)

In addition to feelings of loss for the expected child, parents expressed a sense of loss as a result of thwarted expectations of the type of interaction and connectedness formed between parent and child. One parent described feelings of lost depth of interaction as a consequence of limited communicative ability initially between himself and his child.

I'm fiercely proud of my son, and I wanted, you know, this certain interaction that I couldn't have at first because I was so limited in my communication and [my child] was limited in his communication right. You feel robbed of connectedness. (F)

Participants also assessed the meaning of the child's hearing loss to the child. Parents evaluated whether the child's educational options, communication skills, and social interaction would be affected by the hearing loss.

And I still remember buying that first Signed English dictionary. And I'm looking at the cover and I say "two thousand signs." I said "ah!" But the English language has hundreds of thousands of words. That's it. [My child is] going to be limited to this. [My child] will never learn how to communicate exquisitely and beautifully in a complex manner. Two thousand signs—and trying to find signs for you know "to assess" and this kind of stuff. And it's like they're not there, they're not there, they're not there. So it was pretty rough. It was pretty rough at first. (F)

The consequence associated with each parent's appraisal of meaning of the hearing loss for the child was that many participants felt sadness and, again, loss. This sense of loss was related to feelings of sadness for the child's potential limits in experiences and abilities. In other words, parents felt a sense of loss for the life experiences and skills they perceived their child had lost.

One time I remember thinking [pause] there's one thing [my child] will never say, that's "papa." And that, I think that thought came up or that feeling if you like—the sadness. The sadness of [pause] I won't be able to ... I won't be able to discuss things with him .... But just the thought [that] I will never hear what he sounds like, what he could be saying you know—little expressions or whatever else it is. And I know sometimes I hide in the bedroom and cry a bit about that, that loss. That loss, if you like, of an opportunity you know. (F)

#### Sense of enrichment

Appraisal of the meaning of deafness also was associated with a sense of

enrichment. Participants expressed that deafness was not necessarily equated with perceptions of deficiencies or limitations in their child or in the parent-child relationship. Parents described positive consequences to their own lives that were directly attributable to the presence of deafness in their family. Some felt that they had been brought closer together by nature of the focus and intensity of involvement needed to establish language and a communicative relationship with the child.

By nature of [my child's] deafness I have to play a bigger role than I naturally do. Because I have to spend more time with him, because I have to plan more hours, okay all the side benefits of knowing my child better, knowing more what's going on in his life, knowing what maybe he's worrying about or thinking about, just getting to know him better. (F)

In addition to a sense of connectedness with the child, parents also described how the child's hearing loss had enriched their social and professional lives. By becoming involved with services and educational programs for deaf individuals and their families, parents established friendships and ties with other parents of deaf children, deaf individuals, and professionals. These connections not only contributed to the density of their social network, but also in some instances contributed to an interest and involvement in deaf education and services for the deaf.

... the awareness of you know the deaf friends and other deaf people that I know and the awareness of that whole [deaf] perspective. My career is based on my experience and my knowledge of the whole field. A lot of my friends I've made through the work that I've done in the area. (B)

Parents also described feeling enriched in the acquisition of knowledge and skills related to the child's hearing loss. For some parents, enrichment was associated with the discovery of a different language or of a different culture.

Well, I mean the whole Deaf world has been opened to us. We knew nothing about it. It's been a wonderful experience.... I mean learning a new language, you know, a beautiful, exciting language. I don't know. It's been a whole new purpose in life that we didn't know we had, you know. It's really neat. (A)

Parents also felt enriched in what the experiences associated with being the parent of a child who was deaf had drawn out of them, whether it was inner strength, assertiveness, or becoming more pro-active.

I think [my child] has taught me that unless you get involved you aren't able to change anything. And I probably knew that before, and I probably was able to get involved. And I like getting involved and doing some changes, but he really, he himself really brings it home. You look at him and you say, "Well if I'm not going to get involved, nothing is going to change, and this guy's not going to benefit from that." So that's why you have to get into it. (D)

The way of approaching events in day-to-day life was influenced by experiences in being the parent of a child who was deaf. One parent, for example, described becoming more assertive as a result of numerous struggles to advocate for her child's educational needs and, in relation, another parent described feeling greater inner strength in the ability to handle any hurdles or challenges that arose. One parent described personal growth and strength that developed over time as a result of the challenges and struggles associated with being the parent of a child who was deaf.

... because as much as [my child] grew, obviously I grew as well.... Well look at my lifestyle now. My inclination is to be rather reclusive, well not reclusive, I'm social. And I like time with friends, but I spend a lot of time

alone. I spend a lot of time in fantasy pursuits—reading books, going to movies, reflecting, philosophizing. I could have spent my life doing that but not with [my child] in my face. So I could have spent my life just sort of you know in dreamland .... So that's how my life's been enriched by what's been drawn out of me—a lot of strength and confidence. (B)

## Broadened perspective

Part of each parent's appraisal of the meaning of deafness included the way in which parents assigned meaning to such words as "deaf," "hearing impaired," "Deaf Community," or "cochlear implant." Meanings assigned to these words influenced how that individual reacted to and perceived encounters related to the child's hearing loss. With new information or experiences, parents' assigned meanings were often modified to include other concepts or dimensions. This broadened perspective of the meaning of deafness was a reflection that each parent's former reality had been expanded to include other conceptions of what deafness involved, what deaf people were like, what was a "normal" family life, and what constituted a challenge. Each parent initially had expectations that were based upon previous upbringing, experiences, and knowledge about the world. Then with increased experience and knowledge, participants' perceptions of aspects of the world and of their own lives changed. They began to integrate what was happening in their lives into their own world definition of "normal."

But this became our news book. It became a little bit of the diary of the family.... And then it's a very somber little story about when we discovered [our child] had a hearing impairment at 14 months. And we gave some dates and other things. And I know that later on, and I don't remember exactly when, I went back and crossed out "hearing impaired" and put "deaf." That was something that was very important to me and it still really is because [our child] is not hearing impaired as a negative view, like

something is broken, we must fix it. I agree with the Deaf Community that "deaf" is a much more positive, powerful sort of thing. (D)

One parent also described a broadened perspective of the meaning of rich communication and, more generally, a broadened perspective of language. Initially, this parent appraised the communication possibilities for his child as limiting and lacking complexity and richness. This view of language was soon modified, however, when he observed the depth and detail in his child's language.

You know his signing and my ability to understand it have become sophisticated enough that I can see, you know, we've gone beyond the second language learning manuals interpretation [where] I'm just looking at the sequence of signs and I read the message.... [Now] there's expression. There's sentiment. There's feeling in how we communicate. So I'm not only decoding what the words are, I'm also decoding what's underneath, how he signs "papa," how he pauses and goes on. So that loss of voice has now been substituted by his expressiveness in his signing—how he does it—the nuances that he does. (F)

Another parental appraisal of the meaning of deafness pertained to parents' views of the child's career opportunities. Parents felt that the child's hearing loss would limit their child's career choices. The significance of hearing loss to various careers was assessed. Some careers were immediately discounted due to the significance of sound. These conceptions of potential career opportunities expanded for some parents to include a wide range of potential careers with few or no limits associated with the child's hearing loss.

I knew that what I wanted was for [my child] to have any [career] possibility. You know like nothing should stand in her way. And then I started to go "well, these are the real jobs." And I remember taking

musician right off the list. But then afterwards ... I kind of went back and looked at the list again, and I went "why not a musician?" She can hear drums just fine. Why couldn't she be a percussion musician? Why not? Why couldn't she be a dancer? I read one book about a deaf girl who was taking ballet classes and then saw some videos of deaf dancers. And so the things I took off the list .... Right now I'm kind of back to "why not?" (G)

Parents' views of deaf individuals also shifted over time. Preconceptions of qualities, skills, and career prospects of deaf individuals were compared with each parent's life encounters with individuals who were deaf. Many parents' conceptions of the competency and success of individuals who were deaf changed with increased interaction with deaf people.

We met these two deaf adults that were a couple who both worked there [educational institution]—wonderful people—bright, educated, warm, you know, well adjusted. And [my spouse and I] just kind of went "okay [our child's] fine." Honestly, I remember coming home and I said [to my spouse], "I feel so much better." And [my spouse] said the same thing. Only [deaf] people I ever thought of were people with a little can on the side of the street, you know, begging for money.... [The deaf individuals we met] were the really key people, so dynamic and you know really vibrant people. And you go "okay, if [my child] can grow up to be like that, he'll be fine." (A)

Integration of deafness into life. Broadened perspective also involved incorporating deafness into the parent's perceptions of her/his child as well as into perceptions of what constituted the "normal" parts of daily life. More specifically, participants described how deafness was part of their children's identities and also how deafness became integrated into life. This integration reflected a broadening of perspective because for many parents, particularly immediately following diagnosis, images of the child and of life were greatly

influenced by expectations present prior to diagnosis and, moreover, by the sense of loss associated with the anticipated child and way of life.

While describing qualities of their children, parents included deafness as part of each child's identity presently and also in the future. Deafness itself, however, was not considered to be the defining or core characteristic of the child. Children were described to have many special and unique qualities of which deafness was identified as only one quality among many.

It's [deafness] part of him ... I mean it's only one factor of many things but if you took that away, he wouldn't be who he is either... he is so visually alert and obviously with stuff like that and some of his concentration abilities. It might be because he doesn't get all the distractions that other kids do, I don't know. But I mean it's just part of him. I wouldn't change him for the world. (A)

Just as the child's hearing loss became integrated into perceptions of the child's identity, the events and activities associated with the child's hearing loss became just a part of everyday life. The effort and planning associated with communication with the child, using assistive devices (e.g., teletypewriter, doorbell and telephone flashes), using an interpreter, or involving the child in extracurricular activities became just part of the basic, necessary, and routine aspects of being a parent.

We [my spouse and I] have come to the point where we accept that when [my child] goes to [extracurricular club meetings] we will go along. We will sign most of the time. And sometimes we'll leave him on his own. That's okay too. I guess I feel anyway that we are more at the stage [where] I've accepted so much that there are certain things that we have to do extra. They have become just a normal part of being a parent now .... So I guess the adjustment stage—I feel it has passed me. I've integrated the changes

that we need to make pretty well. Having the flashes in my room or having to drive [my child] extra or going out of my way is now just all being part of a parent. (F)

Parents suggested that part of integrating deafness into life was letting go of the prior expectations of what was "normal." Parents began to view their lives not as lacking or "less than normal" in any way, but more as just a way of life that included some experiences that were different from those of other individuals. These differences in day-to-day living became simply identified as the necessary components of family life or, in other words, as being part of the family's conception of "normal."

Because initially you think well if I just do this, then everything will be fine. Or if I just do this, then everything will be fine. Then you find out, everything is fine the way it is. You know, what is, is. That's the way it is. Initially I started thinking of making things all like they used to be—normal. Then it became for us saying this is our normal. And it's fine, you know, it's life. (B)

#### Summary

Parents appraised the meaning of deafness not only in terms of significance to self but also in terms of perceived significance to the child. More specifically, parents judged the significance of deafness to the child's qualities, skills, and the parent-child relationship. Factors influencing each parent's appraisals of meaning were information provided, information gathered, and prior experience with deafness. Varying consequences ensued depending upon the nature of the appraisal. Some parent's appraisals were associated with a sense of loss, while some appraisals were associated with a broadened perspective and/or a sense of enrichment. These consequences of appraisal occurred at variable points in time and were in no set sequence although sense of loss was

particularly associated with parents' reactions immediately following diagnosis of the child's hearing loss. The next type of appraisal to be discussed is appraisal of roles related to the child's hearing loss.

# **Appraisal of Roles**

Appraisal of roles involved the evaluation of the nature and extent of the roles played by the parent, the child, and by society. Each type of role appraisal was associated with different sets of intervening conditions, consequences, and strategies.

# Factors influencing appraisal of parent and child roles

While all parents felt a great need for parental involvement, some parents became more or less involved depending upon the age of the child and also the perceived roles assigned to the child and society. The age or maturity level of the child influenced the degree of a parent's sense of responsibility. That is, as the child grew older, parents gradually lessened their own role or involvement with respect to events associated with the child's hearing loss. Similarly, the child, as s/he matured, began to take on more responsibility regarding events in her/his own life. As well, the role assigned to society such as extended family, professionals, educational programs, and the Deaf Community influenced the extent of a parent's sense of parental responsibility. For example, the lesser the extent of societal involvement with the activities or events associated with the child who was deaf, the greater the sense of parental responsibility.

# Appraisal of the parental role

With diagnosis of the child's hearing loss, parents would assess the extent to which they would be involved in situations related to the child's hearing loss. Parents in this study appraised their role in their child's life as significant and

necessary for the child's social, emotional, and intellectual development. The extent of this role, however, varied.

The outcome of appraisal of parental role for the participants in this study was a great sense of parental responsibility. Many parents expressed that they did what they had to do because they were parents and had no other choice.

There are all the initial expenses and there's been the surgery and fittings for ear molds and hearing aids and getting her into special sports programs. But those are just things that you do that have to be done.... I mean [it's] our daughter. We need to help her become a mature, responsible citizen and so a lot of these things just had to be done. (E)

Parents' great sense of commitment to the child was also associated with sense of responsibility. Participants felt that a child was a lifelong commitment and that involvement in various activities associated with the child's hearing loss was just part of that commitment. One parent, for example, indicated that sense of commitment and responsibility greatly influenced her perseverance and patience in acquiring sign language skills.

This is real life. I can't lose momentum. I might get depressed. I might have down days and whatever, but I don't have any choice. I have to learn how to sign well .... Right now I try to be patient with myself because I'm not getting it as fast as I want to. But I just kind of sit back and kind of go, "I'm in it for the rest of my life. And what choice do I really have? This is where I have to be." (G)

Participants also commented upon the importance of feeling needed by the child. This perception that the child needed the parent to be involved was influential in each parent's sense of responsibility. One parent for example said, "Actually something that's helped me get through recently too is 'well, you know [my child] needs me.' It's not like I have the choice to you know lay down and die

## either!" (G)

The consequence associated with a sense of parental responsibility was that parents would take the lead by initiating action in support of the children who were deaf. Some parents, for example, expressed a particular sense of responsibility to prepare and plan for the child's future. The provision of skills and knowledge and specific planning by the parent were viewed as tools to support their child's career aspirations and interests.

So that's the route I'm taking now. Provide [my child] with practical, hands-on skill so that he can eventually earn an independent living. I think of [my child] as a very smart, bright [child] who's very outgoing, who has great skills in many areas. But eventually [my child] needs to have specific skills. And so I've got to make sure that he gets those.... And just because you know I love him and I want him to do well and I don't expect anybody else to do the job. He's my kid. He's not anybody else's kid, so I've got to do the job. (F)

#### Appraisal of child's role

Parents of deaf children also assessed the child's role in activities and events related to the child's hearing loss. Events included choosing an educational program, choosing a communication mode, interaction with peers, and choosing assistive devices. Parents would evaluate the extent to which the children were able to take on responsibility related to events in their own lives. For some, this appraisal was associated with a greater sense of parental responsibility. That is, some parents continued to take on the primary responsibility of decision-making and planning for the child's future. This occurred in circumstances where the parent felt the child was not ready to take on greater responsibility or, perhaps, when the parent felt the need for advocacy on behalf of the child given the presence of perceived societal barriers and challenges. The parent's allocation of responsibility to the child, then, was

dependent upon the parent's appraisal of the child's role.

Some parents' appraisals resulted in a shared responsibility with the child. Parents believed that the child was capable of making decisions regarding her/his own life. For example, parents described sharing the responsibility of choosing the child's educational program with the child. In this way, the child who was deaf was beginning to be involved in making decisions influencing her/his own life. This tended to be influenced by the maturity level of the child. For example, one parent stated that once her child had reached a particular age, her child would decide which communication mode was desirable.

If [my child] wants to develop speech, fine. If she never talks, that's fine. But if they told me tomorrow that there was a cochlear implant that was one hundred percent like that could make [my child] hear, I would still wait for [my child] to make the choice .... It's like I expect her at age twelve or so to tell me if she wants to have a cochlear implant .... But if she says she never wants one, that's okay too. It's like if she never speaks, I don't care. If she doesn't care to hear, that's fine. Really, it's her life. (G)

Another participant described the importance of releasing responsibility to the child as s/he matured in order to encourage the development of independence. For example, this parent commented upon her feeling of responsibility to be a language and conceptual interpreter for her child. Eventually, this parent felt it was important to stop taking on this role and to encourage the child's sense of responsibility and independence. The child, then, would be required to develop other means of adapting and learning about the world.

Well, it felt burdensome at times. It felt like too much of a responsibility. I don't know. It's very complex because there comes a certain time where I just don't want to do that anymore. And by giving it up, then it forces [my

child] to develop other strategies. And as he grows, I mean he has other strategies you know. (B)

The strategies that emerged were dependent upon the appraisals parents made about the extent of the child's role. If a parent assigned her/his own parental role as primary and significant, then a strategy of taking the lead would result. If, on the other hand, a parent began to view the child as being capable of making decisions on her/his own behalf, then the parent began to lessen the pressure on her/himself and share responsibility with the child who was deaf.

## Appraisal of society's role

Just as parents made appraisals concerning parental and child roles, they also made appraisals of the extent of society's role in the child's life. Society in this study referred to the services and educational programs available for the child, professionals, family, friends, the child's communicative partners, and the Deaf Community. The influence of each of these societal components depended upon the information provided from professionals and service-providers, the information acquired by parents from reading books and research articles, and also information acquired from talking with other hearing parents of deaf children, family, friends, and members of the Deaf Community. This information was used to make judgements of the quality and desirability of the various types of societal support available.

Parents, for example, assessed the significance of the Deaf Community to the child's present and future well-being. Some viewed the Deaf Community as being of minimal influence in their children's lives, while others perceived the Deaf Community as an important source of support for both themselves and for the children who were deaf.

I can tell [my child] about our lives and we can talk about things like that and in time maybe I'll acquire enough language that we can talk about some deeper subjects, but I still have a faith and trust in the community, the Deaf Community, that they will at one point take over for the things that we lack. You know, if he goes into a technical specialty, I can't help him out with that, I can't, you know, I can't fix cars. I don't design cars or anything like that. In fact, I don't even do that well at banking—talking to him about that, you know. So someone will though, and that's the neatest thing about him being part of the Deaf Culture and my acceptance of that whole life in that someone else is going to help us out with exposing [my child] to the rest of the world. (D)

But I'm really counting on that [Deaf] Community to be, you know, a place where [my child] can grow up and be healthy. It doesn't have to be perfect. I can accept that it won't be as cushy as I originally thought it would be. But I really need for it to be there. (G)

Another form of societal appraisal involved the extent to which parents felt that other individuals had a responsibility in interacting and effecting communication with the child who was deaf. One participant commented on her primary communicative role for her child and how she eventually acknowledged that others had a responsibility as communication partners with her child, not just her.

It's really, really hard to contemplate because in a way I'm there I can communicate with [my child]. It's my moral responsibility to do that. And well there are times when you know people would say, "Tell him this, tell him that," and when he was little I did. But eventually, when he was older, I would say, "Tell him yourself." (B)

The consequences associated with the varying types of appraisals that emerged from this study included a sense of parental responsibility and sense of shared responsibility with society. That is, if the parent viewed society as

providing minimal or inapplicable support to the parent and/or child, then the parent retained primary responsibility for the events associated with the child's hearing loss. If, however, society was perceived as providing valuable services and information with reference to the child's hearing loss, then parents would share responsibility with society to support or assist the child in her/his educational and communicative endeavors.

Each consequence was related to two different strategies: taking the lead and lessening pressure on self. If parents retained the role of primary decision-makers for the child, then the parent would continue to initiate action and take the lead in events associated with the child who was deaf. Greater confidence in the services and support provided by society sources, on the other hand, was related to the parent relieving the pressure on self and accepting assistance from others. One parent commented upon the significance of the positive attitudes of friends, family, and professionals not only to her child but also to herself.

And when people would focus on, "I can do this. [My child] can do that. We can do this." Then that relationship was one of acceptance and that's where we're at. And so I think that just helped me to just really breathe a huge sigh of relief for [my child] and secondly for me. For one thing, I don't have to do everything. I don't have to be everybody. I don't have to be [my child's] playmate and [my child's] mom and [my child's] teacher and [my child's] speech therapist and [my child's] nurse. (B)

Appraisal of roles involved the evaluation of parental roles, the child's roles, and societal roles. Each type of role appraisal was associated with a number of different conditions, consequences, and strategies. The third type of appraisal that emerged concerned the appraisal of resources.

## **Appraisal of Resources**

Each parent evaluated to varying degrees the type and extent of available

resources. These resources were appraised for their applicability and utility with reference to the needs of the child with a hearing loss. Five types of appraisal of resources emerged from the data. These included appraisal of personal resources, interpersonal resources, societal resources, child's resources, and finally a comparison between personal resources and societal resources.

#### Factors influencing appraisal of personal, interpersonal, and societal resources

Conditions influencing appraisal of personal, interpersonal, and societal resources included the type of services available, the information provided about the child's hearing loss, and information gathered about the child's hearing loss. The varying types of information influenced how parents viewed what they, family, friends, and society could do to assist or support the child. Some parents, for instance, who had at one time lived in rural areas, described the lack of specialized educational support for deaf children present in these areas. This lack of societal support influenced parent's appraisals of what type of support that particular rural area could provide to the child.

Other parents described the impact that information acquired from books and previous research had on them. For these parents, this literature was the first real introduction into what options were available for children who were deaf. The literature, for example, influenced how parents viewed specific types of educational programs or communication modes. Some parents described how oralism and total communication were the first two approaches they were introduced to in the literature, and how these descriptions influenced initial perceptions of what support and intervention would be needed and most beneficial for the deaf child.

Parental appraisal of personal, interpersonal, and societal resources resulted in parents feeling a sense of adequacy or inadequacy for the resources available. These feelings of adequacy or inadequacy are discussed in greater detail in subsequent sections.

#### Appraisal of personal resources

Personal resources included the parent's personal qualities, skills, and knowledge. These personal resources were evaluated by each parent in terms of their degree of usefulness to the parent or for the child who was deaf. For example, some parents continually assessed self-proficiency in sign language. Parents also tended to evaluate the level of knowledge that they possessed about deafness or about child development in general. One participant commented upon feelings of self-doubt and inadequacy following her child's diagnosis of deafness: "Here's something that's happened to my child and I don't have the information or the skill or whatever or even the knowledge to know what to do to help him." (B)

Another parent commented on inadequacies felt in his knowledge about the educational programs and communication options available.

And if you like, unfortunately, at the time there were so many options from what does that mean exactly? How deaf is he? Being new, what does profound exactly mean? Maybe our first route was then hearing aids and then speaking to him especially since we didn't have any signing whatsoever. And what do we do? In the signing world, once we've learned about this thing called sign language, is it going to be cue assisted? Is it going to be Signed English? Is it going to be this really weird thing called ASL? Is it going to be somewhere in the middle? And are we going to screw him up if we wait too long. How can we make this decision? (F)

Parents also appraised the ability to influence social situations involving their children who were deaf and other children. Many parents felt frustrated with social situations and felt powerless because of their lack of control in orchestrating social interaction between their children and other children.

I think as a parent one of the hardest things to watch is your child not to be included and knowing that you are very, very powerless in terms of him being included. Playing with kids, or the cousins getting together, you can't go intervene and say, "Okay kids, now make sure you include [my child]." (B)

## Appraisal of interpersonal resources

Parental appraisal of interpersonal resources included evaluation of the support provided by spouse, family, and friends. Appraisal of family support varied between either helpful or unhelpful. For example, some parents described the difficulties associated with extended family members' denial of the child's hearing loss. Some parents expressed that they felt ready to mobilize with interventions associated with the child's hearing loss, but that the need to humor or satisfy family members with secondary assessments or opinions was often a source of increased anxiety and stress.

Support provided by friends was viewed by some parents as helpful when friends showed interest but were unassuming: "And where we lived, having good friends all very supportive and understanding saying, 'Okay, what are you going to do now?" (F) Other parents, on the other hand, viewed the lack of involvement or effort by friends as a source of frustration. For example, one parent described the frustration felt because friends did not make an effort to learn to communicate with her child.

Spousal influence emerged as a particularly significant interpersonal resource. Spousal influence was appraised on three dimensions: involvement, support, and congruency. Participants appraised the involvement of the spouse in the daily events and activities associated with the child and her/his hearing loss. One parent expressed frustration concerning the lack of her spouse's involvement either emotionally or practically (e.g., decision-making, learning communication modes). "My husband didn't cry or anything and he also developed total inertia. He did nothing either. It drove me nuts. It was a real

strain on our relationship." (G) Appraisal of spousal support also pertained to the perceived emotional support received from the spouse.

And I know that's something that [my spouse] and I talked about was that if it wasn't for the two of us, if we hadn't done this together, it would have been hard. Like if I didn't have [my spouse] supporting what I thought or vice versa. (A)

Finally, appraisal of spousal congruency pertained to the degree to which each parent perceived agreement between parent and spouse on issues related to the child's hearing loss. One parent, for example, said

So we [my spouse and I] have a very different approach I think to it [choosing a communication mode or educational program for the child], but in the end I think we arrive at a very similar end if you like .... So those things have resolved themselves, but that was more I think to me the worry that we both agreed we had to do something. We didn't quite see eye-to-eye what we wanted to do. (F)

## Appraisal of societal resources

Each parent assessed the societal resources available to assist the family to adapt to the day-to-day events related to the child's hearing loss. These resources included availability of professional support, presence of agencies or services specifically for deaf individuals and their families, interaction with deaf individuals, interaction with other parents of deaf children, and information or literature regarding deafness. One parent expressed frustration with the lack of established services for her child who was deaf.

The other time I get a little frustrated maybe and I realize there are going to be hurdles even though I don't think there should be but there are is

when we're trying to get [my child] involved in sports and activities and stuff. And he doesn't have all those things without us setting it up or hiring an interpreter or whatever. It's just everything is more of a production. And I know I'm going to get annoyed and frustrated sometimes. (A)

Societal resources were evaluated according to their utility, relevance, and availability to the family with the child who was deaf. That is, parents often evaluated the quality of the services available and the fittingness of these services to the needs of both the parent and the child.

There's a reason he cried when he went to school. He didn't want to go to that school because he went to other schools with great joy. So whether it was that particular setting or the particular personalities, I didn't feel comfortable. (B)

#### Appraisal of the child's resources

Following diagnosis of the child's hearing loss, parents would assess the impact of the hearing loss on the child's skills, abilities, and experiences. Part of this appraisal was also influenced by each parent's perception of the child's personality, attitude, and outlook in events related to the hearing loss. Two consequences that emerged from this type of appraisal were a sense of loss and a sense of pride.

Many parents assessed the child's abilities and felt sadness and loss for what they believed the child was lacking. Parents also described feelings of loss for the lack of or limits in the child's experiences due to the child's hearing loss.

I love bird-watching and that's something my daughter can't do because the first thing you do when you bird-watch is you get that first clue—like you don't watch for birds. You listen for birds. And after you hear them, you look for them. So although she and I can go bird-watching, I point to where a bird is and her eye tracks somewhere else ... So those sorts of things still choke me up. (G)

These feelings of sadness and loss were often recurring and accentuated by peer comparisons. Parents would compare the child's abilities with those of children who were not deaf. These comparisons would result in feeling a sense of loss for the child's perceived limits and deficiencies.

It was hard to be with people whose children were not disabled and to look at all they could do and know that [my child] either at the time wasn't doing it or would not be able to do that or a sense that he couldn't. And seeing how he was doing at the time in a deficit kind of position. You know he's not able to do that. He's not able to do that. (C)

Recurring feelings of sadness and loss were also associated with moments of seeing the child who was deaf experience difficulties or distress.

One participant commented on the recurring sadness felt when he saw his child struggling.

Well, it's never really over. You know every now and then I look at [my child] or... or she's frustrated and you know you just start to grieve all over again. But yeah you never really get over it. It just comes up and hits you in the head every now and then." (E)

Another consequence that was associated with appraisals of the child's resources was a sense of pride. Parents would evaluate the child's attitude, skills, and abilities and feel proud not only for what the child was capable of doing but also for the child's attitude and determination in persevering through adversity.

We're really fortunate in that respect that we haven't had to deal with a lot of, "Well, I can't do that because I'm deaf or I've got [a disability]." [My child] accepts that, but she's still a cheerful, outgoing, wonderfully loving kid. And we can all learn from that .... It hasn't knocked her down and defeated her in any way. (E)

<u>Strategies.</u> Two strategies were associated with appraisal of the child's resources: focus upon adaptability and pragmatism and child-centered responsiveness.

Parents' appraisals of the nature and extent of the child's resources influenced the strategies the parent would take with regard to the child's hearing loss. One strategy, referred to in this study as a focus on adaptability and pragmatism, pertained to parents emphasizing unconditional love as well as those skills and abilities the child did possess. That is, the idea of loving the child that was given and to love her/him for who s/he was rather than focusing on what s/he did not have. One parent stated, "... you take the package that you receive and you love them to pieces for what they are and you help them develop within that, you know, given package." (A)

Focus upon adaptability and pragmatism involved working with the child's abilities, interests, and capabilities.

I don't want [my child] to ever feel like she has lost something either. I don't want someone to tell her that "There's this wonderful world of sound out there that is magnificent and you can hear it if you try," because I don't want her to feel a sense of loss. I want some artist to work with her and teach her how to look at the world. I want people to work with her abilities. (G)

Emphasis was placed not on what experiences the child did not have, but rather on the existing qualities of the experience.

Even, to be honest, even now my mom will sometimes still say at Christmas time with Christmas carols, she's sad that [my child] can't hear [Christmas] carols. And I'm like, "Mom, he doesn't know. He's never heard a carol. Christmas is wonderful for him. There are tons of memories and you know festive things, not just carols." (A)

#### Appraisal of personal resources in comparison to societal resources

The parents in this study evaluated not only the resources they thought would assist them in adapting to events related to the child's hearing loss, but they also compared the resources they possessed personally with those provided by society. This type of appraisal ranged from comparisons between what the literature cited was important for deaf children and what the parents felt they could do to support the child who was deaf. Parents would consider if the actions or suggestions from societal resources were indeed feasible or applicable given the personal resources the parent possessed. Three consequences of this type of appraisal were that parents felt their resources were adequate or inadequate, parents felt overwhelmed or, alternately, parents felt a sense of empowerment.

Factors influencing appraisal of personal resources in comparison to societal resources. The nature of the services available, the information provided, and the information gathered all affected this appraisal type. More specifically, these factors included access to service-providers, type of information professionals provided to the parents, as well as type of information gathered by parents from their own research into the literature, talking with other parents of deaf children, or from talking with deaf individuals. The information acquired about the potential impact of personal and/or societal resources on the child would then influence each parent's appraisal of the actual effectiveness of each type of resource. Each parent would then assess which types of resources, whether personal and/or societal could provide the best assistance or support to

her/himself and to the child who was deaf.

Feeling inadequate and overwhelmed. Many parents, particularly immediately following diagnosis, felt they lacked the knowledge or skills to help the child sufficiently especially given what the literature and professionals suggested was needed. These perceived deficiencies or limitations in personal resources were often associated with feelings of inadequacy or feelings of being overwhelmed. Parents felt overwhelmed and inadequate when they perceived that societal resources far exceeded what the parent could provide or handle.

Some parents, for example, felt overwhelmed with the nature and extent of information provided to them from societal resources such as doctors, audiologists, or agency and school professionals immediately following diagnosis of the child's hearing loss. More specifically, participants felt overwhelmed when they perceived information coming from a variety of different sources and seemingly simultaneously. As a result, many parents felt unable at the time of diagnosis to assimilate all the information provided.

Parents expressed uncertainty regarding what to do for their children and what the next steps were in terms of communication mode, programs, and education. Feelings of inadequacy would result from comparisons with other deaf children and their hearing parents. Parents would see the skill levels of other children who were deaf and feel continual feelings of uncertainty and self-doubt concerning the most appropriate communication mode or educational program for their own deaf children.

I remember one lady there [at a Deaf camp] with her children both of them with hearing aids but fairly verbal. And so you are going, "Your kids are basically speaking. They are not really signing." You want to find out exactly how deaf are these kids. So you're saying, "Maybe this is instead what I should be doing with [my child] because maybe [my child] could be talking just the same".... And it's always no matter how certain you feel, you go like, "Okay you've got to think about this again." And so you

wonder again, "are we doing the right thing? Should we consider this? Should we not consider this? Why would they make this decision? Why are they doing this? Are we doing the right thing?" (F)

Feelings of inadequacy also stemmed from appraisal of the communicative competency of the parent in comparison with other individuals. For example, many parents felt self-conscious and inadequate in their sign language skills particularly in the presence of a fluent deaf or hearing signer. These feelings appeared to stem from perceptions that their skill level was being judged by others.

I'm so self-conscious [signing] in front of hearing people who can sign well. If a person didn't sign, it didn't bother me at all. Then it doesn't matter because they weren't judging my signing skills. That's why I think I felt like my signing skills were being judged and it made me feel uncomfortable.

(A)

Not all parents experienced feelings of being overwhelmed or inadequate to the same degree. In fact, many parents' appraisals of their personal resources in comparison to societal resources led to a sense of adequacy and empowerment.

<u>Feelings of adequacy and empowerment.</u> Some parents felt that they had the resources to handle the events related to the child's hearing loss given the information they had acquired from society, such as discussions with professionals, with deaf adults, or with other hearing parents of deaf children.

Parents felt that their actions, skills, and personal qualities would support them in assisting and supporting the child who was deaf. Parents felt a sense of control. More specifically, parents felt a sense of self as primary decision-maker as well as a sense of self as a primary influence in their children's lives. Participants emphasized their own roles in influencing the children's lives rather

than what any external sources suggested (e.g., professional, other parents, and research literature). Often participants emphasized the importance of information gathering as a contributing factor to this sense of empowerment and adequacy.

We were doing it based on research that we had done rather than listening to all the "experts." I just felt that we were able to come to our own decision without a lot of bias from other people... although people say "well you can't do that," then you just don't believe them. You say, "well has anyone tried?" And if no one's tried, well then obviously someone could. (D)

I don't care what the statistics say anymore because I think in the end it depends on how many times I will sit down with [my child] and practice—force him to write, spell, read, tell me again, explain to him the grammar rules, or whatever. That in the end will determine how much he will improve whether you go beyond whatever grade one, two, three, four, ten, twelve, whatever level. So it's up to me. (F)

Feelings of adequacy and empowerment also resulted from perceived equivalencies between parental resources (e.g., what parents could do for the child) and societal resources (e.g., what other hearing parents were doing for their deaf children). That is, parents felt more adequate and empowered when parents' appraisals indicated similarity in experience between themselves and other hearing parents of deaf children. Parents no longer felt alone in experience. Participants commented upon a sense of shared experience and being supported as well as a sense of stability. One participant discussed the impact of a parent group for parents of deaf children. It was comforting to know that there were other parents with similar experiences and feelings. Here the participant's feelings were not only heard but acknowledged.

Well, the exchange that I had through [the parents' group] with other parents was the most empowering situation possible because it gave me a view of a variety of other parental situations, other situations with children, and brought me to a place where I realized that I was the decision-maker here .... Having that talking circle where people have the same experience. There's nothing more empowering than shared experience and I don't know what that is or why that is. But I guess just knowing that your experience is not unique and that you're not alone in the feelings that you have, the hopes you have, and dreams you have.

Three strategies were associated with parents' feelings of adequacy and empowerment. They were a) taking the lead, b) focus upon adaptability and pragmatism, and c) planning ahead. Once parents felt that they possessed the resources to manage events and activities related to the child's hearing loss, then parents became more pro-active. Parents would take the lead in making decisions and advocating on behalf of the child.

Feelings of adequacy for personal resources available also were associated with parents beginning to focus much more on the existing resources rather than those lacking. In other words, parents indicated the importance of focusing on adaptability. Parents were doing what they believed they could do and on doing the best they could with what they were given.

The overall conclusion may be more for me than for [my spouse] was, "Yeah we're doing the best we can." It may not be the best thing that could be done. Yes, ideally we would live in a "deaf village" where we would have these [language] models all day long. That would be the best scenario. But it is not so. Given that it is not so, we'll do the best we can. If some things will be missed or something will be slow or delayed, so be it. (F)

Some parents emphasized adaptability when discussing events

associated with learning a new language, such as American Sign Language. None of the participants interviewed were fluent in sign language prior to the child's diagnosis of hearing loss. Therefore, parents expressed the significance of using whatever sign language skills they did have rather than on those skills still lacking.

Like if you tell a child, "Oh, see the dog. The dog is jumping" right. Well I wouldn't say that. I said like, "Oh see the dog," because I wouldn't know the word "jumping" yet, you know, stuff like that. [I] just didn't give [my child] as enriched a language as I did with [my hearing child]. But hey, you do what you can." (A)

In addition to focusing upon adaptability, parents described the importance of focusing on pragmatism. This included focusing upon next steps or planning ahead as well as focusing upon being patient and moving one step at a time. This strategy, again, just as with focus upon adaptability, was particularly applicable to parents' approaches to learning a new language.

And you suddenly go, "Okay, I one day will be able to do the same thing and actually communicate. And it will come. It's not a mystery. It is like so many things, it's practice." Yes, I know tomorrow I will not be a fluent signer and chances are very good that three years from now, I won't be a fluent signer. But every time I learn a little bit more, I say, "One more thing in my bank of things that I know." Yes things will eventually happen if I make them happen. (F)

Right now I try to be patient with myself because I'm not getting [sign language skills] as fast as I want to. But I just kind of sit back and kind of go, "I'm in it for the rest of my life, and what choice do I really have?" This is where I have to be. So okay I didn't do it this time—[but maybe] two years from now. (G)

Three types of appraisal have been discussed thus far: appraisal of the meaning of deafness, appraisal of roles, and appraisal of resources. The fourth type of appraisal that emerged from the data was appraisal of reactions to deafness.

## **Appraisal of Reactions to Deafness**

Two types of reaction appraisals emerged from the data: appraisal of parental reactions to the child's hearing loss and appraisal of the child's reaction to the hearing loss.

## Appraisal of Parental Reactions

Parents often evaluated their own reactions and actions in response to events associated with the child's hearing loss. Parents, for example, continually evaluated decisions regarding educational program or communication mode for the child. Parents evaluated their own ability to make the appropriate choices and decisions not only for themselves but also for the children.

Factors influencing this appraisal of personal reaction were the feedback received from the information gathered and the feedback received from the information provided. That is, parents acquired information from the existing literature, professionals, deaf adults, other parents of deaf children, friends, and family and used it to evaluate the appropriateness or utility of their reactions. For instance, one parent reevaluated the appropriateness of his decision to use sign language with his child after he learned about the experiences of another parent and child who used an alternate form of communication.

The consequences associated with a parent's appraisal of personal reaction included feelings of adequacy or inadequacy and sense of validation. Parents' evaluations of the appropriateness of a particular response would result in parents' feeling that their own reaction had either been adequate or

inadequate. For example, appraisal of parental behaviors prior to birth of the child and just prior to diagnosis occurred. One mother felt inadequate in terms of self-care while pregnant with her deaf child. This parent felt that she might have been responsible for her child's deafness in that she might have done something wrong or not done enough (e.g., diet while pregnant).

I still struggle with this and lots of other mothers do. It's sort of like, "Was this my fault? Did I do something wrong?" And I go over my pregnancy so many times, and I still do this ... whether or not I ate right while I was pregnant. Did I have enough folic acid? Did I eat enough green, leafy vegetables? (G)

While self-blame concerning the cause of deafness was described by parents, some parents also expressed intense feelings of self-blame or guilt for not being able to identify the child's hearing loss earlier.

One thing I remember during that beginning time was we did, both of us [my spouse and I], felt somewhat guilty for not picking it [child's hearing loss] up earlier. That's been something that bothered us probably longer than not so much why he's deaf but why didn't we pick it up. (A)

Participants also described feelings of adequacy or inadequacy resulting from appraisals of decisions, choices, and actions related to the child's hearing loss. For example, one parent's feelings of inadequacy stemmed from evaluation of his ability to ask stimulating questions and to meet all of the child's needs linguistically (e.g., communication mode) and socio-emotionally (e.g., immersion into a Deaf environment).

Half the time it was okay, "Oops I am screwing [my child] up. I'm doing the wrong thing. I'm using the wrong signing mode. I'm not doing it clear.

Oops, I'm not integrating [my child] into Deaf Culture—that's what he needs." (F)

Feelings of adequacy or inadequacy also stemmed from evaluation of personal knowledge, skills, strategies, and experience.

Have I been a good enough mom? I know I've not been a perfect mom—dealing with that guilt all the time. Am I doing the best job I can or not? Or I should say that I'm probably doing the best job I can given the circumstances. I certainly try hard, but could I do better? Yeah, probably! Will I be able to in the future meet my child's needs? Probably not. Probably not. I need a lot of help doing that. (G)

Another consequence that emerged from evaluations of parental reactions was a sense of validation. Sense of validation referred to parents feeling like they had made the right choice for the children and also for themselves. Parents felt greater comfort and ease when social comparison with other individuals led to validation of each parent's decisions, actions, and choices. For example, similarity in experiences, choices, and needs amongst parents validated the perceived appropriateness of each parent's reactions.

If I come to this camp and I'm only seeing couples that said, "Well we took these fourteen classes and every afternoon we take our kids to this and this and this. And look at where we are now." If it's the only example, then I would have went, "Oh boy, I'm going to be screwing [my child] up for sure. I've got to do something completely different. I've got to quit my job. I've got to move otherwise my kid won't ever be [where I want him to be linguistically and educationally]." But we didn't see that. We saw, "Oh they're also getting videotapes. They're also using dictionaries." They may have a deaf person coming to their home once in a while, but we're

looking and we're saying, "Oh they're okay. They're communicating." So we're in a similar situation so that's okay. (F)

One strategy associated with appraisal of parents' reactions to the child's hearing loss was a focus on adaptability and pragmatism. As indicated previously, focus on adaptability and pragmatism involved emphasizing the resources the parent did possess rather than those that were lacking. Focus on adaptability and pragmatism was associated with parents' sense of adequacy in their reactions as well as a sense of validation. That is, when a parent perceived that her/his reactions and actions were appropriate or beneficial to the child, then the parent would feel greater confidence in her/his abilities to manage an event associated with the child's hearing loss. This increased confidence was then influential to a parent's increased focus on capabilities rather than limitations.

## Appraisal of the Child's Reactions

Parents often evaluated the child's reactions to the hearing loss. That is, parents assessed the child's interest, skill or knowledge acquisition, and enjoyment in events or activities related to the child's hearing loss. This evaluation of the child's resources had three consequences for the parents in this study: sense of loss, sense of pride in the child's reaction, and sense of validation.

If the child did not react as the parent had expected or hoped, many parents expressed a sense of loss. This sense of loss was evident, for example, when the parent perceived the child's lack of interaction in social settings with same-age, hearing peers.

Just watching [my child] be alone and I think he shouldn't be. [My child] should be part of the group, and I feel kind of sad for him, not angry—the kids are not shunning him at all. That's not it .... But it just seems so

obvious when they [hearing children] are horsing around and stuff and he doesn't want to. You know, it's like, "Poor kid, I feel bad for you." (A)

If, however, a parent evaluated the child's reaction and this evaluation matched or exceeded the parent's expectation of the child's abilities, knowledge, or attitude, then the parent felt a sense of pride. For example, one parent expressed great pride in the generative, creative, and complex nature of his child's language.

What [my child] did then was he created a sign basically that would show me literally the art of jumping up and turning around and sitting down ....

And so I would go around and tell the neighbors. "Oh you know [my child], he just combined [three signs into one]." And it's beautiful, all right. (F)

Another consequence that emerged from parents' appraisals of the child's reaction was a sense of validation. Sense of validation, as indicated previously, referred to the extent that the parent felt that s/he had made an appropriate choice for both the child and parent. This sense of validation was directly attributable to the parent's appraisals of the child's reactions. For example, parents evaluated the appropriateness of a particular communication mode by observing the nature of the child's reaction to that communication mode. More specifically, parents expressed greater satisfaction in the appropriateness of their decision to use a particular communication mode when the child expressed interest, enjoyment, and competency in that communication mode.

We signed what we could, and [our child] automatically picked it up, just like a sponge. "Washing machine" was one of his favorites, you know, "car" was another. But I remember the excitement of giving him a few words and getting them back from him. It was very, very satisfying. (D)

Two strategies associated with parental appraisal of the child's reaction

were focus upon adaptability and pragmatism, and child-centered responsiveness. Evaluations of the child's reaction that resulted in a sense of pride and a sense of validation were often associated with parents emphasizing the identification of the child's skills, abilities, and knowledge. This focus on what the children were capable of or, in other words, a focus on adaptability and pragmatism was associated with the strategy of child-centered responsiveness. Once parents emphasized the skills and capabilities of the child, then parents were likely to evaluate events related to the child's hearing loss based more upon what the *child* was interested in and skilled at than on what others, including themselves, wanted or thought was best. For example, one parent's observation of the child's enjoyment and skill level in learning sign language influenced her decision to change from one educational program to another. This parent put aside her own needs for what she wanted for the child at the time in favor of what the child was interested in and skilled at.

And that whole time frame of giving up on the auditory [program] and moving to the TC [Total Communication] program was very unsettling. It was difficult for me and it wasn't until as I say that incident of [my child] coming back from the classroom and signing away with this great big grin on his face ... [that] I embraced [the use of sign language] whole-heartedly when I saw his reaction to it, no question. (B)

# Comparing the Findings to the Original Research Questions

As indicated in Chapter II, the original research questions served to identify *potential* theoretical areas of exploration and guides to inquiry. Whether the research questions were "answered" depended upon the concepts and, moreover, the theory that emerged from the data. This reflects the emphasis upon *emergence* rather than pre-determined conceptions in grounded theory methodology. At this point, each of the original research questions will be discussed with reference to the findings of this study in order to compare the

expected focus of this investigation with the emergent focus.

1) What types of thoughts, feelings, or emotional reactions were experienced by mothers and fathers at various points in time following diagnosis?

The thoughts and feelings of the participants were central to the theory of parental appraisal. Thoughts in this study emerged as the specific types of parental appraisals. Parents continually evaluated the meaning of deafness, the existing and required resources, assigned roles, and specific parent and child reactions. These thoughts or perceptions influenced subsequent feelings and actions of the parent.

Feelings of the hearing parents in this study were also indicated in the theory of parental appraisal. These feelings were identified within the theoretical framework as consequences to appraisal. Parents in this study indicated numerous and variable feelings in response to specific types of appraisals. Some examples of feelings expressed by the parents interviewed include feelings of adequacy or inadequacy, sense of loss, sense of pride, and feelings of enrichment. We shall see in Chapter V, how these specific feelings were identified as specific emotion-focused and problem-focused ways of coping.

The associations between specific emotional reactions and types of appraisal were not present in this study's theory of parental appraisal. While generalized feelings were identified, the specific emotional reactions associated with them did not emerge. Emotional reactions such as anger, frustration, and denial were indicated by parents, however, their precise relationship to each type of appraisal was unclear.

2) What factors were associated with varying responses?

Factors influencing parental responses following diagnosis were identified in this study. In fact, parental appraisal emerged to be the primary factor influencing all parents' responses. Parental appraisal not only influenced

subsequent emotional and coping responses but also accounted for any variability in parental reactions. That is, the presence of diversity in reactions to the child's diagnosis of deafness could be attributed to the varying influence of individualized and specific parental appraisals on emotion and behavior.

Numerous intervening conditions emerged with each type of parental appraisal. For example, appraisals of the meaning of the child's hearing loss to both the parent and the child were influenced by such intervening conditions as information provided about deafness, information gathered about deafness, and prior experience with deafness.

3) How did parents compare in their reactions? What similarities or differences existed?

The appraisal theory that emerged from the data in this study did indicate similarities and differences in responses. For example, similarities in types of appraisal emerged from this study suggesting that each parent tended to assess various encounters according to their significance or meaning, resources available, roles assigned, and reactions. As well, parents did appear to experience similar outcomes to these appraisals and used similar management strategies. The extent or degree of these outcomes and strategies, however, varied between individuals. Differences were attributed to the individualized nature of parent appraisals as well as to the presence of unique intervening conditions and context for each participant in the study.

It is interesting to note that parents, overall, did appear to possess many similarities in terms of *types* of parental appraisals, consequences, and conditions. The *extent* of these variables and their *pattern of interaction* and *mutual influence*, however, contributed to the presence of and potential for diversity in responses between participants. Specific patterns of diversity between mothers' and fathers' responses did <u>not</u> emerge from the data. Specific similarities or differences in mothers' and fathers' patterns of appraisals, consequences, and strategies may exist, however, their presence or lack thereof

did not emerge from the findings of this study.

#### Summary

Grounded theory techniques for coding and interpreting the data were used to develop a theoretical framework representative of the experiences of the seven participants interviewed. Specifically, the core category that emerged was identified as "parental appraisal of a child's deafness." Four types of appraisal emerged including appraisal of meaning, appraisal of resources, appraisal of roles, and appraisal of reactions. Each type of appraisal along with its associated set of intervening conditions, consequences, and strategies was presented in this chapter. Chapter V includes a discussion of the theory with respect to previous research. Implications of the study, methodological limitations of the study, as well as suggestions for future research are also provided.

#### CHAPTER V -- DISCUSSION

Grounded theory analysis allowed for the emergence of conceptual categories. These categories were integrated into a theory of parental appraisal for hearing parents of deaf children. Chapter IV presented the theory as a pattern of four appraisal types consisting of five theoretical codes (see Glaser, 1978): cause, context, condition, consequence, and strategy. This chapter, however, will relate the findings and, moreover, the theory of parental appraisal to previous research. Since limited research existed pertaining to parental appraisal for hearing parents of deaf children, an examination of appraisal within a more general framework of stress and coping was necessary. That is, appraisal of hearing parents of deaf children that emerged in this study was compared with appraisal as described in stress and coping theory, with particular reference to the work of Lazarus and his colleagues (e.g., Folkman, Lazarus, Dunkel-Schetter, & DeLongis, & Gruen, 1986; Folkman, Lazarus, Gruen, & DeLongis 1986; Lazarus & Folkman, 1984, 1986; Lazarus, 1991a, 1991b, 1993, 1995).

## Stress and Coping

To better understand the various aspects of stress and coping and particularly their interaction with one another, the key terms within stress and coping literature are briefly defined.

Stress: quality of experience created by perception of a transaction as demanding to personal well-being and taxing to personal resources (Aldwin, 1994; Lazarus & Folkman, 1984)

Cognitive appraisal: evaluation of the meaning of a transaction to personal well-being (Lazarus & Folkman, 1984)

**Transaction:** the mutually influencing relationship between a person and the environment (Lazarus, 1995)

Coping: efforts to manage demands or stress (Miller, Gordon, Daniele, & Diller, 1992; Schilling et al., 1984)

Adaptation: adjustment or accommodation to new demands (Hanson & Hanline, 1990)

#### Models of Stress and Coping

Many models of stress and coping emphasized the concept of transactionism. Transactionism included two assumptions: a) reciprocity between variables, and b) reciprocity between variables resulted in changes in mind and body (Aldwin, 1994). Lazarus and Folkman (1984) applied this model of transactionism to their cognitive-behavioral model of stress and coping. The mutually influencing variables were person and environment, appraisal, and coping response. Barakat and Linney's (1992) multivariate ecological model also incorporated Lazarus and Folkman's (1984) model of stress and coping with a transactional model.

Another model referred to as the ABCX model of family adaptation was proposed by Hill (1958; as cited by Singer & Irvin, 1989). This model included four components: a stressor (A), family resources (B), family's appraisal of the stressor (C), and family crisis or successful family adaptation (X). The stressor, family resources, and family appraisals interacted to produce one of two consequences: family crisis or positive adaptation.

Given the pervasiveness of transactionism, appraisal, and the cognitivebehavioral model proposed by Lazarus and Folkman (1984) in the stress and coping literature, an overview of their potential relationships is provided.

Cognitive-behavioral model of stress and coping. According to this model,

coping and appraisal were "critical mediators of stressful person-environment relationships and their immediate and long-term outcomes" (Folkman, Lazarus, Gruen, et al., 1986). This theory emphasized the transactional interaction between person and environment as well as its effects on stress and coping. Person and environment were viewed as having a dynamic, mutually influencing relationship. Reciprocity and bi-directionality were also prevalent in the relationship between appraisal and coping. That is, appraisal was suggested to influence coping while coping then influenced the person's appraisal or reappraisal of the meaning of the transaction and the coping resources available (Folkman, Lazarus, Dunkel-Schetter, et al., 1986).

Components of the cognitive-behavioral model of stress included a stressor, personal resources for coping, cognitive appraisal of a stressful encounter, and coping responses (Miller et al., 1992). Each of these components was present in the theory of parental appraisal of deafness that emerged in this study. The stressor could be equated with the cause or, in other words, the child's hearing loss. Personal resources for coping could be equated with the parental resources and personal context in the present study. Cognitive appraisal was equivalent to the four types of appraisal that emerged: meaning, resource, reaction, and role. Coping responses included some of the consequences and strategies that emerged from the data. Some coping responses that parents used in the present study included focus upon adaptability and pragmatism, child-centered responsiveness, taking the lead, and lessening the pressure on self.

Two ways of coping were described in the literature: problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984; Miller et al., 1992). Coping was viewed as neither positive nor negative and was independent of outcome (Lazarus, 1993). That is, all strategies that were used to manage a stressful encounter were viewed as "ways of coping" or "coping strategies" regardless of whether the outcomes were adaptive or maladaptive. Problem-focused coping referred to those strategies used to manage the source of stress. Emotion-focused coping included strategies to regulate emotional reactions

associated with a stressor. Problem-focused coping strategies that emerged in the present study included focus upon adaptability and pragmatism, taking the lead, integration of deafness into life, and child-centered responsiveness. Emotion-focused coping included lessening the pressure on self.

<u>Summary.</u> What was central to these various models of stress and coping was appraisal. Appraisal was viewed as a primary influence on coping responses and person-environment relationships. It was also a determining factor to family experiences of crisis or adaptation. Given the significance of appraisal in stress and coping models as well as in the theory that emerged from the present study, the nature of appraisal will be the focus of discussion.

#### Cognitive appraisal

Two assumptions regarding cognitive appraisal were suggested in models of stress and coping: a) cognitive appraisal was a mediator between stress, coping, and emotional reaction, and b) consequences of cognitive appraisal were variable and, thus, contributed to great individuality in behavior.

Appraisal, according to Lazarus (1991a), includes an evaluation of the meaning or significance of an encounter to personal well-being. Two types of appraisal have been identified: primary appraisal and secondary appraisal. Primary appraisal refers to evaluations of the meaning of a stressor (Folkman, Lazarus, Dunkel-Schetter, et al., 1986; Lazarus & Folkman, 1984; Miller et al., 1992). Secondary appraisal involves evaluations of the possible options and coping resources that are available (Folkman, Lazarus, Dunkel-Schetter, et al., 1986; Lazarus & Folkman, 1984; Miller et al., 1992).

Cognitive appraisal as described within a stress and coping theoretical framework appeared to be very related to the concept of appraisal that emerged in the present study. More specifically, parents of the children who were deaf did evaluate the meaning of encounters to personal well-being (i.e., primary appraisal) as well as the resources available to manage an encounter (i.e.,

secondary appraisal). Appraisal of meaning of deafness was related to primary appraisal while the other three types of appraisal (i.e., role, resource, and reaction) pertained to secondary appraisal. When an encounter related to the child's hearing loss appeared, parents tended to assess the significance of that encounter in terms of its influence on personal meanings of deafness. If the significance was perceived to be great by the parent, then the parent would try to determine the possible options for managing that encounter by evaluating the resources available, potential or existing reactions, and roles assigned.

For example, if a parent was trying to decide upon a communication mode for the child, then the parent would evaluate the impact or meaning of this situation on a parent's meaning of deafness for both her/himself and for the child (i.e., primary appraisal). In this way, parents would evaluate if a particular communication mode was compatible with personal philosophies or beliefs about what deafness entailed. As well, parents would evaluate whether a particular communication mode would influence the child's skills, capabilities, or career aspirations.

To assist the parent in making a decision regarding communication mode, the parent evaluated each communication mode according to its accessibility and feasibility (i.e., secondary appraisal). This type of appraisal involved evaluation of the types of resources that were available and identifying those believed to be most useful for any particular communication mode. For instance, the presence of in-home signing programs may influence parents' appraisal of using sign language as a communication mode. Secondary appraisal involved evaluating the parent and child reactions or actions necessary for use of any particular communication mode. For example, if parents noticed that a child was particularly responsive to aural-oral methods, then this might influence how the parent perceived the aural-oral communication method. Finally, secondary appraisal involved evaluating the extent of the roles in using any particular communication mode. For instance, appraisal of a communication mode may vary depending on the extent to which a parent felt that s/he had the primary role of teaching the child that particular communication mode. If, however, parents

perceived professional support in providing the child with language experiences, then this might impact choice of one communication mode over another.

According to stress and coping theory, cognitive appraisal acts as a mediator between stress, coping responses, and emotional reactions (Folkman, Lazarus, Dunkel-Schetter, et al., 1986). In the present study, the four types of appraisal were intermediary to the cause (e.g., the child's hearing loss) and subsequent coping responses (e.g., focus on adaptability and pragmatism, lessening pressure on self). The nature and extent of each parent's appraisal determined the nature of the particular consequence or strategy. For example, appraisal of the meaning of the child's deafness as the loss of an idealized image of the expected child or the relationship with that child was associated with a sense of loss. On the other hand, the appraisal of the meaning of the child's deafness as an opportunity to become more involved in the development of her/his child was associated with a sense of enrichment.

Concepts such as sense of loss, sense of enrichment, broadened perspective, feelings of adequacy or inadequacy, feeling overwhelmed, sense of empowerment, sense of validation, sense of pride, sense of parental responsibility, sense of shared responsibility, and sense of child's responsibility were classified as core relational themes. Core relational themes according to Smith and Lazarus in 1990 (as cited by Smith et al., 1993) involved the "the central meanings underlying the various emotions" (p. 918) that resulted from evaluations made about a particular transaction. They represented "the patterns of answers to the appraisal questions that have special adaptational significance" (p. 918). According to Smith et al., specific emotions such as anger, guilt, sadness, and happiness were linked to specific core relational themes such as blaming others, self-blame, loss or helplessness, and success. So in this study, sense of loss (e.g., theme of loss) and sense of enrichment (e.g., theme of success) were identified as core relational themes associated with a parent's appraisal of the meaning of the child's hearing loss and may be associated to specific emotions of sadness and happiness, respectively.

While associations between appraisal and emotion were suggested, it was

less evident from the present study the nature of each parent's specific emotional reactions (e.g., anger, sadness, guilt) and their relationships to varying types of appraisal. For example, while the study found a relationship between the appraisal of parental resources in comparison with societal resources and feelings of being overwhelmed, the present study did not determine potential relationships to specific emotional reactions such as despair. This lack of a clear emergent relationship between appraisal and emotional reactions in this study, then, indicates the need to examine the nature and range of these relationships in future research.

In relation, difficulties in classification of concepts as emotion or appraisal stemmed from uncertainties related to the definition of "emotion." Controversy exists pertaining to what constitutes emotion. According to Lazarus (1991b) concepts could be identified as emotions resulting from harms, losses, and threats (e.g., anger, anxiety, fear, guilt); emotions resulting from benefits (e.g., happiness, love); borderline cases (e.g., hope, contentment, relief); and non-emotions (e.g., states of grief, states of depression, confidence, determination). The concepts that emerged in the present study appeared to be linked to Lazarus's (1991b) description of borderline cases and non-emotion rather than emotion resulting from harm, loss, and threat or emotion resulting from benefits. Sense of loss, for example, emerged as a concept in this study and was classified as a core relational theme rather than an emotion. It appeared to be intermediary between appraisal and emotion rather than classified as one or the other exclusively.

Thus, ambiguities present in the relationship between emotion and appraisal as well as in the definition of emotion contributed to uncertainties in classifying concepts as associated with appraisal, emotion, or ways of coping. The boundaries were unclear. That is, some emergent concepts seemed to include aspects of emotion, coping, and appraisal. Overlapping concepts and lack of clear boundaries suggested that "It is artificial to separate these concepts, as if they belonged to different psychological arenas, when they operate in nature interdependently and in an overlapping way" (Lazarus, 1991b, p. 831).

According to both the findings of the present study and the previous literature pertaining to stress and coping, appraisal appears to be influential to subsequent responses. This suggests that individuality and variability in appraisals would similarly result in individuality and variability in the *specific nature and extent* of subsequent responses. While similar appraisal types, consequences, and strategies emerged, the specific nature and extent of these variables would be specific to each parent. For example, while many parents expressed a sense of loss with appraisals of the meaning of deafness to the parent and for the child, the extent and severity of this sense of loss was dependent upon the nature of the appraisal and its related contextual and intervening conditions. In other words, not every parent experienced a sense of loss in exactly the same way, nor was this sense of loss based on precisely the same appraisals.

While appraisal has been described in the coping and stress literature, little has been described in terms of its influence on the experiences of parents of children with disabilities or, moreover, on experiences of hearing parents of deaf children. Much of the literature involving disability or deafness pertained to the process of grieving experienced. Before reviewing the literature pertaining to appraisal and parents of children with disabilities, a brief overview of the findings in this study in comparison to the proposed models of grieving is presented.

## Comparing the Appraisal Model with Grieving Models

As indicated in Chapter II, literature concerning the reactions of parents of children who were deaf often referred to parents' phases of grief and sadness. Models of grieving tended to emphasize specific emotional responses exhibited by an individual following the loss of a significant attachment relationship or bond. The emotional responses of the seven participants in this study did not emerge as primary components in the proposed appraisal model. Rather, the relationships that emerged pertained to specific types of appraisal, core relational themes, and coping responses of the parents. The theoretical relationship

between appraisal and emotional responses (e.g., grief reactions), however, can be discussed.

Appraisal has been suggested as an influential factor to subsequent emotional responses (Lazarus, 1991a, 1991b, 1995; Lazarus & Folkman, 1984). Therefore, links between appraisal and grief reactions may exist and, indeed, appraisal stages may parallel the grief process. As discussed in Chapter II, two types of grieving models were prevalent in the literature: discrete stage models and process models. If appraisal does parallel grief reactions, then a stage model of grieving suggests that discrete stages of grief would parallel discrete stages of appraisal. The findings from this study, however, did not support these theoretical concepts.

In fact, discrete stages of appraisal, coping responses, or emotional reactions were not indicated. Different types of appraisal emerged (i.e., meaning, resource, reaction, and role), but were not found to occur in any particular sequence. Appraisal types were not mutually exclusive as some appraisal components (e.g., feelings of adequacy or inadequacy, sense of pride) overlapped across appraisal types. In addition, just as appraisal types were recurring and overlapping, so were the coping responses and emotional reactions associated with the appraisals. As well, the variable consequences and outcomes that emerged indicated the great variability in reactions of participants. These recurrent, overlapping, and variable aspects of the appraisal model for hearing parents of deaf children were not consistent with the discrete prescribed stages associated with some grieving models.

Process models of grieving, on the other hand, such as Martin and Elder's (1993) "Pathways through Grief" model, were more consistent with the findings of the present study. Martin and Elder's model, for example, described the infinite quality of coping responses and emotional reactions. Similarly, coping responses of the parents interviewed tended to recur over time and did not appear to have a distinct start or end point. In addition, Martin and Elder described an outward journey in grieving including hope, invest, and explore. While these specific concepts did not emerge in the present study, they did suggest the presence of

numerous positive and adaptive aspects to loss. Similarly, in the current study, parents experienced many adaptive consequences including broadened perspective, sense of enrichment, and sense of pride.

Martin and Elder's (1993) suggestion that parental expectations influence subsequent responses to loss was also supported in this study. Parents in this study did express a sense of loss associated with discrepancies between reality and expectation. According to Harvey (1989), this would be referred to as narcissistic injury. More specifically, Harvey described how parents' reactions were influenced by their expectations, dreams, and hopes for the child and also for themselves as parents. Narcissistic injury occurred with the disappointment that their dreams and hopes would not become reality.

<u>Summary.</u> The grief process did not emerge to be the primary area of focus in this study. The responses that emerged in this study were associated with the types of *appraisals* made by parents. Models of grieving tended to focus upon the emotional or coping responses themselves rather than the influence of precursory conditions or processes such as appraisal.

## Appraisal Model and Parents of Children with Disabilities

Limited literature related to the experiences of hearing parents of deaf children could be identified that included references to appraisal. Kampfe (1989) applied a multivariate transition model to reactions of parents of children who were deaf. Components of this model were consistent with the findings from this study. For example, both theoretical frameworks included appraisal or perception of the meaning of an event as well as intervening conditions influencing appraisal. This model also emphasized the individuality of parental responses to a child's hearing loss.

Calderon & Greenberg (1993) discussed the applicability of a stress and coping model to families with deaf children. While potential coping factors and coping resources such as problem-solving skills, social networks, and general and specific beliefs for parents of deaf children were identified, the specific

influence of appraisal was not discussed. Singer and Irvin (1989) described the influence of broad, abstract appraisals by parents of children who were disabled. For example, parents evaluated the impact of the child's disability on career fulfillment or personal fulfillment. The findings of the present study did indicate parents' appraisal of personal fulfillment (e.g., effect of an expanded social network), as well as of career fulfillment (e.g., influence on career interests and goals).

Summers, Behr, and Turnbull (1989) presented coping resources associated with positive adaptation. Three coping resources discussed were causal attribution, mastery, and enhancing self-esteem. Each of these coping resources was indicated in the present study. Causal attributions were related to the appraisal of meaning of deafness to the parent and the child. Some parents in this study, for example, continually evaluated the cause of the child's deafness and engaged in a cycle of self-blame and guilt. Mastery pertained to the feeling of control over an event. In this study, parents developed a sense of empowerment. This sense of empowerment resulted from parents' appraisals of their own resources in comparison to societal resources. When parents felt that they had the resources available to manage an event associated with the child's hearing loss, then parents felt a sense of control or empowerment.

Finally, the coping resource of enhancing self-esteem was also evident in this study. Enhancing self-esteem was associated with two appraisal consequences in this study: sense of pride and sense of validation. Sense of pride was associated with parents' appraisals of the child's resources as well as the child's reactions to her/his hearing loss. For example, when parents perceived the child's positive attitude or interest in a particular communication mode, parents felt encouragement and increased confidence in not only the child's skills and abilities but also the parents' abilities to cope and adapt successfully. Parents' sense of validation was associated with appraisal of the child's reaction to deafness. When parents perceived the child to be communicating in a complex manner, for example, then many parents felt a sense of validation that they made the correct choice in communication mode.

Overall, it appears that the findings of the study were consistent with the literature reviewed. These consistencies were primarily in the types of coping resources used and also the emphasis on the positive adaptation possible for parents of children with disabilities. All the studies reviewed, however, were theoretically based, none were empirical investigations of appraisal for hearing parents of deaf children. Thus, this study emphasizes the need to explore the specific nature and effects of appraisal for hearing parents of deaf children.

## Implications of the study

- Hearing parents of deaf children may not suffer from severe emotional distress or depressive symptomatology. Therefore, professional intervention may not be necessary for hearing parents of deaf children.
   Some parents appear to be able to adapt and cope over time.
- 2. If professional intervention was necessary, the findings from this study emphasized the need for professionals to focus upon appraisal in hearing parents of deaf children. By learning about the types of appraisals made and their associated conditions, consequences, and strategies, professionals may be able to encourage those appraisals and ways of coping most associated with adjustment and adaptation. Appraisal modification may be an important area of focus for professionals rather than solely the potential subsequent emotional responses such as grief or depression.
- 3. The centrality of appraisal to the reactions of the parents interviewed in this study suggested that appraisal may the crucial factor influencing subsequent coping responses and emotional reactions. Given that numerous and variable types of appraisal exist, this theory emphasized the likelihood of individuality in parental responses. That is, parents may not necessarily progress through similar stages of coping or

emotional response. Variability may be the result of the influence and interplay of numerous contextual factors and intervening conditions. Therefore, helping professionals should not assume that each parent would react to a child's hearing loss in a similar way. Rather, each individual's unique pattern of appraisals, emotions, and needs should be considered.

# Limitations of the Study and Suggestions for Future Research

Grounded theory methodology involved the development of a theory including a set of hypotheses related to the participants under study. These hypotheses were presented in Chapter IV as a framework of interconnected conceptual concepts. Glaser (1978) suggested that the goal of future research was not to verify or disprove emergent grounded theory hypotheses, rather, emphasis was on building or modifying the theory. Therefore, future research can modify or build upon the present model, but it cannot disprove the emergent hypotheses of the model for it represents the reality for the seven participants interviewed. This next section suggests some limitations of the present study and also presents some ideas for future research pertaining to hearing parents' reactions to a child's hearing loss.

- 1. This study was partly dependent on professional opinions. Professionals were used to identify parents who they believed were adjusting or adapting to the child's hearing loss. Potential bias could be present in these selections. A more objective measure of adaptation might be a useful supplement to this study rather than the nomination procedure. A self-report measure could be incorporated in future study such that objective measures of adaptation could be used to identify parents.
- 2. This study involved retrospective parent reports. Parents were required

to reflect on what they believed they felt at various points in time. Whether these were accurate reports of what emotions were actually felt is uncertain. As a result, future study could incorporate a longitudinal design wherein parents could be interviewed at varying points in time. In this way, researchers could acquire a better understanding of the day-to-day emotional reactions occurring. Another useful supplement would be the incorporation of a parent diary so that parents could describe what they were feeling at intervals between interviews.

- 3. The present study emphasized feelings and thoughts as perceived by the seven participants interviewed. That is, the study relied heavily on what the participants believed to be true, but perhaps did not tap into the unconscious appraisals that occurred. What parents say about their emotions may not actually represent the actual emotions felt or the core appraisals linked with these emotions. Therefore, future research could incorporate longitudinal observation so that researchers could try and tap into the responses and reactions that occur in day-to-day life. These observations could be compared with what parents say about their emotions and reactions in interviews. Any discrepancies found between what was observed and what was reported could be influenced by unconscious appraisal (Lazarus, 1995).
- 4. The present study lacked a cross-cultural component. Future study could investigate the nature of parental appraisals for individuals from a different culture. In this way, the effects, if any, of pervasive cultural values and beliefs on parental appraisal of a child's hearing loss could be explored (Lazarus, 1995).

5. This study focused upon the hearing parent and how her/his appraisals influenced coping responses and strategies. Little description was

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provided about the impact that the environment (e.g., Deaf Community) and, more specifically, other family members such as spouses and siblings had on parent appraisals. A family systems ecological approach (Bubolz & Whiren, 1984), then, would be useful in future research. A family systems ecological approach emphasizes the importance of considering the bi-directionality of interaction between family members and also the influence of family member transactions with the environment on cognition and behavior.

- 6. The transactional relationship between appraisal and coping responses did not emerge in this study. While appraisal was found to influence coping responses, the nature and extent of the influence of coping responses on appraisal was not clear. This area, then, would be an important area to investigate in future research.
- 7. The relationship between the four appraisal types that emerged was unclear. While overlap between appraisal components was indicated, the nature and extent of mutual influence and cross-over effects requires further examination.
- 8. Stress and coping theory indicates the associations between appraisal, coping responses, and emotional responses. While associations between appraisal and coping responses emerged from the data, the relationship between appraisal and emotional reactions was virtually unexplored. Therefore, future study is needed examining the nature of the relationship between appraisal and emotion for hearing parents of deaf children.

### Summary of the Study

The purpose of this study was to explore the emotional reactions and responses of hearing parents of deaf children. Seven parents of deaf children were interviewed to better understand their emotions, feelings, and thoughts from the time of diagnosis to the present. Using grounded theory techniques, a theory pertaining to parental appraisal was developed. This theory of appraisal was compared to previous research of stress and coping as well as to literature related to parenting children with disabilities. Few researchers have investigated the nature of appraisals for parents of children who were deaf. Parental appraisals emerged as significant factors in subsequent coping responses and, thus, supported the potential for individuality and variability in parental reactions post-diagnosis. Future study is necessary to determine the specific nature of the relationship between parental appraisals and ways of coping. This research has implications for a) the need for professional intervention in assisting parents with emotional or coping responses, b) the value of focussing upon appraisal in professional intervention, and c) the need to emphasize the variability in response rather than fittedness to pre-determined stages of response.

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## **APPENDIX - CONSENT FORM**

Project Title: Hearing Parents' Reactions to Child's Deafness
Researcher: Brenda Poon, MEd Candidate, University of Alberta, 465-4301
Supervisor: Dr. M. Rodda, Department of Educational Psychology, University of Alberta
<u>Purpose of Study:</u> The purpose of this study is to better understand experiences and feelings of hearing parents of deaf children. Mothers and fathers will be interviewed individually and asked to describe experiences related to raising her/his child. It is hoped that the information acquired will be helpful to other parents of deaf children as well as to professionals working with hearing parents and their families.
I,, do consent to participate in the thesis study "Hearing Parents' Reactions to a Child's Deafness." The study has been explained to me and I understand the following about it:
<ul> <li>I will be interviewed at least once.</li> <li>Each interview will be audio-taped and transcribed.</li> <li>Interview lengths will vary but the average length will be 1-2 hours.</li> <li>I will be asked to read the interview transcripts and elaborate upon or clarify descriptions of my experiences in a follow-up meeting.</li> <li>I will be asked to review the results so that interpretations may be shared and discussed.</li> <li>All information is confidential so that interview transcripts will be referred to by arbitrary code numbers and my name will be replaced by a code letter.</li> <li>To protect anonymity, contextual information and perhaps, descriptions of the gender of my child will be altered.</li> <li>I may withdraw from the study at any time without penalty.</li> <li>I may refuse to answer a question at any time.</li> <li>Audio-recordings will be preserved but only identified by their code number.</li> <li>The information obtained from this project will be used for the thesis under study and any future study, poster presentation, or publication that may result.</li> </ul>
I understand that I may contact the researcher if I have any questions or concerns about the project. I have had the opportunity to ask questions about the study and am free to ask any further questions throughout the project.

Date

Participant Signature