

**AN ECOSYSTEMIC PERSPECTIVE ON THE RAISING OF DEAF  
CHILDREN BY HEARING PARENTS IN SOUTH AFRICA:  
A MIXED METHODS STUDY**

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**AN ECOSYSTEMIC PERSPECTIVE ON THE RAISING OF DEAF  
CHILDREN BY HEARING PARENTS IN SOUTH AFRICA:**

**A MIXED METHODS STUDY**

**by**

**Vijialakshmi John**

**THESIS**

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**at the**

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**Supervisor: Prof N de Lange**

**January 2009**

## DECLARATION

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Mrs Vijjalakshmi John

## **DEDICATION**

This study is dedicated to all those committed to the education and development of deaf children in South Africa.

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I thank Jesus Christ for blessing me with good health and inspiration to pursue this study.

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## ABSTRACT

Deafness is one of the most common types of disability in South Africa with 90% of deaf children being born to hearing parents, many of whom are unprepared for the consequences of deafness. Since deafness is an invisible disability, the severity of its impact upon both the child and the family is often underestimated. The aim of this study was to explore the experiences of hearing parents raising deaf children. Thus, the primary research questions were: *What are the experiences of hearing parents raising deaf children in South Africa, and how do various ecosystemic variables affect the way they manage their parenting role?*

This study was informed by the ecological systems theory which is the theoretical framework that underpins this study. The research paradigm shaping this study was pragmatism, while the strategy used was phenomenology. The mixed methods approach was employed, using both qualitative and quantitative approaches concurrently in a triangulation design. The findings emanating from the quantitative data served to complement the findings from the qualitative data. These findings were corroborated in the interpretation stage.

The findings, representing the lived experiences of hearing parents raising deaf children, show that although the parenting experiences differ according to the unique circumstances in the family, school and community, there are several commonalities. These include issues associated with the diagnosis and parenting of deaf children. Some of these issues included the challenge of communicating with the deaf child, the financial burden, stigmatization from the general public, strained interpersonal relationships, concern about the child's future, as well as lack of opportunities for the Deaf to study at tertiary institutions and limited employment opportunities for deaf persons.

The findings from both sets of data reveal that, despite the resilience of participants, there is a need for formal support for parents from professionals in the community, as well as informal parental support from the family, friends, and community members, including other hearing parents raising deaf children, and the need for a central location to access information on deafness and related matters. Recommendations were made to address these issues, with a view to facilitating the emotional well-being of hearing parents raising deaf children, and consequently improving the quality of life of the deaf child and the family.

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## CHAPTER 1

### ORIENTATION: INTRODUCTION TO THE INQUIRY

#### 1.1 INTRODUCTION AND RATIONALE

*“I then found out he was deaf, and I think, if I could have, I would probably have given him back. In fact, I really did not like him very much. I had no option but to love him because he was my child.”*

(Amy, participant, 2006)

Deafness is one of the most common types of disability in South Africa, and covers the full range of hearing loss from mild hearing loss to total deafness. However, since it is an invisible disability, it is often not fully understood, and the severity of its impact upon both the child and the family is often underestimated (Storbeck, 2005: 348). Hellen Keller regarded deafness as a deeper and more complex problem than blindness, and maintained that deafness “is a much worse misfortune, for it means the loss of voice that brings language, sets thought astir, and keeps us in the intellectual company of man” (Ross, Storbeck & Wemmer, 2004: 152).

Besides the language restriction that results from hearing loss, it could give rise to a host of secondary problems that have far reaching consequences for the deaf child such as problems of communication, perception, cognitive and intellectual functioning, emotional adjustment and adaptation to society (Op’t Hof, 1991: 31). This, in turn, can have serious consequences for the quality of life of the deaf child and his/her family (Bibby & Foster, 2004: 13; Ross *et al.*, 2004: 154; Scheetz, 2001: 1; Northern & Downs, 2002: 2; Schirmer, 2001: 9; Marschark, 1997: 16; Dysart, 1993: 31).

The researcher’s interest in deafness stems from having taught deaf student teachers at Springfield College of Education (subsequently known as South African College of Education) during the period 1998 to 2003. Interactions with these students and with

their parents led to the idea of exploring the experiences of hearing parents raising deaf children.

The World Health Organization statistics reveal that deafness ranks as the commonest form of sensory deprivation in the world. The same prevails in South Africa where deafness is the largest single disability, affecting approximately three million individuals (DeafSA, 2000). Thirty-three percent of deaf South African adults are illiterate, while seventy-five percent have functional literacy problems, and seventy percent are unemployed. As a result many deaf people are unable to participate fully in community life. This scenario could indeed weigh heavily on the emotional well-being of hearing parents raising deaf children in South Africa. Research shows that 90% of deaf children are born to hearing parents, many of whom are not prepared for the consequences of deafness in the family (DeafSA, 2006; Storbeck, 2005: 354; Bibby & Foster, 2004: 14; 160; Ross *et al.*, 2004: 155; Marschark, 1997: 9). These statistics inform this research which focuses on the experiences of hearing parents raising deaf children in South Africa.

The quality of life of a child who is born deaf hinges on early identification (*i.e.* audiological diagnosis before 12 months of age), followed by immediate and appropriate intervention (DeafSA, 2006). The emphasis on early intervention is based on the critical necessity of developing communication skills early in the lives of young, deaf children. The critical age for learning language is between birth and 3 years. During this critical period language stimulation is essential for the development of signed or spoken communication (DeafSA, 2006). The important role parents play in stimulating language development, and in turn, cognitive development of their deaf children cannot be sufficiently emphasised. Issues such as the need for developing alternative forms of communication with their deaf children, making correct decisions regarding educational options, and for maintaining consistency in parenting, can be stressful.

Parents need to understand the nature of deafness so that they can make informed decisions regarding the type of educational options that are best for the child, namely, ordinary schools (mainstream education), full service schools(mainstream education),

or special schools which cater for the needs of deaf children (Department of Education (DoE), 2001). The White Paper 6 on building an inclusive education and training system (DoE, 2001) acknowledges, accepts and respects differences in learners, whether due to age, gender, ethnicity, language, class, disability or HIV/AIDS status and enables education structures, systems and learning methodologies to meet all learners' needs. Inclusive education therefore requires changing attitudes, behaviours, teaching methodologies, curricula and environment so that all learners can be allowed to develop their individual strengths and participate fully in the process of learning.

The introduction of inclusive education in South Africa however, requires parents to make choices about the kind of educational experience for their children who have moderate to severe disabilities. Issues often associated with inclusion, namely, the quality of teaching, communication, financial implications, stereotyping, and the safety of learners can be daunting for parents (DoE, 2001) and can adversely affect the emotional well-being of hearing parents of deaf children. For the purpose of this study, inclusive education will inform the research by providing a broad framework of reference for the educational options available for deaf learners. Considering the current educational context in South Africa, the 'voice' of the parent is not often heard, less so the 'voice of the parent raising a deaf child. Returning to the words of one of the participants at the beginning of the section, the dilemma of the parent raising the deaf child is highlighted, and provides the reason for this study and for making their voices heard.

## **1.2 STATEMENT OF THE PROBLEM**

The primary responsibility for the holistic development of all children lies with parents. The parents of deaf children in particular are faced with an even greater task of creating an enabling environment that will facilitate the full participation of their children in all levels of society, even in the event of society's inability or often unwillingness to accommodate deaf children and their families. Parents need to find ways of maximising their deaf child's potential through the effective integration of the child into a hearing community, as well as through the forging of strong partnerships between the family, school and community, while simultaneously maintaining stable

relationships within the family (Swart & Phasha, 2005: 220; Mittler, 2000: 10). While the parenting of hearing children can at times be a complex and daunting task, the raising of deaf children by hearing parents in a hearing world could pose an even greater challenge. Since parents have to make major decisions and take appropriate actions regarding alternate forms of communication and educational options for the deaf child, these have to be informed decisions, owing to the impact on their lives, and this “great modality debate” can be extremely frustrating and stressful to parents (Storbeck, 2005: 352). Learning to communicate effectively with the deaf child can be an arduous task for hearing adults, and poor communicative competences could severely hamper the deaf child’s interaction with family and community. Raising a deaf child could be very demanding and taxing in terms of time, patience as well as financial obligations, and it could affect family stability and interpersonal relationships within the family and the community (Ross *et al.*, 2004: 156-157). The stress associated with raising deaf children in a hearing family can also affect the emotional well-being of the parents, which in turn can have a profound impact on the child’s development and progress (Lessenberry & Rehfeldt, 2004: 242).

The central focus of this study is to explore hearing parents’ experiences with regard to raising their deaf children in a hearing world, and the extent to which they are able to support the holistic development of their deaf children so as to maximise their potential. In an attempt to gain a deeper understanding of the phenomenon of hearing parents raising deaf children, this study also seeks to explore the extent to which various ecosystemic variables influence the experiences of hearing parents raising deaf children in three provinces in South Africa. It is argued that parents require critical support, including emotional support, from the family, school and community to increase their capacity to provide an enabling environment for their deaf children. In particular, an attempt will be made to explore how hearing parents manage the parenting and education of deaf children. In view of the above, the purpose statement of this study can be formulated as follows:

This mixed methods study addresses, from an ecosystemic perspective, the way hearing parents experience and manage their parental role of raising deaf children. A mixed methods concurrent triangulation design will be used, a type of design in which

different but complementary data will be generated on the same phenomenon. In this study, a survey instrument will be used to generate data about the extent to which various ecosystemic variables influence the experiences of hearing parents raising their deaf children in three provinces (KwaZulu-Natal, Gauteng, and Western Cape) in South Africa. Concurrent with this data generation, qualitative interviews exploring the phenomenon of hearing parents raising deaf children will be undertaken. Generating both quantitative and qualitative data can bring together the strengths of both forms of research to corroborate results, so that a better understanding of the research problem may be gained as answers are sought to the research questions outlined in the following section.

### **1.3 RESEARCH QUESTIONS**

In essence, the *primary research questions* to be investigated in this study are:

- To what extent do various ecosystemic variables influence the experiences of hearing parents raising their deaf children in this country?
- What are the experiences of hearing parents in the raising of deaf children?

Based on the findings of the above questions, a *secondary research question* can be posed:

- How might hearing parents be supported in their unique role of raising deaf children, so as to facilitate their own emotional well-being and in turn, provide an enabling environment for the holistic development of their deaf children?

### **1.4 AIMS OF THIS RESEARCH**

The *primary* aims of this mixed methods study, which involve qualitative research through in-depth, unstructured interviews with hearing parents who are raising deaf children, as well as a quantitative survey of such parents in three provinces in South Africa, are to:

- explore how various ecosystemic variables influence the experiences of hearing parents in the raising of their deaf children
- explore the experiences of hearing parents in the raising of their deaf children and the way they manage their parenting role.

The *secondary aim* is to:

- reflect on the data and to generate guidelines in the form of recommendations with regard to facilitating the emotional well-being of hearing parents, thereby enabling them to support the holistic development of their deaf children and maximise their potential.

## **1.5 THEORETICAL FRAMEWORK AND CONCEPTUAL CLARIFICATION**

### **1.5.1 Theoretical framework**

The theoretical framework underpinning this study is based on Bronfenbrenner's (1992; 1998) ecological systems theory (subsequently revised as the bioecological model), which is an example of a multidimensional model of human development. This theory provides a framework for understanding the complexity of influences, interactions and interrelationships between an individual and various other systems that are linked to the individual. The levels of interacting systems give rise to multifaceted and reciprocal relationships that result in change, growth and development (Swart & Pettipher, 2005: 10). Bronfenbrenner (in Luster & Okagaki, 1995: 236) drew attention to the fact that forces external to the family also influence family functioning and ultimately the development of children. Characteristics of the parent, the child, as well as the context or the social environment, therefore affect child rearing.

Bronfenbrenner's ecological systems theory has relevance for this study, since the deaf child's development, as well as the experiences of hearing parents who are raising deaf children, can be explained using an ecosystemic framework (*c.f.* 2.2). Three contexts,

namely, family, school and community, and the interconnections between them, influence children's development and parents' lives. The ecological systems theory serves as a framework for understanding parental engagement in the education and development of their children, as well as the way families and schools are embedded in the community. Bronfenbrenner's theory suggests that the social context could be viewed as a set of interrelated "nested structures" which include the microsystem, the mesosystem, the exosystem and the macrosystem, all of which influence human development (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 215; Donald, Lazarus & Lolwana, 2002: 52).

For the purpose of this study, Bronfenbrenner's ecological systems theory will be used to create meaning from hearing parents' experiences in the raising of deaf children. The nested structures referred to above are indicative of the overlapping spheres of influence of family, school and community on children's learning and development (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 215; Donald *et al.*, 2002: 51). The child is born into a family (where the parents play a pivotal role in his/her development). However, the family does not exist in isolation, but is embedded in the community where access (or a lack thereof) to resources such as employment opportunities for parents, social welfare services, health and educational services, all contribute to the quality of learning and development of the child.

Of importance is the relationship between and among the different systems. The society in which the family lives can affect the development of the child. The relationships that prevail between the parents and employers can influence the way parents manage in maintaining a balance between the demands of work and family life. Likewise, the relationships that exist between the parents and the child's educators could influence the manner in which the parent relates to the child. Tensions here could impact on the relationship between parent and educator as well as between parent and child. This consequently influences the emotional well-being of parents and other members of the family. Bronfenbrenner's bioecological systems theory will be explained more fully in chapter two.



### **1.5.2 Concept clarification**

In the interest of clarity and understanding, important concepts in this study need to be elucidated. **In this study all references to any gender include references to the other gender.** For the purpose of this research the following terms are explained:

#### **1.5.2.1 Experiences**

All human beings have experiences, but individuals experience things in different ways. According to Cullingford (1995: 80), we learn from experiences, which consist of a series of events which happen to affect us. In addition these experiences influence our response to them, and thus our behaviour and action. Vrey (1990: 39) adds that all behaviour is accompanied by feelings. According to Dilthey, (in Van Manen, 1992: 35) lived experience, in its most basic form, involves our immediate and spontaneous awareness of life. A lived experience has a certain quality that is recognised in retrospect. The meaning we give to lived experience is always of some past event or happening and can be regarded as an episode in the totality of life. Human experiences can vary in number and nature. For the purpose of this study experiences refer to the lived experiences of hearing parents of deaf children.

#### **1.5.2.2 Parenting**

The concept “parent” may refer to a biological mother or father in some contexts, but it could also include legal guardians or caregivers such as siblings or grandparents or other close family or community members who can contribute to the child’s educational development (DoE, 1997: vii; Turnbull & Turnbull, 1997: 11). Parenting is the process of caring for and rearing a child. Parenthood involves taking responsibility for the upbringing and well-being of the child, in accordance with generally accepted norms and values. These norms and values could be determined by factors such as culture, society and religion.

Gerdes (1998: 34) holds the view that the three pillars underpinning parenting are knowledge, love and discipline, all of which should be strong and reinforcing, and

based on a foundation of values. Effective parenting involves ensuring the physical well-being of a child, stimulating intellectual growth, providing emotional security, and giving direction regarding socially acceptable and responsible behaviour based on moral and spiritual values (Gerdes, 1998: 65). For the purpose of this study parenting refers to the raising and educating of deaf children.

### **1.5.2.3 Deafness and related terminology**

The terms “hearing impairment”, “hearing disability” and “hearing handicap” are often used synonymously in the medical or pathological model, to describe deafness, and a distinction is made for diagnostic purposes. These concepts will be explained for the sake of clarity, followed by a clarification of the more appropriate concepts within the model of social justice and inclusion.

*Impairment*, as defined by Lysons (in Levitz, 1991: 2) is “anatomical, pathological or psychological loss or defect describable in diagnostic or symptomatic terms”. The term “impairment” stems from the act of being impaired, the cause of which could be congenital, or brought on through injury, weakness or damage. Hearing impairment is the condition involving the impairment of hearing to the extent that it interferes with communication. As a result, the emotional, social, educational and vocational aspects of the individual child’s life can thereby be adversely affected (DeafSA, 2006: 2). The term “hearing impaired” is used by some authors to refer to any person with some degree of hearing loss.

*Disability*, according to Suran and Rizzo (in Levitz, 1991: 2), refers to a defect in physical make-up or functioning that can be specified and described objectively. It is a restriction of performance in one or more of the faculties which are deemed essential for coping with the ordinary activities of everyday life. The resultant interference in normal functioning calls for some measure of dependence on a device or another person. Disabilities may be congenital or acquired, and inevitably lead to complications in the development of the child. The term “hearing disability” refers to some degree of hearing loss that restricts communication.

*Handicap* is a term that refers to the restrictions or limitations experienced by a person, as a result of an impairment or disability. Suran & Rizzo (in Levitz, 1991: 2) maintain that an individual can be regarded as handicapped when complications resulting from a disability limit the person's development. According to Kapp (1991: 27), a handicap refers to an identifiable deficiency in the child's given potential, whether sensory, neural, physical or intellectual. The term "hearing handicap" refers to limitations experienced by an individual as a result of hearing loss.

Furthermore, terms such as "deaf", "deafness" and "hard-of-hearing" are also used. *Deafness* refers to injury or damage to the auditory capacity of an individual. Deafness refers to hearing loss from a medical perspective, and although the degrees of hearing loss differ, individuals may experience the same measure of hearing loss differently (DeafSA, 2006:10).

*Hard-of-hearing* is a term used to describe a condition in a person who has residual hearing which, with the use of a hearing aid, is generally sufficient to enable the successful processing of linguistic information through the auditory sense. An individual who is hard of hearing may supplement information perceived through the auditory modality with information perceived through the visual modality (Diefendorf, 1996: 9)

*Deaf* is a term used to describe an individual, whose hearing loss does not allow for linguistic information to be successfully processed through the auditory channel, even with amplification (Muthukrishna, 2001: 151). According to Stewart and Kluwin (2001: 15), the term deaf refers to any person whose hearing loss is serious enough to impede educational progress. A deaf learner is one who has a degree of hearing loss that is severe enough to affect adversely his or her learning. This generic term includes those learners who are referred to as hard-of-hearing, deaf, hearing impaired or Deaf.

Deaf (with a capital D) refers to persons whose experience of hearing loss necessitates the use of sign language as the medium of learning and teaching, and for the development of language and communication skills, and who identify themselves as a distinct cultural and linguistic group (DeafSA, 2006: 9). The term Deaf is used by

various authors to refer to people who have some degree of hearing loss, use sign language to communicate, and are affiliated with the Deaf community in some manner (Ross *et al.*, 2004: 146-147; Muthukrishna, 2001: 151; Scheetz, 2001: 1; Stewart & Kluwin, 2001: 15).

With regard to the definition of deafness two opposing schools of thought exist and these represent the medical model, and the social, or socio-cultural model. In the medical model deafness is defined audiologically, and deaf people are regarded as deficient in their ability to communicate, whereas in the social model the Deaf are regarded as a linguistic group with their own identity and culture (Storbeck, 2005: 349).

The term “deafness” is preferred by proponents of the social model, to refer broadly to the full spectrum of hearing loss, from mild to total deafness, and only when it is necessary, do they make a distinction between ‘deaf’ and ‘hard-of-hearing’. The human rights movement and the resultant focus on inclusive education has led to the trend of researchers internationally, to move away from discriminatory labeling, which includes terms such as “hearing impairment”, “hearing impaired”, and “hearing disorder”. Instead, they prefer to use the more generic term, ‘deafness’ as it shifts emphasis away from a deficit approach (Storbeck, 2005: 348-349).

In a socio-cultural model deafness is not perceived as a handicap or deficit. Instead, it is viewed as a form of diversity present within a culture, and promotes the human and social rights of the Deaf community (Ross *et al.*, 2004: 146; Muthukrishna, 2001: 151). For the purpose of this research, and in keeping with the principles underpinning inclusive education, namely, social justice and human rights, the terms ‘deafness’ and ‘deaf’ will be used instead of terms such as “hearing impairment”, “hearing impaired”, “hearing disabled” and “handicapped”. The use of non-discriminatory terms is necessary to move away from the deficit discourses in education, associated with a pathological or medical model of hearing loss.

#### **1.5.2.4 Deaf children**

For the purpose of this study the term “deaf children” includes children whose hearing loss falls within a range which required a level of service that necessitated their having to attend special schools or centres that cater for deaf children. These deaf children are between the ages of 3 and 20 years. The reason for regarding 20 year old deaf persons as children is that they are students who are living with their parents and who are being cared for by their parents.

#### **1.5.2.5 Emotional well-being**

The term emotional well-being refers to the emotional and intellectual capacity of individuals as they respond to their environment, and includes the psychological adjustment of the individual. It involves a person being in control of his existence, and having a sense of purpose and satisfaction with himself and his life (Cowen, 1991: 404), the main component being self-esteem. Emotional well-being is also referred to as mental health or emotional wellness (Schirmer, 2001: 149), or emotional intelligence (Bar-On, 2005a: 2-4; Goleman, 1998: 317-318).

Caruss, Dulewicz, Higgs and Chapman (2001: 40) state that emotional intelligence is considered a mental skill, which could also contribute to well-being. It refers to the ability to be aware of, understand and effectively apply the power of emotions as a source of information, human energy, and influence (Cooper & Sawaf, 1997: XIII). Goleman (1996: 43) maintains that the core of emotional intelligence is self-awareness, which contributes to individuals' knowledge of their own emotions, which in turn gives them more control in their lives. Lessenberry and Rehfeldt, 2004: 242) state that the emotional well-being of hearing parents can be affected by the strain of raising deaf children, and this could affect their children's learning and development. Since the progress of deaf children is associated with the emotional well-being of their parents, it is deemed necessary to facilitate their emotional well-being so as to maximise their deaf children's potential. For the purposes of this study, *emotional well-being* refers to the mental health or emotional wellness of hearing parents of deaf children.

## **1.6 RESEARCH DESIGN AND METHODOLOGY**

### **1.6.1 Research design**

In this mixed method study a concurrent triangulation design will be used. This design entails the use of both qualitative and quantitative approaches concurrently, although priority will be given to the qualitative approach. In addition to triangulating data sources, the use of a mixed methods approach allows for the results of one method to inform the other method and provide insight into different levels of analysis (Creswell, 2009: 4; Creswell & Plano Clark, 2007: 62; Creswell, 2003: 15-16).

The pragmatic paradigm, which is considered to be most suitable for a mixed methods study (Creswell, 2009: 10-11; Morgan, 2007: 70; Tashakkori & Teddlie, 2003: 20) underpins this study, since pragmatism is based on a practical research philosophy. Furthermore, pragmatism supports the combined use of quantitative and qualitative research methods within the same study, and rejects the “forced choice between positivism and constructivism” (Tashakkori & Teddlie, 2003: 21). However, the positivist paradigm will be used in the generation of quantitative survey data to provide an objective description of how various ecosystemic variables affect the way hearing parents raise their deaf children, while the interpretive paradigm will also be used in the qualitative data generation of the study as it is best suited to the study of participants’ “subjective experiences of the external world” (Terre Blanche & Durrheim, 1999: 6), and it will facilitate understanding of their experiences. The interpretive paradigm allows for the use of methodologies that are sensitive to the values underpinning people’s lives. In order to understand fully the values linked to people’s experiences, the researcher requires access to in-depth knowledge and understanding of the participants’ life worlds, as well as qualitative and subjective interpretation. It would not be possible to discover and understand how people create meaning in natural settings without the researcher being personally involved (Terre Blanche & Durrheim, 1999: 214-215).

A qualitative approach lends itself to the use of the phenomenological strategy in this study since its roots are in phenomenology. Van Manen (1990: 9) states that

phenomenological research is a study of “lived experience” and aims to gain a deeper understanding of the meaning attached to everyday human experiences. Fouché (2002: 276) maintains that phenomenology attempts to understand and interpret the essence of meaning that participants assign to their daily lives. Creswell (2009: 13; 2003: 15) refers to a phenomenological study as one that describes the meaning that experiences of a topic, concept or phenomena have for various individuals. The researcher identifies the essence of the experiences as described by the participants. Moustakas (in Creswell, 2009: 13) and Fouché (2005: 270) state that the researcher collapses the experiences into a central meaning to derive the essence of experience, and that it is the description of the essence of experience that becomes the product of research.

In this study a quantitative method of inquiry which will seek answers to the question: *How do various ecosystemic variables influence the experiences of hearing parents raising their deaf children?* The qualitative phenomenological strategy will help provide answers to the question: *What are the experiences of hearing parents raising deaf children?* A combination of both methods of inquiry will allow for triangulation.

Mouton and Marais (1990: 169-170) support the view that a single approach cannot successfully facilitate exploring the complexity that surrounds human beings, because of the “enmeshed” nature of phenomena investigated in social science. These authors suggest that to understand human nature and social reality more fully, combining approaches is useful. Posavac and Carey (in De Vos, 2002: 364-365) concur that the best approach is to mix quantitative and qualitative methods, although purists might object.

## **1.6.2 Research methodology**

### **1.6.2.1 Data generation**

The research with regard to this study will be conducted as follows:

A survey of relevant literature will first be undertaken. This study draws from three main areas of literature, namely, deafness, an ecosystemic perspective on the development of the deaf child in relation to parenting, and emotional well-being.

The qualitative method of data generation involved interviews. Semi-structured one-to-one interviews were conducted with hearing parents of deaf children attending, or who had attended, schools for the Deaf. Semi-structured interviews are used to gain a detailed understanding of participants' perceptions, beliefs or accounts of a particular topic (Greeff, 2005: 296).

With the permission of the participants the interviews were tape-recorded. Tape recording allows for a much fuller record than notes taken during the interview (Smith, Harre & Van Langenhoven, 1995: 17). The tapes will subsequently be transcribed for close analysis. Sacks (in Denzin & Lincoln, 2003: 354) strongly recommends the use of the tape recorder to record interviews on the grounds that it is impossible to remember every detail such as "pauses, overlaps, and inbreaths", and that by studying the tapes of conversations the researcher is able to focus on "actual details of actual events" of one aspect of social life.

In this study these interviews focussed on hearing parents' experiences of raising deaf children. The main question will be: "What is it like being a parent of a deaf child?" This will be followed, where necessary, by further probing as well as clarifying questions to gain in-depth insight into parental experiences of raising deaf children. The purpose of the interviews would be to generate "thick descriptions" of deaf children's parents' subjective parenting experiences. Denzin (in Creswell, 2007: 194) describes the term "thick descriptions" as "going beyond mere facts and surface experiences", taking into account details, emotionality, as well as networks of social relationships, and contextualising experience so that "the voices, feelings, actions and meanings of interacting individuals are heard". Geertz (in Denzin & Lincoln, 2003: 25) and Van Manen (1990: 178) suggest the use of interpretive, open-ended approaches as a means of gathering "thick descriptions" of particular events, so as to make sense out of a local situation.



The quantitative data generation method complements the qualitative data. An empirical survey comprising a structured questionnaire developed on the basis of discussions with relevant stakeholders, namely, psychologists, social workers, educators, and parents of deaf children was administered. The questionnaire was completed by hearing parents of children attending schools for the Deaf. A Likert-type scale with three response categories, *viz.* Agree, Disagree, Uncertain, was used. The three response categories allow the researcher to measure the direction and intensity of responses.

#### **1.6.2.2 Sampling method**

Qualitative research requires the data collected to be “rich in description of people and places” (De Vos, 2002: 91). The decision regarding the sampling method took into consideration the identification of sources rich in information. The overarching purpose of the use of relevant sampling techniques in qualitative research, according to Strydom and Delport (2002: 336), is “to collect the richest data”.

For the qualitative part of this study, non-probability sampling procedures, using a combination of purposive, criterion and snowball as well as convenience sampling techniques were used. Convenience sampling, also known as availability sampling, is a technique that the researcher uses to select those participants that can be easily accessed (Creswell, 2003: 157). Criterion sampling involves selecting participants who meet certain criteria and it is useful for quality assurance, while snowball or chain sampling involves identifying “cases of interest from people who know people who know what cases are information rich” (Creswell, 2007: 127). Semi-structured one-to-one interviews were conducted with 20 hearing parents raising deaf children in the three provinces mentioned. Only hearing parents whose deaf children were attending or have attended schools for the Deaf were purposively selected and interviewed. This ensured that the participants met the criterion of having experience of parenting deaf children, increasing the likelihood of collecting rich data needed to address the research questions.

In non-probability sampling a researcher cannot be certain that the population is accurately represented, because it is not possible to determine whether each element of the population is included in the sample. However, this sampling procedure has the advantage of being cost effective and time-saving (Neuman, 2006: 222; Strydom, 2005: 202; Somekh & Lewin, 2005: 218; McIntyre, 2005: 105). Silverman (2000: 104) states that in purposive sampling, certain participants are selected because they illustrate some process or feature that is of interest for particular research, and that the purposive sampling technique narrows down the parameters of the population to suit the purpose of the study. Therefore, the purposive sampling technique will be used for the qualitative part of the study.

For the quantitative part of this study multiple probability techniques were used, incorporating a selection of three provinces in South Africa, and a random selection of schools through multiple cluster sampling. According to Teddlie and Yu (2007: 80), such sampling involves a first stage where clusters (schools) are randomly selected and a second stage where “units of interest” (participants) are sampled within the clusters. 250 questionnaires were sent to hearing parents whose deaf children were attending one of the randomly selected schools for the Deaf in Gauteng, Western Cape and KwaZulu-Natal.

#### **1.6.2.3 Analysis of the data**

Data analysis is the process whereby the researcher brings order, structure and meaning into the mass of data collected, and making sense of it so that an interpretation of the larger meaning of the data can be made (De Vos, 2005: 333; Creswell, 2003: 190). Qualitative data analysis, “is a search for general statements about relationships among categories of data” (De Vos, 2005: 334). In this study, the qualitative analysis of data collected through semi-structured, one-to-one interviews were coded through a process of carefully examining the text data, organising it into chunks, and segmenting the sentences or paragraphs into units of meaning, so that concepts pertaining to the same phenomena can be named and categorised (Creswell, 2009: 186; 2003: 192; De Vos, 2002: 341; Rossman & Rallis, 1998: 171). Salient themes and subthemes were identified in order to make an interpretation of the data

and identify lessons learnt (Creswell, 2009: 186; De Vos, 2005: 339; Creswell, 2003: 194). For the purpose of this study Tesch's (1990: 142-145) guidelines for the coding process were followed.

The quantitative data generated through the questionnaires completed by hearing parents, whose deaf children were attending schools for the Deaf in KwaZulu-Natal, Gauteng and Western Cape, were analysed and descriptive statistics were generated. The analyses of data gathered from the questionnaires were presented as graphs which were interpreted descriptively.

#### **1.6.2.4 Validation procedures**

Researchers who adopt a quantitative approach place great value on reliability and validity as an indication of the accuracy and conclusivity of their findings. On the other hand, researchers who espouse the qualitative approach do not assume that they are investigating an unchanging and stable reality. Instead, they believe that participants in the research will behave differently and express different views in changing contexts. For this reason, they do not expect to find the same results if the research is repeated. They therefore propose, in place of reliability, the criterion of dependability, which refers to the extent to which the reader can be convinced that the researcher's findings did indeed occur. "Dependability is achieved through rich and detailed descriptions that show how certain actions and opinions are rooted in and develop out of contextual interaction" (Terre Blanche & Durrheim, 1999: 64). In this study, the criterion of dependability is also applicable.

Validity is seen as the strength of quantitative research, and it is used to determine whether the findings are accurate from the point of view of the researcher, participant or the reader of the account. Content validity relating to the representativeness of the content of an instrument, such as items of a questionnaire, and is regarded as a means of establishing the validity of an instrument (Delport, 2005: 160-161).

Qualitative research draws on terms such as "trustworthiness", "authenticity" and "credibility" to refer to validity (Creswell, 2003: 195-196). Validity, or credibility,

according to Terre Blanche and Durrheim (1999: 61-62), refers to the extent to which the research conclusions are sound. Guba (in Krefting, 1991: 215) proposed a model for assessing the trustworthiness of data collected through qualitative research designs. This model is based on four criteria of trustworthiness, namely, truth value, acceptability, consistency and neutrality. The model defines different strategies enabling researchers to design ways of increasing the trustworthiness of their qualitative study.

In mixed methods research, validity refers to the ability of the researcher to draw accurate and meaningful inferences from all the data in the study, while the term “inference quality” is used to refer to the accuracy of conclusions derived from mixed methods research, and “triangulation validity” refers to mixed methods research that is guided by the pragmatic paradigm (Creswell & Plano Clark, 2007: 146-147).

In this study, every effort was made to ensure that both the quantitative and qualitative data are validated and are accurate representations of the findings, and that appropriate conclusions are drawn from the data. The triangulation of both qualitative and quantitative data generation and analysis contributed to the validity of the research.

#### **1.6.2.5 Ethical guidelines**

Ethical concerns traditionally focussed on three topics, namely, informed consent (*i.e.* receiving the participants’ consent after carefully and truthfully informing them about the purpose of the research), right to privacy (*i.e.* protecting the identity of the participants), and protection from harm (*i.e.* emotional, physical or any other type of harm) (Denzin & Lincoln, 2003: 89-90). However, there are other ethical issues to be considered, such as surreptitious use of tape-recording devices, manipulating the participants while interviewing them, and breaching confidentiality, which are deemed unethical.

To prevent such unwanted outcomes, Terre Blanche and Durrheim (1999: 66) suggest three ethical principles, *viz.* autonomy, nonmaleficence and beneficence that should guide all research. The principle of autonomy requires the researcher to respect the

autonomy of the participants in the study. It requires the researcher to obtain voluntary and informed consent from the participants, allowing them the freedom to withdraw from the research at any time, while at the same time ensuring the participants' right to autonomy in any publication that may emanate from the research. The principle of nonmaleficence ensures that the participants will not be harmed in any way. The researcher is required to consider potential risks, whether physical, emotional, social or any other form of harm that may be inflicted upon those who participate in the study. Consideration of this principle may lead to changes being made in the research design of the study. The principle of beneficence requires that the researcher design research that will be of benefit to other researchers and to society at large, even if the participants do not benefit directly from the research.

Cohen, Manion and Morrison (2007: 49-52) state that research should be conducted in a manner that can be ethically defended, and that researchers should strike a balance between demands placed on them as researchers in search of truth, and their participants' rights and values that may be threatened by the research. Punch (in Denzin & Lincoln, 2003: 90) suggests that researchers doing fieldwork need to exercise common sense and a responsibility firstly to the participants, secondly to the text, and thirdly to themselves. The essential purpose of ethical concerns in research is the protection of the welfare and rights of the participants.

In this study every effort was made to conform to the requirements of the ethical guidelines outlined above. Participants were made aware of the purpose of the research before informed consent was obtained. They were informed that no harm would be inflicted on them, and that their identity would not be revealed. They were assured that their responses would be treated in a confidential manner. Participants were also informed that they could withdraw from the investigation at any time without fear of recrimination.

Permission was sought from principals and governing bodies of schools for the Deaf to conduct research and interview hearing parents of deaf learners at the schools. The identity and institutional association of the researcher and supervisor, as well as contact details were made available to participants. All documents and audio tapes

would be stored safely in a cupboard in an office at the university for a period of five years, after which time they would be destroyed.

## **1.7 DELIMITATION OF THE STUDY**

The research falls within the ambit of Educational Psychology, which focuses on the learning and development of children, in this instance the deaf child. However, the crucial importance of the hearing parent in optimising the potential of the deaf child will be the focus of this study. The study does not include deaf parents, and was conducted in three better resourced provinces, in terms of deaf education, in South Africa.

## **1.8 COURSE OF THE STUDY**

Chapter 1 focuses on the orientation and introduction to the study. It includes a rationale for the investigation and statement of the problem. The aims of the research, the research questions, the research design and methodology, and the theoretical framework are briefly explained, and concepts clarified. The focus of this study is on the experiences of hearing parents raising deaf children, the way they manage their parenting responsibilities, and how the family, school and community influence their parenting role.

Chapter 2 focuses on deafness, an ecosystemic perspective of parenting, and the development of the deaf child. It includes the prevalence and clinical features of deafness. Bronfenbrenner's (1992; 1998) ecological systems theory and its relevance for this study is covered. The influence of the child's deafness on the family and interpersonal relationships within and beyond the family, as well as the challenges facing hearing parents of deaf children, are problematised.

Chapter 3 covers the research design and methodology. The mixed methods concurrent triangulation design is used in this study and combines both quantitative as well as qualitative approaches. The qualitative approach is foregrounded and complemented by a quantitative approach to gain a deeper insight into the experiences

of hearing parents raising deaf children. The inferences emanating from both sets of data are merged in the interpretation and discussion of findings. Validation procedures are discussed and ethical issues are addressed.

Chapter 4 focuses on the findings, the discussion of findings, the integration of the quantitative and qualitative data, and a literature control to recontextualise the findings.

Chapter 5 includes a summary, inferences, and recommendations for facilitating the emotional well-being of hearing parents raising deaf children. The significance of the study is explained. The limitations of the study and recommendations for further research are also addressed.

## CHAPTER 2

### THEORETICAL FRAMEWORK FOR UNDERSTANDING DEAFNESS AND PARENTING FROM AN ECOSYSTEMIC PERSPECTIVE

#### 2.1 INTRODUCTION

*“I found out they were deaf when they were three and a half years old ...We decided on this school (Western Cape)...We had to give up everything in Gauteng – our business... our house...but for my twins, I would do anything because they are my life...We had to live in a caravan park. We had no money...When they were four and a half years old I got divorced because my husband was seeing someone else, and since then it was all on me. I had to look at everything and feed them, and it was such a challenge!...They are deaf, but they are very clever...They’re really very, very special. I’m very happy with everything! I feel very rich!”*

(Queenie, participant: 2006)

Chapter 1 focussed on an orientation and introduction into the inquiry. In addition the theoretical framework and certain key concepts were clarified, the aims of the research were explained, and the design and methodology were briefly mapped out.

In this chapter attention will be given, *inter alia*, to:

- Ecological systems theory
- prevalence of deafness
- clinical features of deafness
- types and causes of deafness
- development of the deaf child
- parenthood and parental responsibilities
- parenting and the deaf child
- parenting and the family
- the child’s deafness and the emotional well-being of hearing parents
- challenges facing hearing parents of deaf children



Bearing in mind that research has shown that over 90% of deaf children are born to hearing parents, many of whom find it very difficult to adjust to their child's deafness and are ill-prepared for the consequences of deafness (DeafSA, 2006; Bibby & Foster, 2004: 14; Ross *et al.*, 2004: 155), this chapter will therefore try to explain the notion of deafness and the consequences it has for the child's development. This in turn will provide some insight into what a hearing parent has to deal with when raising a deaf child. An ecosystemic perspective on parenting the deaf child will help in understanding the phenomenon of hearing parents raising deaf children.

## **2.2 AN ECOSYSTEMIC PERSPECTIVE TO DEAFNESS AND PARENTING**

The development of the deaf child and the nature of parenting deaf children are best understood from an ecosystemic perspective, since child development and parenting do not occur in a vacuum, but rather in a complex set of interrelated systems over a period of time. Bronfenbrenner's (1992: 191) ecological systems theory, which was developed in the 70s, and revised in the eighties as the bioecological model (Bronfenbrenner & Morris, 1998: 996), has relevance for this study. The ecological systems theory is an example of a multidimensional model of human development (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 214; Engelbrecht & Green, 2001: 8). According to this theory there are several layers of systems which interact, resulting in change, growth, and development. The relationships among the various systems are multifaceted and reciprocal; what happens in one system influences and is influenced by other systems (Swart & Pettipher, 2005: 10). The ecosystemic theory of human development explains the complexity of interrelationships between the child and various other systems that influence the child within the environment (Green, 2001: 3; Donald *et al.*, 2002: 47).

At the centre of the ecosystem is the deaf child. However, the child does not live in isolation but within a family unit which, in turn, does not function in isolation but within a community. The community is an integral part of society in which other systems such as the school, clinic or hospital function in direct or indirect relation to the child and the family. An ecosystemic perspective of development takes into

consideration that the characteristics of the child “interact with the characteristics of the environment to produce a unique system that influences, and is influenced by, interactions in ever-broadening, hierarchically layered contexts” (Spencer, Erting & Marschark, 2000: xviii).

Bronfenbrenner’s ecosystemic theory suggests that the environment can be conceived of as “a set of nested structures”, each contained within the next and therefore interdependent and interrelated. The four nested systems are the microsystem, the mesosystem, the exosystem and the macrosystem, all of which interact with, and are influenced by the chronosystem (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 215; Donald *et al.*, 2002: 51). Microsystems are systems such as family, school, and peer group in which the child is an active participants and is involved in continuous, face to face interactions with familiar people. Mesosystems refer to a set of interrelated microsystems and the interactions that exist between them, for example, the interrelationships between the peer group, family and school. Exosystems include other systems in which the child is not directly involved as an active participant, but which may influence or be influenced by what happens in settings and relationships that directly influence the child. For example, the parent’s stressful relationship with an employer may indirectly affect the parent’s relationship with the child. Macrosystems refer to the dominant social structures which include attitudes, beliefs, and values of a particular society or culture. For example, democracy, human rights and social justice policies, may influence or be influenced by other systems. All these systems are interrelated with the chronosystem, which marks changes over time.

Bronfenbrenner’s ecological systems theory has direct relevance for our understanding of the deaf child’s relationships within the family, school, and classroom, the interrelationships within them, as well as how these systems are embedded in the community. Although the family, school and community are systems in themselves, they are interrelated within the broader social context. The multidirectionality of the relationships within and between families, schools and communities and the levels of interacting systems result in change, growth and development (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 215; Donald *et al.*, 2002: 47).

An analogy is made, using the concept of a spider's web, to explain the multifaceted and reciprocal nature of these relationships. Anything that happens in any part of the web affects all parts of the web. Further, the ecosystemic way of thinking is that actions can trigger other actions within and between systems in a cyclical way. Thus the way individuals behave, feel, think, and develop is interwoven with the relationships, forces, and social structures that constitute their environment (Donald *et al.*, 2002: 45-49).

In order to understand fully the development of the deaf child and parenting from an ecosystemic perspective the psycho-sociological and sociological determinants of parenting must be considered (Bornstein, 1995: xxiii). Just as the child's development does not take place in isolation from the context of the family, home, school and social setting, so too does parenting not occur in a vacuum. The context in which parents nurture, educate and strive to understand their children as well as themselves as parents, is influenced by the forces that constitute the larger, socio-political world (Zigler, 1995: x). In order to strive towards the goal that "parenting practice must fit the child, the parents and the culture", we need to understand the parenting process, the dynamics of the parent-child relationship, as well as the consequences for both parent and child (Hinde, 1995: xi).

Donald *et al.* (2002: 51) maintain that Bronfenbrenner's ecological systems theory of human development has probably been "the most influential contribution" to understanding how the development of children is shaped by their social contexts. The ecological systems theory involves different levels of interacting systems in the social context. Four interacting dimensions that are basic to Bronfenbrenner's model are person factors (such as temperament or personal characteristics); process factors (such as the types of interaction that occur in a family); contexts (such as the family, school or local community); and time (for instance, changes take place over time in the child, parent or environment) (Swart & Pettipher, 2005: 10; Donald *et al.*, 2002: 51).

Bronfenbrenner's theory draws attention to the importance of the face-to-face interactions that occur in long term close relationships, (*e.g.* between parent and child), as these are most influential in shaping lasting aspects of development. These are

referred to as “proximal interactions” which are specific social interactions that bring about growth and development in the child. Described as “the mechanisms that produce development” (Bronfenbrenner, 2000: 129), they are influenced by person factors as well as by the type of contexts in which they occur. These factors associated with the process, person, and context are subject to change over a period of time owing to changes in the environment as well as the process of maturation of the individual (Donald *et al.*, 2002: 51). Furthermore, the four levels consist of a hierarchy of systems moving from the innermost to the outermost levels (Bronfenbrenner, 1992: 226), and “extending beyond the immediate family to national and societal levels” (Wall, 2003: 25).

The **microsystem** is defined by Bronfenbrenner (1992: 227) as follows:

The microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features, *and containing other persons with distinctive characteristics of temperament, personality, and systems of belief.*

Bronfenbrenner (1992: 227) added to the original definition by including elements pertaining to the potential importance of “the developmentally-relevant characteristics” of significant others participating in the immediate environment of the developing person (indicated in italics above). The definition of the microsystem, which is the innermost level of the ecological model, has been expanded to include other elements that link it to the “centre of gravity” of the bioecological paradigm (Bronfenbrenner & Morris, 1998: 1013). In this study the deaf child is at the centre of the ecosystem.

The contemporary definition of a microsystem (Bronfenbrenner, 1994: 1645) is as follows:

A microsystem is a pattern of activities, social roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical, social, and symbolic features that invite,

permit or inhibit engagement in sustained progressively more complex interaction with, and activity in, the immediate environment.

Thus, microsystems include the family, the school, and developmentally-relevant characteristics of others in the environment, with whom the developing individual is closely involved in continuous face-to-face interactions. Such systems entail “patterns of daily interactions, activities, relationships and roles”, and “it is at this level that the key proximal interactions” occur (Donald *et al.*, 2002: 51). When two or more microsystems interact, they constitute a mesosystem.

The **mesosystem** according to Bronfenbrenner (1992: 227) “comprises the linkages and processes taking place between two or more settings containing the developing person”, for example, the interaction between the home and school, the family and extended family or neighbourhood. The individual and the family are embedded in the broader mesosystems and the relations that develop or exist between the microsystems influence and are influenced by each other.

Thus, what happens in the home can influence the child’s performance at school; for example, the child who does not receive support at home may experience loving support and care from the educator at school. In this way a positive secure environment may be provided over a sustained period, which could compensate for the lack of support and feeling of insecurity experienced in the home (Swart & Pettipher, 2005: 11; Donald *et al.*, 2002: 52). Similarly, a deaf learner who is marginalised by the other children in the neighbourhood because of the use of sign language, may find that the support of educators and peers at his school, where sign language is the medium of instruction, makes up for the shortfall in his social networks in the neighbourhood.

The mesosystem is embedded in the larger **exosystem** which is defined by Bronfenbrenner (1992: 227) as follows:

The exosystem encompasses the linkage and processes taking place between two or more settings, at least one of which does not ordinarily

contain the developing person, but in which events occur that influence the processes within the immediate settings that does contain that person.

The exosystem includes, for example, the broader education system, health and social services, the media, the parents' workplace and local community organisations or professional agencies that do not involve the developing individual directly, but affect or are affected by what happens in the settings that do involve the individual (Swart & Phasha, 2005: 215; Swart & Pettipher, 2005: 11; Donald *et al.*, 2002: 52). For example, a parent of a deaf child who has a supportive employer may be allowed to take time off from work to attend regular parent guidance meetings or sign language classes arranged by the child's school. This can have a positive influence on the home-school relations, which in turn can positively impact the child's progress and development (Swart & Phasha, 2005: 215; Swart & Pettipher, 2005: 11; Donald *et al.*, 2002: 52).

The **macrosystem** is defined by Bronfenbrenner (1992: 228) as follows:

The macrosystem consists of an overarching pattern of micro-, meso-, and exosystems characteristics of a given culture, subculture or other broader social context, with particular reference to the developmentally-institutive belief systems, resources, operations, and patterns of social interchange that are embedded in each of these systems. The macrosystem may be thought of as a social blueprint for a particular culture, subculture or other broader social context.

The main types of macrosystems that exist within a culture or subculture may be identified by social labels such as "social class, ethnicity, or region (*e.g.* rural vs. urban)". Other types include different professions, or different historical events, or life styles. In effect, this means that over time, new social structures may evolve, with the possibility of an emergent subculture thorough the development of a distinct set of values, lifestyle, and other characteristic feature of a macrosystem (Bronfenbrenner, 1992: 229).

An example of the emergence of such a subculture is that of the Deaf, which espouses sign language as its first language. Writers have described the emergence of Deaf culture, Deaf communities and Deaf identities for over 150 years. They have identified three factors, namely, “deafness, communication and mutual support” that have led to the creation of Deaf communities as a consequence of the negative experiences of deaf people within hearing communities. Through interaction with other members of the Deaf community, as well as participation in various activities of this community, it is possible for deaf people to develop “a multidimensional sense of self-esteem” (Marschark & Spencer, 2003: 153).

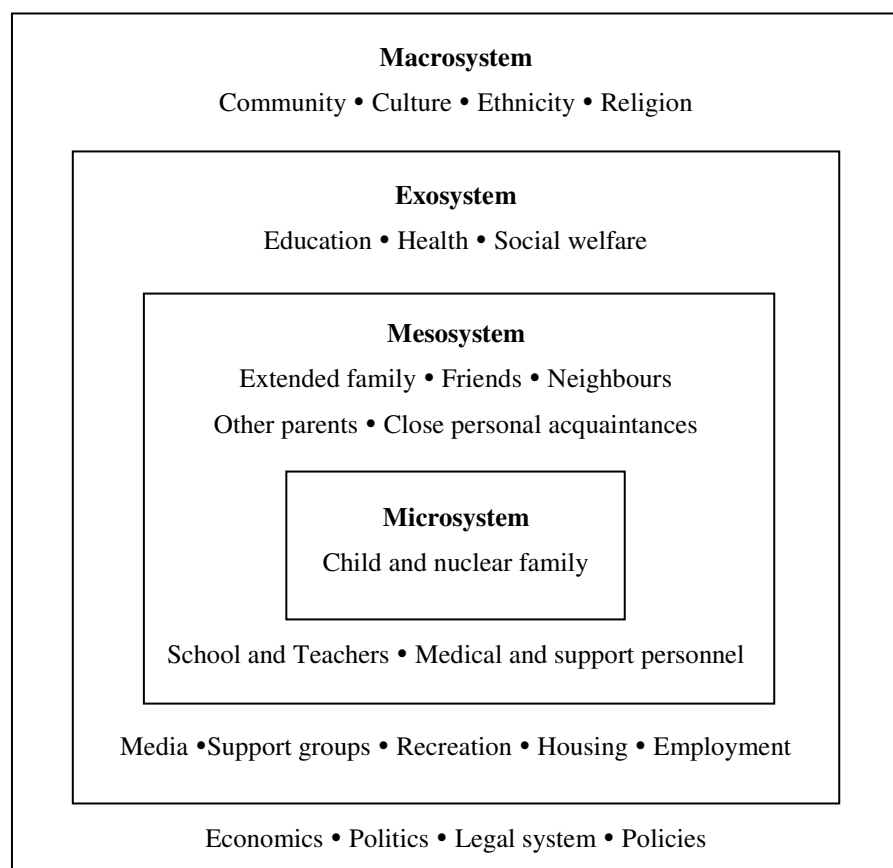
Bronfenbrenner’s ecological systems theory provides a conceptual framework for understanding not only the development of the deaf child but also the complexity of parenting. Swart and Phasha (2005: 215), Wall (2003: 25), Christenson and Sheridan (2001: 32), Seligman (2000: 60-62), as well as Bronfenbrenner and Morris (1998: 997) maintain that parental involvement extends beyond the family, and also includes the school and community. The multi-directionality of relationships within and between families, schools, and communities emphasises the influence that each of these nested systems exert on one another and on the individuals within the systems. Seligman (2000: 62) draws attention to the influence of the larger social, economic, and political realities on the family, school, and community contexts. Inevitably, the effects of these systems on parents and other members of the family will also influence family-school relationships, and in turn, children’s learning and development.

The child and the family constitute a microsystem embedded in the innermost level of the ecosystem, while the family unit is nested in the broader mesosystems consisting of interacting units such as the extended family, peers, educators, neighbours, and close personal acquaintances. Further, these units are nested in the larger exosystem consisting of broader education, health and social systems as well as other social organisations and professional agencies that exert an indirect influence on parents and children. The broader social context in which various South African cultures and subcultures with different belief systems exist, under different socio-economic conditions and in different geographical regions, is likely to impact on the way different families experience the responsibility of raising deaf children.

Fundamental to the functioning of the family unit is the family's interaction with members of the extended family, friends, the school, and the community. The ecological systems theory helps us to understand the influence of social factors such as discrimination, relocation, and poverty on family functioning and children's development. Bronfenbrenner's theory contributed to the interpretation of the crucial and on-going role of parents in the education of their children, and laid the foundation for the understanding and promotion of collaboration and cooperation between the most important systems influencing children's lives (Swart & Phasha 2005: 215-216).

Figure 2.1 below represents the "nested systems" of the ecological model, showing the reciprocal interactions that occur between the family, school, and community.

**Figure 2.1 An illustration of Bronfenbrenner's ecological systems theory, adapted from Seligman (Swart & Phasha, 2005: 215)**



Bronfenbrenner's ecological systems theory of human development focussed primarily on the environment as a set of nested systems in which human development occurs. The current, evolving paradigm, referred to as the *bioecological model* places equal



importance on the biopsychological characteristics of the person in the role of development. The primary focus of the bioecological model is on *proximal processes*, defined as “the mechanisms that produce development” (Bronfenbrenner, 2000: 129), or as the primary engines of development (Bronfenbrenner & Morris, 1998: 996). In the bioecological model human development is seen as a continuous life course process that spans successive generations. Thus importance is accorded to “historical continuity and change” which are forces that impact indirectly on human development through their influence on proximal processes (Bronfenbrenner, 2000: 130).

The defining properties of the bioecological model are stated in the form of two propositions (Bronfenbrenner, 2000: 130; Bronfenbrenner & Morris, 1998: 996):

Proposition 1:

Human development takes place throughout life through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment. To be effective the interaction must occur on a fairly regular basis over extended periods of time. Such enduring forms of interaction in the immediate environment are referred to as *proximal processes*.

A corollary of proposition 1 pertaining to the proximal processes that involve other persons, reads as follows (Bronfenbrenner, 2000: 130):

The developmental power of proximal processes is substantially enhanced when they occur within the context of a relationship between persons who have developed a strong emotional attachment to each other.

It is essential for a close bond to be formed between parent and child especially in the early years. This is especially critical in the case of hearing parents raising deaf children to enable the parents to cope better with the stress and strain associated with child rearing. At the same time parents can be guided to be more aware of and

responsive to the child's needs for attention, "thereby initiating and sustaining mutually rewarding interactions" (Bronfenbrenner, 2000: 130).

Proposition II focuses on four dynamic forces (Bronfenbrenner, 2000: 130; Bronfenbrenner & Morris, 1998: 996):

The form, power, content and direction of the proximal processes effecting development vary systematically as a joint function of the characteristics of the developing *person*; the *environment* – both immediate and more remote – in which the processes are taking place; the nature of the *developmental outcomes* under consideration; and the social continuities and changes occurring over *time* through the life course and the historical period during which the person has lived.

These forces are played out in the way hearing parents experience raising their deaf children in this study. Both propositions are theoretically interdependent, and "the characteristics of the person function both as an indirect producer and product of development" (Bronfenbrenner & Morris, 1998: 996).

A specific meaning is attached to the concept of proximal process within the context of the bioecological model and it has certain important distinctive features that are worthy of mention. These features include the following: the person must participate in an activity for development to take place, and the activity must occur at fairly regular intervals, over a long period of time; for developmental effectiveness, activities must occur over a long enough period to become "increasingly more complex"; proximal processes that are developmentally effective are bidirectional, that is, interpersonal interaction must, to some extent, be reciprocal; proximal processes can also involve interactions with objects and symbols in the immediate environment, and for reciprocal interactions to take place, the symbols and objects must be the type that "invites attention, exploration, manipulation, elaboration, and imagination" (Bronfenbrenner & Morris, 1998: 996-997).

The content, effectiveness and timing of proximal process undergo substantial changes as a result of the powerful moderating factors spelt out in the second proposition, *e.g.* children's developmental capacities increase as they grow older, while intervals between "increasingly more complex" interactions can become longer. Parents are the chief persons that young children interact with "on a fairly regular basis over extended periods of time". As children grow older they interact with "significant others" including caregivers, siblings, peers, relatives, educators, mentors, close friends, spouses or partners, colleagues, subordinates or superiors at the work place. The realisation of human potential is influenced by biological and evolutionary factors as well as environmental conditions. In the absence of the necessary conditions and experiences, such potential for development will not be realised (Bronfenbrenner & Morris, 1998: 997).

With regard to person characteristics, Bronfenbrenner and Morris (1998: 1009) identify three types of characteristics that are regarded as "process-relevant", namely, force characteristics, resources characteristics and demand characteristics.

**Force characteristics** are positive or negative behavioural dispositions that can shape human development. *Developmentally generative* characteristic can set in motion sustained proximal processes. These involve active behavioural dispositions such as curiosity, an inclination toward initiating and engaging in activity, readiness to engage in activities initiated by others, and willingness to defer immediate reward so that long term goals can be attained. In the case of this study, an example of such a positive force characteristic would apply to those hearing parents who shelve their personal goals in life and patiently endure the long journey towards developing their deaf children's communication skills so that their adjustment to life in the family, school and community can be enhanced.

On the other hand, negative force characteristics, referred to as *developmentally disruptive* behavioural dispositions, can "actively interfere with, retard, or even prevent" proximal processes from occurring. Examples of such dispositions manifest themselves in the inability to exercise control over behaviour and emotions, or apathy, lack of interest, insecurity and an inclination towards non-participation in activity.

Persons with negative force characteristics would have difficulty in engaging in proximal processes that require “progressively more complex patterns of reciprocal interaction over extended periods of time” (Bronfenbrenner & Morris, 1998: 1009).

**Resource characteristics** of the person which can influence development include “biopsychological liability and assets” that can affect the person’s ability to participate actively in proximal processes. Developmental liabilities include conditions that disrupt or limit the person’s functional integrity, for example, physical handicaps or chronic illness. Developmental assets, on the other hand, include knowledge, experience and skills that evolve over an extended period of time thereby increasing the possibility of “progressively more complex” patterns of interaction occurring (Bronfenbrenner & Morris, 1998: 1011).

**Demand characteristics** of the person that can shape development involve the ability to encourage or restrict reactions from the social context which can promote or disrupt psychological growth, for example, the person’s temperament, the active or passive nature of the person, or physical appearance of the person (Bronfenbrenner & Morris, 1998: 1011).

With regard to the effects of the physical environment on psychological development, Bronfenbrenner and Morris, (1998: 1014) put forward, from an ecological perspective, a new working hypothesis: “Not only do developmentally generative features of the surroundings have greater impact in more stable settings, but they also function as a buffer against the disruptive influences of disorganising environments”. For example, greater maternal responsiveness acts as a buffer against emotional and behavioural problems in children.

Bronfenbrenner and Morris (1998: 1014) state that a strong body of research supports the view that mother-infant dyads serve as a context for development and foster a greater degree of emotional attachment between them. This paves the way for increasing the quality of future interactions between mother and child. The quality of the attachment relationship between mother and infant influences the child’s later development in other social interactions, for example, with educators and peers. A

child who has developed a secure attachment relationship with a primary caregiver expects and elicits positive interactions with others in society. Research on attachment theory has important implications for the bioecological model. Its relevance is conveyed by assessing the quality of the attachment at different times in the occurrence of interactions. A long-standing proposition derived from the bioecological model (Bronfenbrenner & Morris, 1998: 1015), reads as follows:

In order to develop – intellectually, emotionally, socially and morally – a child requires, for all of them, the same thing: participation in progressively more complex reciprocal activity, on a regular basis over extended periods of time with one or more other persons with whom the child develops a strong, mutual, irrational attachment, and who are committed to that child's development, preferably for life.

A second proposition is taken a step further and reads as follows:

The establishment and maintenance of patterns of progressively more complex interaction and emotional attachment between caregiver and child depend in substantial degree on the availability and active involvement of another adult who assists, encourages, spells off, gives status to, and expresses admiration and affection for the person caring for and engaging in joint activity with the child.

Hetherington and Clingempeel (in Bronfenbrenner & Morris, 1998: 1015) attest to the importance of these two propositions which qualify the finding that children who grow up in families with a single parent are more at risk developmentally, than those in families with two parents. However, more importantly, it is the quality of the interactions and relationships that occur within the family that count most, and in such situations “quality overrides quantity”. The relevance of both these propositions could extend beyond relationships with parents to close relationships with others in society. The propositions may apply to relationships over an extended period of time, from childhood, through adolescence, to adulthood and even old age.

These two propositions bear relevance to this study and have important implications for hearing parents raising deaf children. Bronfenbrenner's theories of human development, although focussed on child development, are also applicable to adults, and in the case of this study, to the hearing parents raising deaf children, as their parenting role evolves over time, through changes in environmental conditions, personal dispositions, life transitions and experiences. More importantly, the parenting of the deaf child happens within the ecosystemic context.

Knowledge about the prevalence of deafness, which is discussed in the next section, will contribute to understanding how widespread the phenomenon of hearing parents raising deaf children is in South Africa.

## **2.3 PREVALENCE OF DEAFNESS**

Information on the prevalence of deafness internationally and in South Africa, can be used as an indication of how many families are affected and how many parents have to manage and deal with raising a child who is deaf. I will refer to available prevalence figures of the United States, the United Kingdom, and Africa as well as for South Africa where possible.

### **2.3.1 Prevalence internationally**

The prevalence of deafness is influenced by worldwide medical factors, sometimes resulting in great fluctuations in statistics. For instance, a rubella epidemic may result in high numbers of children being born deaf in one year, and relatively few in the following year. Vaccines against rubella, among other medical discoveries, have drastically reduced the incidence of hearing loss (Vernon & Andrews, 1990: 40).

In 1999 the National Centre for Health Statistics (Schirmer, 2001: 19) indicated that approximately 22 million persons in the United States, or 8.6% of the population, have hearing loss. It is estimated that severe to profound deafness ranges from 0.18% to 0.49%, of which 0.10% of children fall into this category. Prevalence of hearing loss by age indicates that the highest prevalence, 29.1%, is among people 65 years and

older. The lowest prevalence, 1.8%, is among children between the ages 3 and 17 years (Schirmer, 2001: 20). 1 in every 1000 infants born in the US has severe to profound hearing loss, while 10 in every 1000 school age children of have permanent sensorineural hearing loss (Hake & Hake, 2008).

According to the 1999 United States National Centre for Education Statistics, approximately 1.3% of all school children aged 6 to 21, who received special education during the period 1996 – 1997, fell into the category of deafness. Approximately 25% of these children have one other disability, while 9% have two or more additional disabilities. For this reason, the prevalence of deafness reported above is definitely higher, since some deaf children are included under one of the other disability categories (Schirmer, 2001: 20).

In the United Kingdom, according to the Royal National Institute for the Deaf (RNID, 2008), there are more than 34,000 deaf children and young people in the UK. Approximately 20,000 children, aged 0 – 15 years, are moderately to profoundly deaf, of which about 12,000 are born deaf. In the UK, 3,800 children between 0 – 4 years of age are deaf; 17,700 deaf children are between the ages of 5 – 16 years, while there are 13, 300 young deaf people in the age range 17 – 25years. The number of children born deaf as a result of their mothers contracting German measles (rubella) during pregnancy has decreased since the introduction of vaccination, However, the number of infants being born deaf as a result of other causes, such as lack of oxygen during birth, or premature birth, has increased.

In Africa, it is estimated that in sub-Saharan countries there are more than 1.2 million children between the ages of 5 and 14 who are deaf. Prevalence figures in general show higher rates of severe to profound deafness in this part of Africa than in other developing countries. In Nigeria, about 14% of school age children have some kind of hearing loss; in Swaziland, 4.1% of children between 5 and 15 years of age are deaf, while in Kenya, Gambia, and Tanzania, 2.5 to 3.5 children per 1000 are severely to profoundly deaf.

### 2.3.2 Prevalence in South Africa

DeafSA (2006) suggests that the recorded number of deaf persons in South Africa (383 408, as indicated by the 1996 census), is an under-representation of the prevalence of deaf persons in South Africa, perhaps due to the negative stigma associated with being identified as a person with a disability. However, DeafSA agrees to work with the above figure as mentioned in Education White Paper 6 (DoE, 2001), since the 2001 census is problematic as the questionnaire made provision for only severe disabilities (DeafSA, 2006). The following data (Table 2.1) shows the distribution of deaf people in South Africa (DoE, 2001: 14). This excludes those who are in institutions, and therefore the figure could be much higher. There is an estimated half million deaf people in South Africa, nearly 1% of the total population are profoundly deaf while 3% are extremely hard of hearing (DeafSA, 2006).

**Table 2.1 Distribution of deaf people in South Africa (DoE, 2001: 14)**

<b>PROVINCE</b>	<b>NUMBER</b>
Eastern Cape	68,531
Free State	33,045
<b>Gauteng</b>	59,868
<b>KwaZulu-Natal</b>	76,034
Mpumalanga	31,895
Northern Cape	6,083
Northern Province	51,416
North West	37,571
<b>Western Cape</b>	18,965

The statistics must be read keeping in mind that some provinces are bigger than others and not all are equally densely populated. There is a paucity of information regarding the number of deaf children in South Africa. According to the International Journal of Pediatric Otorhinolaryngology, in 1997 the prevalence rates of 7.5% of South African learners suffering from varying degrees of deafness highlight the possibility of many children being affected and therefore many families too (Press Hear-It, 2008). To understand the experiences of parents more comprehensively, it is necessary to look at the clinical features of deafness.



## **2.4 CLINICAL FEATURES OF DEAFNESS**

Deafness manifests itself in many ways, interacting with a wide range of other variables such as motor, visual, or mental disabilities. Any additional disabilities or obstacles that the deaf child has to cope with will impact on the child's development, while the child's unique personality, family, social, cultural and linguistic environment will have a significant influence too (Diefendorf, 1996: 3-4). Deafness differs from other disabilities in one important respect, in that it involves not only the loss of hearing, but also the loss of spontaneous speech and language acquisition. Consequently the restricted or total lack of language has major implications for the child's development (Kapp, 1991: 332). The one characteristic that all children with hearing loss have in common is that they do not have normal hearing. Apart from this fact, the group is heterogeneous, varying in terms of age of onset and degree of hearing loss, and the type of family support and appropriateness of services available to the child. Therefore each child presents a unique combination of characteristics which can affect the developmental process.

Since deafness does not have clearly marked physical features, deafness may go undetected for a considerable period of time, especially since the symptoms of deafness in young children are not as conspicuous as in the case of some of the other disabilities. Northern and Downs (2002: 2) describe hearing loss as a "silent, hidden disability" because infants and toddlers are not able to express concerns that they cannot hear very well.

From a purely physiological point of view, deafness may be regarded as a consequence of hearing loss resulting from an inherited or acquired defect in some part of the hearing mechanism. In other words, a deaf child is one who lacks or partially lacks the sense of hearing (Levitz, 1991: 46). If it is not detected and treated early enough, it can result in delay in speech and language development, emotional and social problems as well as academic failure (Northern & Downs, 2002: 2).

In order to understand the clinical features of deafness and the parameters by which it is defined and described, it is necessary to explain briefly some basic facts such as the anatomy of the ear and the way sound waves are processed.

### **2.4.1 The anatomy and functioning of the ear**

The ear mechanisms are highly complex and the functioning of the auditory system is a delicate process. Northern and Downs (2002: 4-6), Schirmer (2001: 2-3) and Kapp (1991: 320-322) explain the anatomy of the ear and the way the auditory system functions as follows:

The ear consists of three major sections, namely, the outer ear or external, middle ear and inner ear. The outer ear includes the auricle and the external auditory canal. The middle ear consists of the eardrum (tympanic membrane) and a small cavity containing the three smallest bones of the body. The inner ear includes the cochlea which contains sensory cells that stimulate the auditory nerve impulses. The ear is designed to pick up sound vibrations from the air, to transmit this information to the brain, where it can be interpreted. Every sound causes air to vibrate in a certain way.

The visible outer ear, which is called the pinna or oracle, is designed to trap sound vibrations from the air and feed them along the auditory canal, until they meet the eardrum, or tympanum, which separates the external auditory canal from the middle ear cavity. The main function of the eardrum is to transmit sound waves to the middle ear through vibrating as the sound waves beat against it.

The middle ear cavity is a small air-filled space in the temporal bone of the skull, and is lined with a mucous membrane. This cavity houses three tiny bones, namely, the malleus (hammer), incus (anvil) and stapes (stirrup). Their main function is to conduct incoming sound vibrations from the tympanic membrane across the middle ear cavity to the oval window, which leads to the inner ear. The eustachian tube, which ventilates the middle ear section, also connects this cavity to the nose and throat, and equalises the atmospheric pressure on either side of the eardrum.

The inner ear, which is a cavity filled with fluid called the perilymph, is the most complex section. It consists of two main parts, namely the cochlea and the semicircular canals. The structure concerned with hearing is the cochlea which converts information transmitted through the oval window into electrical nerve

impulses. These are then passed to the brain, where the information is made sense of through a complex process of analysis by cochlea nerves. The individual then has to decide how to respond. The semicircular canals are not related to hearing. However, they enable the individual to maintain balance, and any disturbance in the semicircular canals can lead to dizziness.

A healthy auditory system depends on the normal functioning of the three separate sections. Loss of hearing is a result of malfunctioning of one or more of these sections of the ear. Sometimes malfunction involves different parts of the system concurrently. Whatever the cause of hearing loss, the effects on a young child are far-reaching. The entire developmental process of the growing child is hampered if hearing loss occurs prior to the acquisition of language. The impact of deafness on the child's development also hinges on the level or degree of hearing loss, which is the focus of the next section.

#### **2.4.2 Levels of hearing loss**

Knowledge of the levels or degrees of hearing loss will help enhance the understanding of the nature of deafness, and is especially relevant for parents raising deaf children so that appropriate decisions can be made regarding their deaf children's learning and development. There are different degrees of hearing loss, and the level of hearing loss that children experience can have a profound impact on their overall learning and development. Ideally babies should be tested by an audiologist as early as possible soon after birth so that appropriate interventions can be implemented timeously in the event that deafness is detected. Based on the results of the audiological tests, a child who is suspected of experiencing a hearing loss is then identified as deaf or hard of hearing.

Kapp (1991: 322) maintains that although measurement of the degree of hearing loss is important for educational purposes, care should be taken not to be too rigid in this regard, as it may compromise the individual child's specific educational needs. Classification according to the degree of hearing loss should not be regarded as

absolute, since it is not the only criterion for determining the child's placement in a particular type of school.

The intensity or loudness of sounds is measured on the vertical axis of the audiogram in decibels (dB), while the frequency (high or low pitch of the sound) is plotted on the horizontal axis, and is measured in hertz (Hz) (Storbeck, 2005: 351; Northern & Downs, 2002: 6-7). A decibel (named after Alexander Graham Bell) is defined as a unit of measure which is "one tenth of a bel", an "arbitrary unit that expresses the ratio of a measured power or pressure to a specified reference value" (Northern & Downs, 2002: 7).

The levels of hearing loss are shown in Table 2.2 which has been adapted from Marschark *et al.* and Schirmer (in Storbeck, 2005: 352).

**Table 2.2 Levels of hearing loss**

Hearing person		0 – 25dB
Hard of hearing	Mild hearing loss	26 – 40dB
	Moderate hearing loss	41 – 55dB
Deaf	Moderately severe hearing loss	56 – 70dB
	Severe hearing loss	71 – 90dB
	Profound hearing loss	91dB+

The levels of hearing loss can be explained as follows (Storbeck, 2005: 352; Schirmer, 2001: 13-14):

#### **Normal hearing sensitivity (0-25dB)**

A hearing person's level of hearing falls within this category.

#### **Mild hearing loss (25-40dB)**

A person who falls into this category is hard of hearing. Schirmer (2001: 18) states that a person with mild hearing loss has no difficulty in communicating in quiet

environments in which the topic is familiar and the vocabulary is limited. However, faint or distant speech presents a problem even in a quiet environment, and classroom discussions are difficult to follow. Without the use of hearing aids and assistive listening devices a child who has a 35-40% hearing loss can miss up to 50% of class discussion, when voices are soft or far away (Flexer, 1994: 38). A child with an unmanaged mild hearing loss is likely to lag behind at least one grade (Northern & Downs, 2002: 14).

Moderate hearing loss (41 – 55dB): Anyone who fits into this category would also be regarded as hard of hearing. The person can hear conversational speech only at close proximity. Group work such as class discussions can be challenging (Schirmer, 2001: 18). Several authors state that learners with moderate hearing loss who have not received appropriate early intervention are likely to fall behind by at least two grades by fourth grade (Flexer, 1994: 39).

Moderately severe hearing loss (56 – 70dB): According to Schirmer (2001: 18), a moderately severe deaf person can only hear conversational speech if it is loud and clear, and has much difficulty in group discussions. Although the person's speech is intelligible, it is noticeably impaired. Matkin (in Flexer, 1994: 39) holds the view that a child with a 56dB hearing loss can miss 100% of class discussion, and without appropriate early and continuing intervention, is likely to have marked difficulty in school, as well as experience social behaviour problems.

Severe hearing loss (71 – 90dB): A severely deaf person is unable to hear conversational speech unless it is loud, and even then many of the words cannot be recognised. The person's speech is not quite clear. Even though environmental sounds can be detected, these are not always identified (Schirmer, 2001: 18). Various authors believe that with appropriate amplification and auditory intervention strategies, a child with severe hearing loss can be hard of hearing and not deaf. With the help of some support services, the child will be able to learn and live in a mainstreamed environment (Flexer, 1994: 39).

Profound hearing loss (91dB +): Schirmer (2001: 18) states that a profoundly deaf person may hear loud sounds but simply cannot hear conversational speech. The person's own speech, if developed at all, is not easy to understand. The chief modality of communication is vision. The person cannot hear sounds without amplification. However, the vast majority of persons in this category do have some residual hearing. Nonetheless, the ability of a profoundly deaf child to benefit from amplified sound will depend on several factors.

It is clear from the above discussion that the degree of hearing loss varies and does not on its own determine communicative function. It will therefore impact differently on the developing child (Flexer, 1994: 39).

### **2.4.3 Developmental milestones for childhood communication**

Martin and Clark (1996: 116) state that the stages for the development of auditory skills are similar for children with normal hearing and children with hearing loss in the first few months of life, thereby making it difficult for parents of deaf children to identify hearing loss. If hearing loss is left unidentified it will result in the auditory development of deaf children being arrested. A wide range of variability among children exists with regard to communication development, but a marked deviation from the norms below may be an indication of a developmental lag in communication. It could help to identify a child who is not developing according to expectation with regard to hearing and understanding, as well as talking, thereby indicating the need for an in-depth evaluation of the child (Martin & Clark, 1996: 335-337).

**Birth:** The child should be able to listen to speech, be startled or cry at noises, and awaken at loud sounds. He should be able to make joyful sounds, and when the parent plays with him he should look at the parent, look away and then look at the parent again.

**0 – 3 Months:** The child should be able to turn to the parent and smile when spoken to, recognise the voice and quieten down if crying. He should be able to cry differently for varying needs, and smile upon seeing the parent.

**4 – 6 Months:** The child should be able to respond to “no” and changes in the tone of voice, look around for the source of new sounds, and notice toys that make a sound. His babbling should sound more like speech with different sounds like p, b, and m. Through sound or gesture he should be able to indicate when he wants something to be done again. He should be able to make gurgling sounds when playing with the parent or when left alone.

**7 Months – 1 Year:** The child should be able to recognise words for common items such as “juice” and ‘cup’, respond to requests like “come here”, enjoy games such as peek-a-boo, turn or look when his name is called, and listen when spoken to. He should be able to say one or two words (*e.g.* “dada” and “mama”) although they may not be clear. His babbling should have both long and short groups of sounds. He should be able to imitate different speech sounds and use speech or non-crying sounds to get attention.

**1 – 2 Years:** The child should be able to point to pictures in a book when these are named, and to some body parts when asked. He should be able to follow simple commands *e.g.* “roll the ball”, understand simple questions (*e.g.* “Where’s your shoe?”) and listen to simple stories, songs and rhymes. With regard to talking he should be able to say more words every month, and use many different consonant sounds at the beginning of words, ask a few questions using one or two words, (*e.g.* “What’s that?”) and put two words together, (*e.g.* “No juice”).

**2 – 3 Years:** The child should understand differences in meaning (*e.g.* stop/go, up/down), continue to notice sounds (*e.g.* the telephone ringing), and follow two requests (*e.g.* “get the ball and put it in the box”). With regard to talking, he should have a word for almost everything, use two or three word “sentences” to talk about or ask for something, and ask for or direct attention to objects by naming them. The parent should be able to understand the child’s speech most of the time.

**3 – 4,5 Years:** The child should be able to hear when called from another room, hear radio or television at the same volume as other family members, and answer simple “who”, “what”, “where”, “why” questions. With regard to speaking, he should be able

to say most sounds correctly except for a few (*e.g.* r, l, s and th), talk about what he does at nursery school or a friend's home, talk easily without repeating syllables or words, use four or more word sentences, use sentences that give details (*e.g.* "I have two blue balls at home"), and tell a story sticking to the topic most of the time. The child's voice should sound clear like other children's and people outside the family should be able to understand his speech.

**4,5 – 5 Years:** The child should be able to understand most of what is said in the home and at school, and he should be able to pay attention to a story and answer simple questions about it. With regard to talking, he should be able to communicate easily with other children and adults, say all sounds correctly with the exception of one or two, and use the same grammar as the rest of the family.

Although these developmental milestones are age-related and could vary from child to child, they are offered as mere guidelines to help identify the possibility of hearing loss, of which there are different types.

## **2.5 TYPES OF HEARING LOSS**

Three types of hearing loss have been identified, namely, sensorineural hearing loss, conductive hearing loss and mixed hearing loss. The type, causes and degree of hearing loss have differing, and often far-reaching consequences on the young child's life. The causes of early childhood hearing loss can be divided into two major categories, namely, genetic or hereditary, and acquired or environmental. Within both categories hearing loss can be congenital, that is, present at birth, or it can occur later at any time after birth (Arnos, Israel, Devlin & Wilson, 1996: 20).

Hearing loss is the result of malfunction in the outer, middle, or inner ear. The type of hearing loss in an individual is determined by the area of the ear in which the impairment occurs. There is no single cause of hearing loss as it may result from a wide spectrum of possible causes. These include genetic or congenital causes, diseases, infections, or traumatic situations that affect different parts of the auditory system. The two major types of hearing loss are sensorineural and conductive



(Storbeck, 2005: 352; Northern and Downs, 2002: 8; Scheetz, 2001: 39; Schirmer, 2001: 5; Marschark, 1997: 28).

### **2.5.1 Sensorineural hearing loss**

Sensorineural hearing losses are usually associated with defects in the fine hair cells located within the cochlea or along the nerve pathway from the inner ear to the brain (Storbeck, 2005: 352; Northern & Downs, 2002: 10; Scheetz, 2001: 42; Schirmer, 2001: 5; Flexer, 1994: 55; Kapp, 1991: 326). The cochlea and auditory nerve may be irreversibly damaged in several ways. Sensorineural hearing losses are permanent and unlike conductive hearing losses, the sense of hearing cannot be restored through medical treatment (Scheetz, 2001: 42; Northern & Downs, 2002: 10; Schirmer, 2001: 5).

From an educational point of view, Schirmer (2001: 6-7) states that the time of onset of hearing loss, that is whether it is prelingual or postlingual is considered most important. Prelingual hearing loss is present at birth or occurs before the child has acquired language or before the age of two years. Approximately 95% of deaf school children fall into this category. Postlingual hearing loss occurs after the age of two years, after the child has developed spoken language. Such a child has a distinct advantage over one who has prelingual hearing loss since the child has a language base for communicating and learning. Since birth to two years is deemed an important period for prelinguistic development, severe hearing loss disrupts this process (Schirmer, 2001: 8; Paul & Quigley, 1994: 17).

### **2.5.2 Conductive hearing loss**

Conductive hearing loss occurs when the channels of sound conduction, such as the auditory canal or the middle ear, are damaged to the extent that they prevent sound waves from being conveyed to the inner ear. Thus hearing loss can occur even though the auditory nerves and their connection with the brain are normal. The degree of hearing loss is usually mild, between twenty and sixty decibel loss and can be treated medically. A person with conductive hearing loss is capable of understanding speech

provided this is loud enough (Scheetz, 2001: 42; Marschark, 1997: 28; Silverman, 1995: 21; Flexer, 1994: 43; Dysart, 1993: 19).

Bilateral or unilateral lesion in the outer or middle ear results in conductive hearing loss. A person with a bilateral lesion experiences speech or other sounds as being relatively soft, depending on the severity of the hearing loss. A person with a unilateral lesion experiences sounds as being soft, if the sound is on the same side as, and close to, the affected ear. The main problem experienced is usually difficulty in determining the location of the sound (Silverman, 1995: 20). A conductive hearing problem refers to any difficulty which affects the transmission of sound into the ear and across the middle ear canal.

Conductive hearing loss is thus due mainly to mechanical obstructions in the outer or middle ear and is often treatable (Clark & Jaundl, 1996: 53). The effects of conductive hearing loss are less severe than the effects of sensorineural hearing loss. It is important to bear in mind that most of the causes of conductive hearing loss such as impacted cerumen, foreign objects in the ear, external otitis (infection of the outer ear), otitis media (infection of the middle ear) and perforation of the tympanic membrane can be prevented.

### **2.5.3 Mixed hearing loss**

Mixed hearing loss is the combination of both sensorineural and conductive hearing loss (Storbeck, 2005: 352; Northern & Downs, 2002: 10; Silverman, 1995: 27). Mixed hearing loss may be a result of obstruction in the conduction of sound together with sensorineural damage. For example, a child could have a congenital sensorineural hearing loss of genetic origin and also have an ear infection. Such a hearing loss would be the combination of the individual sensorineural and conductive components, hence mixed hearing loss. The fact that a child has one type of hearing loss does not preclude a child from having another. Both types need to be identified and managed. An understanding of the types of deafness will lead to a better understanding of the development of the deaf child, which is the focus of the next section.

## **2.6 DEVELOPMENT OF THE DEAF CHILD**

Deafness is more than just a loss of hearing. It is far more complicated since the blockage of information through the auditory channel can have a profound influence on the subsequent emotional, intellectual, social and personality development of the child. From a developmental perspective, profound deafness from birth means the loss of the ability to acquire speech and language naturally, and the absence of meaningful sounds that convey information, give rise to emotions, influence actions and attitudes and promote human relationships. This, in turn, could hamper the normal process of the child's development, and may have far-reaching consequences (Northern & Downs, 2002: 19). It is not the hearing loss itself that has a direct impact on the development on the deaf child, but rather, the resulting lack of communication skills that hinders the child and diminishes access to daily family conversations, ideas, and verbal interactions with the outside world (Bibby & Foster, 2004: 13; Northern & Downs, 2002: 2; Marschark, 1997: 16; Kapp, 1991: 332).

### **2.6.1 An ecosystemic perspective**

In the centre of the ecosystem is the child, and for the purposes of this study, a child who is deaf. Deaf children have fewer opportunities to acquire informally information from various situations such as from interactions between family members in the home, between peers and educators at school, and among members of the community. This results in fewer learning experiences for the deaf child, which has a negative impact on the child's overall development and learning. The following aspects of development of the deaf child will be discussed from an ecosystemic perspective encompassing the following: the deaf child; the deaf child in the family; the deaf child in the school and the deaf child in the community.

#### **2.6.1.1 The deaf child**

In this section only the cognitive development, socio-emotional development, and personality development of the deaf child will be covered, yet acknowledging the importance of physical, moral, spiritual and cultural aspects of development. All three

aspects contribute to the total development of the deaf child, and what is offered here is by no means exhaustive, but will help in understanding the complexities associated with parenting a deaf child.

#### **2.6.1.1.1 Cognitive development**

Bernstein and Tiegerman (in Levitz, 1991: 52) define cognition as “the process of knowing, which includes factors such as awareness, perception conceptualisation, and judgement”. Further, a person’s cognition is directly linked to the type of experiences he/she has been exposed to in the world and is thus a process of knowing, perceiving, thinking, and conceiving or conceptualising. Cognitive development therefore refers to the development of such processes. Kapp (1991: 332) states that there are great differences of opinions with regard to the cognitive development of deaf children.

One view is that deaf children’s cognitive development is diminished because thought is dependent on language. Another premise is that thought without language is possible and that deaf children only experience problems with concepts that are language-dependent. A more recent view is that since sign language is a true language for the Deaf, any difficulties experienced with conceptualising are not the result of poor language development per se, but rather of poor communication with others.

Moore (in Marschark, 2003: 465) identified three historical stages of research investigating cognition among deaf individuals. The first stage was described as “the deaf as inferior”; the second stage was termed “the deaf as concrete”, and the third stage refers to “the deaf as intellectually normal”. Thus the perceptions of deaf individuals’ cognitive abilities evolved over time. Marschark (2003: 466) maintains that the general view that “different does not mean deficient” points to the need for research examining the variability that prevails among deaf people as well as between deaf and hearing people.

Ross *et al.* (2004: 153) maintain that it is a fallacy to assume that deaf people can only think on a concrete level, as they are capable of thinking in the abstract and solving abstract problems. In addition, several studies have shown that intellectual functioning

and development are not dependent on spoken language, and that deaf people possess normal intelligence even though their verbal IQ scores are low. However, Luteran and Ross (in Ross *et al.*, 2004: 153) state that deaf students' general level of academic performance would seem to be far below expectation on tests of cognitive development. Even though there is no clarity in the literature regarding the cognitive abilities of deaf children, it is clear that most deaf children do not perform well on verbal tests compared to children who are not deaf. However, this is not an indication of their level of intelligence (Blair, 1996: 326).

### ***Cognition, language and thought***

Theories on the link between cognition and language differ. On the one hand Bernstein and Tiegerman (in Levitz, 1991: 53) maintain that language acquisition is dependent on the development of cognitive structures. They claim that cognitive structures have to be developed as the foundation upon which language acquisition rests, *i.e.* cognitive development precedes language development. On the other hand, Lowenveld (in Levitz, 1991: 53) maintains that the use of linguistic symbols promotes the understanding of concepts and the development of cognition in general, and that language influences the development of cognitive abilities such as the growth of reasoning, the increasing complexity of awareness, and the building up of structures of knowledge.

Schirmer (2001: 104) also holds the view that the association between cognition and language is an interdependent one. Language acquisition occurs as a result of the interaction between the cognitive abilities, conceptual knowledge and cognitive strategies of the child. Based on the analogy of a growing plant, Rice and Kemper (in Schirmer, 2001: 105) describe this interaction in the following way: "Deaf children begin life with a language seed that is full of cognitive potential. They need a fertile environment that will enable the language seed to grow into a mature language plant".

The cognitive development of deaf children has typically been studied using Piaget's developmental tasks. Since the mid-1960s, research has shown that deaf children progress through the same stages of cognitive development and perform in a similar

fashion to hearing children, but somewhat later on certain tasks. Deaf children exhibit cognitive differences as a result of language delay and experiential deficit, and not cognitive capacity (Schirmer, 2001: 102). The key to early language acquisition and overall development of the deaf child is the early establishment of effective communication between the family and the young child (Calderon & Greenberg, 2003: 69).

#### **2.6.1.1.2 Socio-emotional development**

A critical foundation for success in life is the establishment of healthy socio-emotional development (Goleman, 1998: 25). Competence in this regard helps individuals actualise their academic and vocational potential. Greenberg and Kusche (in Calderon & Greenberg, 2003: 177), in defining socio-emotional competence, identify several processes and outcomes necessary for successful development. These include: good communication skills; the ability to think independently; the capacity for self-control and self-direction; understanding the feelings, needs and motivations of self and others; flexibility in adapting appropriately to the needs of each situation; the capacity to rely on and be relied upon by others; understanding and appreciating one's own and others' cultures and values, and the ability to use skilled behaviour to maintain healthy relationships with others and to obtain goals that are socially approved.

Greenberg, Lengua and Calderon (in Calderon & Greenberg, 2003: 178) state that competence in these aspects is related to the ability to cope under different levels of difficulty. Various researchers such as Greenburg and Kusche, Marschark, as well as Meadow, Greenberg, Erting, and Carmichael (in Calderon & Greenberg, 2003: 178) have found that deaf children and adolescents generally are at risk in relations to many adverse outcomes, such as poor academic achievement and higher rates of maladaptive behaviour, as a result of low mastery in several of these areas of socio-emotional competence.

Deafness impacts on the social development of deaf individuals with social isolation being one of the chief consequences. It affects the empathetic relationship between parent and child. Profoundly deaf children are virtually excluded from the human

interaction ordinarily available to hearing children. It means loss of early parent-infant relationship communicated through sound, as the human voice is a means of communicating feeling to the child, especially in the early stages of infancy. Deafness therefore isolates children from the feelings conveyed in their parents' voices (Ross *et al.*, 2004: 153; Northern & Downs, 1992: 19; Kapp, 1991: 337).

Challenges regarding the socio-emotional competence of deaf children are directly linked to delay in language development. Greenberg and Kusche (in Calderon & Greenberg, 2003: 178) found that deaf children generally have poor vocabulary pertaining to the language associated with emotion, tend to act impulsively, and display reduced emotional control. Feuerstein (in Calderon & Greenberg, 2003: 178) argues that the incapacity of deaf children to express and label their feelings spontaneously with appropriate linguistic symbols may be an important contributory factor to major gaps in their socio-emotional development. Meadow-Orlans, Mertens and Sass-Leher (in Kushalnagar, Krull, Hannay, Metha, Caudle & Oghalai, 2007: 336) and Steinberg (in Traci & Koester, 2003: 198) state that without communication reciprocity, young deaf children do not learn to associate words with emotions, and without words, signs or gestures, deaf children are unable to express thoughts, inner experiences, or feelings, and this can lead to developmental delay or arrest.

Of all the things learnt, language is probably one of the most important, as it facilitates interacting more easily with others in a hearing world. It is an integral part of development, and since communication fosters socio-emotional development, any disability in this aspect is likely to have an adverse effect on social interaction. A deaf child, like a hearing child, begins life with the same potential for socio-emotional development. However, in the case of the former, his deafness may restrict his experiences, contact with others and hamper growth toward socio-emotional maturity (Scheetz, 2001: 7; Levitz, 1991: 65). Mundy and Willoughby (in Kushalnagar *et al.*, 2007: 336) as well as Traci and Koester (2003: 196), found that deaf infants who did not have increased non-verbal communication such as visual cues and eye contact with their parents or caregivers, demonstrated poor socio-emotional development.

Kapp (1991: 335-336) concurs that the child's socio-emotional development is directly linked to the acquisition and use of language, and argues that in the case of a deaf child, when the lack of language inhibits the actualisation of cognitive potential, an image of poor emotional development emerges, since language is the core around which his emotions, feelings and desires are organised. References are frequently made to deaf children's poor emotional development as manifested in rebelliousness and temper tantrums, which may be a way of coping with frustration. Temper tantrums are not unique to deaf children, but deafness can aggravate the situation and tantrums may occur more frequently. Furthermore, as a result of the frustration imposed by deafness, some deaf children tend to get angry quickly and are prone to frequent and aggressive outbursts. Vaccari and Marschark (in Kushalnagar *et al.*, 2007: 336) state that there is evidence that deaf children with delayed language development experience many behavioural problems that are more severe and frequent than are observed in deaf children from language-rich homes where there is access to fluent communication.

Hintermair (2006: 496) states that most research studies on the development of deaf children indicate a significantly higher rate of socio-emotional behaviour problems among this group of children. Greenberg and Kusche (in Hintermair, 2006: 496) point out the root of the matter, namely, that many deaf children's developmental experiences are "less than optimal", and include "early and continued communicative deprivation", family difficulties, educational experiences that are "less than adequate", continued prejudice and social stigma.

Other important issues facing deaf children in developing socio-emotional competence include incidental learning, parenting styles, linguistic overprotection, and culture and identity (Calderon & Greenberg, 2003: 178-179). With regard to incidental learning, this is the process whereby learning takes place through passive exposure to events or spoken conversations witnessed or overheard. Since deaf children are not able to overhear spoken conversations they miss out on important information and nuances for behaviour that are consciously or unconsciously transmitted and absorbed by hearing children, and this could lead to misunderstanding of social interactions (Ross *et al.*, 2004: 154; Calderon & Greenberg, 2003: 179; Traci & Koester, 2003: 198).



Results of cross-cultural studies conducted by Meadow and Dyssegaard (in Calderon & Greenberg, 2003: 178) indicate that by and large, deaf children display a general lack of initiative and motivation, which are important aspects of social maturity. These researchers hypothesised that such shortfalls may be attributed to hearing parents and teachers exercising too much control and not giving deaf children enough opportunities to act independently and to take responsibility.

Socio-emotional issues relating to deaf children are also associated with parental access to personal and social resources. Results of a study conducted by Hintermair (2006: 493) link high levels of parental stress with frequent socio-emotional problems in deaf children, while parents who had access to personal and social resources experienced lower stress levels. High levels of parental stress are indicative of tensions in family relations, and studies in the field of early childhood development clearly show that it is mainly parental behaviour informed by higher levels of stress that significantly influences children's development and not vice-versa.

Calderon and Greenberg (2003: 180) state that since more than 90% of deaf children are born to hearing parents, most deaf children are likely to become part of a minority deaf culture to which no other members of their family belong, and deaf children will need to learn to live in both the hearing and deaf worlds in order to be successful members of society. Both the family and the community (including day-care and educational settings, religious organisations, neighbourhoods, and other professional and community services) contribute significantly to the promotion of healthy socio-emotional development of deaf children.

Regarding socio-emotional development of deaf children, Scheetz (2001: 1) and Meadow (in Levitz, 1991: 61) hold the view that children with restricted language development experience limited opportunities for social interaction within and outside of the family. The primary reason for hampered social interaction is not so much the deafness itself, but rather, the lack of communication expertise between the deaf and hearing. This can be very frustrating for the deaf child (as well as the parent), as it results in social isolation of the deaf child from the hearing as he finds solace in the company of other deaf children.

When parents and educators place unrealistic expectations on the deaf child, in the hope that he can become fully integrated into the hearing world, it can increase his feeling of inadequacy contributing to social isolation. The “devaluative attitudes of society towards deaf people” is likely to affect their social development (Ross *et al.*, 2004: 153-154). The hearing world is, to a large extent, audio-dependent and this is a serious disadvantage for deaf people. This has given rise to the establishment of a Deaf community, consisting of deaf people who share a common culture and communicate fluently through sign language.

One of the outcomes of socio-emotional stability is better and more successful social interactions, and this involves strategies to manage emotional experiences. Initially the young deaf child relies on parental guidance but gradually becomes independent in this regard. According to Calkins (in Traci & Koester, 2003: 198), as communication and interaction with the care-giver become more complex, the child learns to exercise control over impulses, cope in stressful situations, and delay gratification.

#### **2.6.1.1.3 Personality development and self-concept**

The powerful impact of the self-concept on the personality development of the young child cannot be underestimated, and Wall (2003: 147-149) suggests that it is essential for developing a positive outlook, and progress towards his/her full potential. Charlton and David (in Wall, 2003: 14) state that the self-concept is formed through a process of socialisation and interaction with, and feedback from significant others *e.g.* parents, teachers, siblings, peers and extended family. Difficulties in social competence could hamper the formation of positive self-concept. A positive or negative self-concept can be created by a range of factors such as motivation, levels of confidence, security and love, positive learning experiences and positive feedback, social and emotional problems and stress. Children with special needs, including deaf children, may find it more difficult to achieve success and may experience lack of self-confidence and a poor self-concept. The self-concept is made up of three interrelated areas, namely self-image (how we see ourselves) the ideal self (the way we would like to see ourselves) and self-esteem (how we feel about ourselves). Self-esteem is high when both self-

image and ideal self are positive, but when self-image and ideal self are polarised and differ considerably, then self-esteem is low.

Hugo (in Ross *et al.*, 2003: 154-155) describes the world of deaf children as insecure and confusing since they find it difficult to make their needs known. They may react with anger, frustration, anxiety or suspicion as they may not always understand others' demands and expectations of them. These factors can impact on the development of the child's self-esteem. According to Meadow (in Ross *et al.*, 2003: 154) earlier studies indicated that deaf children experience more adjustment problems than hearing children, and tend to display personality traits such as egocentricity, rigidity, lack of inner control, impulsivity, and emotional immaturity.

Hardy and Cull (in Levitz, 1991: 70) believe that the deaf child's self-concept begins to develop at the age of two to three years. The particular meaning that a deaf child attaches to his experiences depends on his self-concept, which plays an important role in his development and self-actualisation. His deafness may create problems for the development of a positive self-concept and can lower his self-esteem and confidence. The deaf child's degree of social interaction and the development of his self-concept are therefore reciprocal, since the child's adjustment in society is related to his self-concept.

Deaf children, as a result of language and communication deficiencies, will possibly actualise their potential at a slower rate than will children with normal hearing. The normal stresses of growing up are even more pronounced in deaf children. The new challenges they face at each developmental stage are even greater. In particular, the resultant delay in communication development imposed by deafness hampers mastery of expected levels of performance at an earlier stage. With delay in language development comes delay in reading, social interaction and problem solving, which in turn contributes to low self-esteem. Meadow-Orleans (in Schilling & DeJesus, 1993: 163) report that some data suggest that positive self-concepts of deaf children and adolescents may not be as high as those of their hearing peers.

Suren and Rizzo, (in Levitz, 1991: 70) state that from a psychological perspective, deafness has major implications for the holistic development of the child. An infant who suffers a hearing loss in the very early stages of language growth will have to face the consequences of serious difficulties resulting from acquired deafness. Deaf children, as a result of living in a hearing world and hampered in communication with others, often become introverts and have difficulty establishing a sense of self-worth and confidence in relating to others.

Goffman (in Levitz, 1991: 71) avers that if an individual has a disability that is associated with negative social connotations, such as deafness, the child may learn to regard himself in the same negative way that society regards his deafness. Negative perceptions of the deaf stem from hearing persons perceiving them as possessing a defect. This implies that if a deaf child believes that the hearing regard the deaf as being stupid he might regard himself as being stupid. Such negative perceptions affect the child's self-concept and hamper his progress towards social maturity.

However, Meadow (in Ross, 1998: 149) cautions against stereotyping deaf people since they are highly heterogeneous with regard to education, communication and experience. Lane (in Ross *et al.*, 2003: 154) argues that many of these assumptions that emerge from early studies are based on invalid and unreliable tests that were standardised for hearing people and were not administered through sign language. The low self-concept measured among deaf adolescents arose as a result of insufficient understanding of the test itself rather than from their feelings of low self-esteem.

The negative findings of studies on the socio-emotional, cognitive and personality issues associated with the deaf child are a typical example of the deficit model, which attributes behaviour traits and learning styles to the child's deafness. A more optimistic view is that it is not deafness per se but the indirect impact of deafness which affects emotional adjustment, social maturity, and learning strategies.

Researchers have found that not all deaf children develop adjustment problems, pointing out that several factors positively influence the child's development. These include the quality of the home environment, parental adjustment to the child's

deafness, family coping, the type of resources in the school and community available for deaf children, and the characteristics of the child as well as his interactions with others in each ecological setting (Calderon & Greenberg, 2003: 178; Stinson & Foster, 2000: 194). Moores (in Kapp, 1991: 336) states that considering all the obstacles that deaf children face, the fact remains that as a group they adjust well and contribute to society in a healthy, productive, stable manner.

In concluding this section on the development of the deaf child, suffice to say that a deaf child, whose language acquisition and use is severely hampered, would possibly find it difficult to actualise potentialities. The socio-emotional development of the deaf child is compromised because of restricted language usage and comprehension. Moreover, cognitive development tends to be slower in deaf children since language and cognition are interdependent, and lack of ability to use language effectively is likely to have adverse effects on the child's personality development and self-image. However, Marschark (in Traci & Koester, 2003: 191) maintains that although there are qualitative differences in various aspects of the development of deaf children due to their varying experiences of the world, it is important that these differences not be viewed as deficiencies. Furthermore, an integrated approach to development that emphasises multiple skills including communication and language, socio-emotional, motor and adaptive or functional skills is considered best practice in early childhood (Calderon & Greenberg, 2003: 69).

#### **2.6.1.2 The deaf child and the family**

The diagnosis of deafness in the young child has a major influence on the hearing family's adjustment to the new situation. Even though it is usually the mother who takes the greatest share of responsibility for the child's upbringing, the effects of changed family circumstances are felt by each family member. Siblings tend to feel marginalised, receiving relatively less attention than they did before the deaf sibling's diagnosis. Parents and children in this situation, have to work together with patience and understanding (Marschark, 1997: 15-16).

It is clear that the birth of a deaf child results in a series of adjustments in the lives of parents and the family as a whole. Since each family is unique, different factors will shape the family's accommodation of a deaf child. The family is regarded as a system, and for the system to work effectively, various members have to work harmoniously in order to achieve a common goal. Cunningham and Davis (in Levitz, 1991: 79) maintain that adjustments must take place if changes occur in the structure and functioning of the family system.

The family can only begin to appreciate the deaf child and start to rearrange their lives constructively to accommodate the child's needs once they have truly accepted the child's hearing loss. The hearing family's adjustment to the arrival of a deaf child will have a variety of practical, emotional and financial implications, which will affect each member of the immediate and extended family. After a period of adjustment, most families with a deaf child achieve a level of normal daily functioning, although at the outset, this might seem impossible. Apart from the need to learn and use sign-language consistently, life goes on naturally with relatively little disruption to normal family routines (Marschark, 1997: 79). Parents, members of the family, and caregivers are the most important people in the life of the deaf child, and must give priority to developing ways of communicating effectively with the deaf child (Bibby & Foster, 2004: 14).

The attitudes of parents towards their child being deaf ultimately shape their ability to cope with the responsibilities of raising a deaf child. The deaf child's socio-emotional development and progress at school depends, to a large extent, on the parents' attitude. The home is the place where any child should feel safe, loved and understood, and it should provide emotional support and resources that deaf children need in order to cope in a hearing world. Deaf children need the same kind of parenting and experiences as do their hearing peers if they are to grow up to be emotionally stable. To achieve this, the quantity and quality of parental interaction with their young deaf child needs to be adjusted (Marschark, 1997: 79).

Sound family relationships are important for the well-being, not only of the deaf child, but of all members of the family. Parents play an important role in maintaining family

unity and stability, and in ensuring that the family remains functional. Satir (in Luterman, 1991: 144) believes that the parents are the pivot around which all other relationships are formed as they are the architects of the family.

Successful parenting is influenced by the quality of the marital relationship. The closer the relationship, the better the parents are able to achieve the goal of successful parenting. When marital bonds are not strong, it could result in the child becoming “triangulated” into the marriage. According to Mendelsohn and Rozek (in Luterman, 1991: 144) the unique characteristics of deafness and the caretaking process lend themselves to the child being easily drawn into family problems and conflict situations in the home. The child’s deafness puts him into focus more easily, because of the need for more attention and care.

#### **2.6.1.3 The deaf child and the school**

The importance of collaboration between families, schools and communities as partners with a mutual interest in the learning, welfare and development of children cannot be sufficiently emphasised. Several researchers, namely, Christenson and Sheridan, Hornby, Seligman, Simon and Epstein, and Wall (in Swart & Phasha, 2005: 213), concur that the active involvement of families and communities is, without doubt, of utmost importance for the effective education and development of children.

The idea of the school, families, and communities being equal partners with the common goal of enhancing the learning and development of every child is similar to the idea of an entire village taking responsibility for raising a child. It also reflects the broad principles of inclusive education, and provides challenges to all stakeholders involved. The international research literature on partnerships between schools, families and communities shows evidence of positive spin-offs of such collaboration for learners’ education and development. Such links promote positive attitudes and self-concepts, good behaviour, better attendance and scholastic achievement (Swart & Phasha, 2005: 213).

According to Storbeck (2005: 353) the decision with regard to communication and related method of education is the biggest decision that parents of deaf children have to make. The oral approach and the sign language approach (also known as the manual approach) are two approaches to communication and education in South Africa. An informed decision here can have particular influences on the lives of deaf children and their families.

The oral approach includes auditory training (to tap into residual hearing) as well as speech and lip reading. This approach prohibits gesturing or signing, as the primary goal is to make deaf children communicate orally with the aid of assistive devices, so that they could participate in a hearing world. Deaf children who are orally educated are said to develop better spoken language than those who are educated through sign language. However, researchers agree that research findings appear to be inconsistent in this regard (Storbeck, 2005: 354).

The sign language approach, which the majority of the Deaf community support, is argued to be the natural language of the Deaf as it is barrier-free. Sign language is regarded as the first language of the deaf learner, while spoken language is the second language (DeafSA, 2006). The Department of Education (2002: 139), in its draft guidelines for the implementation of inclusive education, supports sign language as the approach to communication and education of deaf learners since it acknowledges that language barriers can be a hindrance to their progress.

The emergence of Total Communication was an attempt to combine the advantages of both the oral and manual approaches. As an educational approach it draws primarily from whatever means are available to reach the deaf learner. In practice, this approach has come to mean Simultaneous Communication, or as Signed Supported English (Storbeck, 2005: 355). However, deaf people experience difficulties with Total Communication as its grammatical structure is similar to the oral method of communication, unlike the manual approach. The move away from educating deaf people solely through the oral mode, and the acknowledgement that sign language is as important as spoken language can be regarded as “a breakthrough in Deaf education” (Storbeck, 2005: 356).



According to Muthukrishna (2001: 155), in recent years, internationally, the nature of education for the Deaf has undergone significant changes as a result of research findings, advances in technology and policy changes. For instance, in South Africa there is a strong emphasis on human rights in educational policy and legislation as evidenced in the Constitution of the Republic of South Africa of 1996. The Constitution also provides for the right to receive education in an official language of choice. This right is set out in Section 29 (2) of the Constitution which states:

Everyone has the right to receive education in the official language or language of their choice in public educational institutions where that education is reasonably practicable.

The basis for the recognition of Sign Language as the first language of choice for Deaf learners is laid out in the Constitution, which recommends that the Pan South African Language Board “must promote and create conditions for the development and use of Sign Language....” (Muthukrishna, 2001: 156).

There are two educational options for deaf learners, namely, education in a mainstream setting within an inclusive environment, or education in a specialised school for the deaf, where sign language is the chief mode of communication and education. In either case, parents have to understand fully the educational options available in order to make informed decisions for the education of their deaf children.

In South Africa the Department of Education (2001; 1997) conceptualises inclusive education as quality education for all. The inclusive education movement clearly points out that diversity includes disability, and highlights the rights of learners who fall into this category (Green, 2001: 3). Knight (in Muthukrishna, 2001: 161) explains why the Deaf are not in favour of inclusion of deaf learners into mainstream schools. The Deaf see themselves as a linguistic minority with a unique cultural identity that must be nurtured. As such, they hold the view that schools for the Deaf socialise learners into the Deaf culture and sign language. However, Miles (in Muthukrishna, 2001: 161) argues that in developing countries it is not possible to provide special schools for all deaf learners because of the cost factor. It then becomes necessary to

develop the capacity of mainstream schools to cater for the needs of deaf learners, especially those who have no access to any form of specialised education.

The implications of inclusion of deaf learners into mainstream schools should be looked at as a whole, and should take into consideration inclusion at family, school, community and policy level, since education does not take place in a vacuum (Muthukrishna, 2001: 161). The Report of the National Commission on Special Needs in Education and Training and the National Committee on Education Support Services (DoE, 1997) recommends that special educational needs be understood from a systemic perspective, since learning difficulties are not to be perceived as residing only within the learners, but also within the system itself. Bronfenbrenner's ecological systems theory helps one to understand the interaction between the individual and the complex influences apparent in education, schools and classrooms (Green, 2001: 7).

The importance of educators playing a supporting role and relating to deaf learners and their parents in a way that makes them feel included and valued, cannot be sufficiently emphasized. Educators play a vital role in facilitating learning and development through the provision of a stimulating and safe environment that is conducive to learning. Through collaboration with the deaf child's parents a strong partnership can be forged between the home and the school, and this will augur well for the deaf child's development, especially his scholastic progress.

#### **2.6.1.4 The deaf child and the community**

There is growing evidence in the international literature to support the view that the active participation of families and communities in the education of children is essential for an effective inclusive learning community (Swart & Phasha, 2005: 213). The community at large could render much support to families and schools through the provision of services to all children and families, thereby increasing educational participation and addressing the diverse needs of all learners.

In South Africa limited resources and expertise for managing barriers to learning are reasons why educational institutions need to rely on the strengths of existing support

systems to sustain active learning. Community participation would involve all the human resources such as educators, parents, school counsellors, psychologists, health workers, therapists, community organisations, school governing bodies, social workers and other members of the community. “There must be creative and optimal use of existing resources and expertise, and the mobilization of community resources” (Muthukrishna, 2001: 47).

Swart and Phasha (2005: 227) use the term “capable workforce” to refer to learners who are well equipped with knowledge and skills so that they can take their place in society as competent and productive members. The building of partnerships between schools and business will make it possible for schools to know what is relevant for the job market and prepare deaf learners accordingly. Schools and communities can work collaboratively for the development of healthy communities, where members live harmoniously with one another regardless of differences. Kamwangamalu (in Swart & Phasha, 2005: 227) believes that in South Africa there is great potential in this regard since members of the community embrace the philosophy of *ubuntu*, a principle which emphasises values such as respect for human beings, human dignity, sharing, caring, humility, obedience, hospitality and interdependence.

In concluding this section on the development of the deaf child, suffice to say that the impact of deafness on an individual cannot be measured in isolation but within the context of complex social variables. This is in keeping with Bronfenbrenner’s ecological systems theory which draws attention to the influence of a complex set of interacting variables on the child’s development (Swart & Phasha, 2005: 215; Swart & Pettipher, 2005: 10).

## **2.7 PARENTING AND THE DEAF CHILD**

According to Bornstein (1995: xiv) “to state that parenting is complex is to understate the obvious”, and this is especially true in the search for answers to the question regarding the experiences of hearing parents raising deaf children and how they manage their parenting role. Zigler (1995: ix) describes parenting as “the most challenging and complex of all the tasks of adulthood”, and also believes that there is

arguably “no undertaking that is more important to the life of the human community”. However, that community hardly offers sufficient support, guidance or preparation for the responsibilities of parenthood. Adding to the complexity are the “unprecedented levels of social and economic stress” that parents of today face (Ziegler, 1995: ix).

The concept of parenthood is synonymous with the acceptance of responsibility for the upbringing of the child. In some contexts, the concept “parent” may refer to birth parents, but it may also refer to legal guardians, or caregivers, for example, grandparents, older siblings, and other close family or community members who take responsibility for the education of the child (DoE, 1997: vii; Turnbull & Turnbull, 1997: 11). Parenthood includes not only the concepts of motherhood and fatherhood, but also “single parenthood, grandparenthood, adolescent parenthood, non-parental caregiving, sibling caregivers, parenting adopted children, parenting in divorced and remarried families, and lesbian and gay parenthood” (Bornstein, 1995: xiv).

Parents have multifarious roles and responsibilities regarding the education and development of their children. Packard (in Le Roux, 1992: 110-112) and Pringle (1987: 159) describe the skills parents need in nurturing their children, some of which include the following:

- Parents must demonstrate an understanding of the task of rearing a child with loving support and acceptance, and through the establishment of a warm, close relationship the child experiences a feeling of trust, security and self-esteem
- Responsible parents constantly communicate with the child to stimulate language acquisition, intellectual development and enrich the child’s educational potential
- Parents need to acknowledge the child’s positive qualities, be attentive and respect him so that he can develop a positive self-image - they need to encourage the child to achieve his goals without making unrealistically high demands on him

- Parents should provide the child with opportunities for learning and self-discovery through varied and enriching experiences
- Responsible parents promote family unity by forging strong family ties through family meetings, family conversations *e.g.* during meal times, and by becoming involved in their child's day-to-day activities
- Parents need to instill a set of socially accepted values in their child by guiding him to differentiate between right and wrong, good and bad
- Competent parents teach their child self-discipline by laying down clear rules and by explaining to him about socially unacceptable behaviour
- Efficient parents teach their children about responsibility by entrusting them with responsibilities and tasks that they are capable of handling
- Responsible parents develop respect and honesty in their children by treating them with respect and being honest in their dealings with them
- Competent parents avoid ridiculing and labeling their child through the use of vague, descriptive terms that may cause them emotional hurt
- Successful parenting involves not only spending time with their children but also reflecting upon their own behaviour as parents.

In guiding a child towards becoming a responsible person, parents have to consider his potential as well as his limitations. The limitations of a child present the parents with a greater responsibility for his becoming. They have to consider the extent to which this child will need specific attention without neglecting other children in the family. Freude (1991: 13) emphasises the need for all parents to be fully aware that their child needs to be guided and protected in a responsible manner. They need to place high priority on the child's total well-being. In the case of a family with a disabled child, parenthood will be an even more complex and demanding task.

Although the possibility exists that a child may be born with a disability, parents usually have high aspirations for their child. They dream of their child being

successful at school and in life in general. However, upon learning of their child's deafness, their dreams and aspirations are shattered. They realise that their attitudes and lifestyles would have to undergo some drastic changes to cope with the reality of rearing a deaf child. Tulani and Power (1993: 946) maintain that the arrival of a disabled child calls for greater adjustments in the everyday family routine and budget than a child without any disability. The problems associated with a disabled child will cause parents to keep more irregular hours and adopt a different orientation as compared with having a child with no disability.

Parents are the most influential people in the child's development towards adulthood, as they shape the child's cognitive, social, affective, moral, religious, aesthetic and physical development (Zigler, 1995: ix; Du Toit & Kruger, 1991: 12). For a child with a disability, personalised interaction with members of the family offers a safe haven from which he can face the outside world.

Gouws and Kruger (1994: 148) view parenting as a continuous series of interactions between parents and child, in order to help him in his growth to adulthood. Parents consciously mould and equip the child to accept responsibility and lead a meaningful life in accordance with norms and values in society. One of the major challenges of parenthood is to provide for the needs of the child. These include the child's need for love, acceptance, belonging, confidence, discipline, security, praise and recognition, responsibility and new experiences. These challenges are even greater for hearing parents when their child is deaf.

Child rearing therefore includes, *inter alia*, accepting the child; winning his trust and confidence; providing a safe and secure environment where the child can achieve his full potential, showing faith in the child, showing support and understanding of the child's needs, exercising authority and discipline, setting norms and values for the child, and transferring culture (Wall, 2003: 24). These responsibilities become intensified in the case of hearing parents raising a child who is deaf. Wall (2003: 27) maintains that the experiences of families raising children with special needs vary, and that these experiences can result in positive and/or negative spin-offs for individual members of the family.

Hinde (1995: xii) emphasises three issues with regard to parenting. Firstly, “parenting practices must fit the child”. Children at different ages with different needs require different types of parenting and treatment. Parenting issues relating to infants differ from those relating to middle or later childhood or adolescence, while parenting of healthy children differs from that of children with disabilities. Secondly, it is important for the parent-child relationship to be “co-constructed by parent and child, rather than imposed by the parent, as “they are in it together, for better or worse”. Thirdly, there are various ways in which parents can be assisted to provide a secure foundation so that their children can lead full and contented lives. Moreover, the attitudes and beliefs of parents are important, and most parents are eager to learn.

In the case of a family with a deaf child, parents have to provide adequately for the child’s every need, especially the need to develop effective communication skills, so as to optimise his potential for holistic development. This entails providing varied opportunities for the child’s physical, social, cognitive, affective, moral, religious and aesthetic development, in order to minimise the effects of deafness. To ensure optimal development, parents have to meet the child’s needs for love, acceptance, security, responsibility, confidence, recognition, self-worth, guidance and discipline. The intensity of these needs will be greater on the part of the deaf child, owing to the hearing loss, and as such, parenthood in modern society is challenging financially, socially, educationally and morally. Parents of today are confronted with “unprecedented levels of social and economic stress” (Zigler, 1995: ix).

Zigler (1995: ix) and Minuchin (in Luteran, 1991: 143) outline some of the reasons for the increased challenges parents of today face in rearing their children:

- Modern day society is characterised by diverse and conflicting values, which makes it more difficult to effectively guide children
- Crime, violence, poverty, homelessness, and substance abuse create problems for parents and make it difficult to provide for themselves and their families, to protect their children from danger and plan for their future
- Peer pressure, television, movies and books exert a powerful influence, often working at cross purposes with the values parents uphold

- Parents are expected to acquire attitudes and techniques regarding the raising of their children that are quite different from the ones they learnt from their parents
- Differing viewpoints regarding childrearing among experts in the field often confound parents
- The number of economically disadvantaged and single parents is on the increase and in many cases this is combined with extreme youth as there is an increase in the number of teenage mothers
- Among two-parent families where both parents are in full-time employment, a different type of stress is created through having too little time to spend with children.

Attwood and Thomson (in Wall, 2003: 27) identify five main features that set apart parents of children with special needs: they are long-term players; tend to become isolated; are more concerned for their own children than others; know that the welfare of their children is much more dependent on the continued effectiveness of the family, and their emotional involvement is heightened.

In general all parents shoulder a huge responsibility for the upbringing of their children in order to maximise their potential and equip them to become well-balanced, responsible individuals who can contribute to society in a meaningful way. This responsibility is magnified in the case of hearing parents of deaf children because of the limitations imposed upon them as a result of hearing loss.

### **2.7.1 Parental responses to the diagnosis of the child's deafness**

For most hearing parents the discovery that their child is deaf is intensely stressful and presents challenges and demands to which the entire family must adapt. Parental responsibilities take a new dimension for which many are not adequately prepared. The impact of having a deaf child has a ripple effect on the parents' life-world, their relationships with self, others and God. Hearing families with deaf children are confronted with several challenges that often manifest themselves before deafness is diagnosed (Mertens, Sass-Lehrer, & Scott-Olson, 2000: 133).



Parents' reactions to the diagnosis of their child's deafness differ. Many variables influence the way parents respond to the diagnosis of deafness (Scheetz, 2001: 60; Schirmer, 2001: 26-27; Luterman, 1991: 146-147). Firstly, it may well be the case that during the lengthy road to medical diagnosis, parents may have had time to consider the possibility of deafness and learn about the implications. Secondly, parents may have varying degrees of knowledge and understanding of deafness and experience with deaf individuals. Kampfe (in Kricos, 2000: 282) states that the degree to which the emotional reactions of parents will vary from family to family depends on a range of complex factors which may affect the way the family system functions. Parents' responses differ as a result of their perceptions being so different, and social status **indicators** such as ethnic background, age, and gender of parents might influence the extent to which they perceive an event as being undesirable, disruptive or stressful.

The **degree of deafness** is yet another factor determining parents' reactions. Deafness may range in severity from partial to profound, and may give rise to various degrees of adjustment. Suren and Rizzo (in Levitz, 1991: 85) maintain that it is not easy to predict whether parents will be able to adjust more readily to mild or profound deafness, and that there is no direct correlation between the degree of parents' frustration and disappointment, and the degree of severity of their child's disability. Some parents with high expectations for their child may find their dreams shattered by even mild, less conspicuous forms of disability. These parents find difficulty in accepting or admitting that their child is disabled in any way because of fear of stigmatisation. They pretend that there is no problem or they try to hide it, especially in the case of mild deafness. However, such pretence could create more problems for the parent and child, and hamper the child's progress (Kapp, 1991: 347).

Kampfe (in Schirmer, 2001: 27) identified other variables that determine parents' reactions to their children's deafness. These include the **personal characteristics of parents** and their ability to cope, career goals, sensitivity to the opinions of others, education, marital satisfaction, and cultural views towards disability. Some of the personal characteristics that could influence parents' reactions to the birth of a child with a disability include, *inter alia*, the parents' health, parents with disabilities and different coping styles. Parents who have poor health may not be in a position to

manage the added responsibility of raising a child with a disability, and their stress levels may be increased. Parents with disabilities may rely on older children or other children without disabilities to care for the deaf child.

The **hearing status of parents** can influence their response to the diagnosis of deafness. While hearing parents may experience overwhelmingly negative emotions, deaf parents generally respond in a more positive manner (Meadow-Orlans, Mertens & Sass-Lehrer, 2003: 79; Spencer *et al.*, 2000: 52; Koester, Papoušek & Smith-Grey, 2000: 57; Marschark, 1997: 76; Levitz, 1991: 87). Meadow-Orlans *et al.* (2003: 11) found that the impact of the child's deafness was less significant on deaf mothers than on hearing mothers. Deaf parents may be relieved that their child, being deaf, would be able to adjust to the Deaf sub-culture more easily (Scheetz, 2001: 62; Marschark, 1997: 76). According to Meadow-Orleans *et al.* (2003: 79) and Davis and Silverman (Levitz, 1991: 81), several studies show that deaf children of deaf parents tend to be more successful at school and later as adults compared to deaf children of hearing parents. This may be due to the fact that hearing parents, as a result of their lack of experience with deafness, are unable to provide satisfactory role models for their deaf children. In addition, deaf parents of deaf children are able to establish more effective means of communication with their children, and this could contribute to their intellectual development.

The **socio-economic status** of the family also contributes to the parents' attitude to their child's deafness. Often, the assumption is made that the higher the socio-economic status, the greater are the resources available to cope with the child's disability. However, Turnbull and Turnbull (in Levitz, 1991: 84) point out that a higher socio-economic status does not necessarily result in more efficient ways of coping with a child with a disability because of the high priority given to achievement. In such a family a disability may be seen as a disappointment and hindrance. In families with a lower socio-economic status, other values such as family togetherness and happiness may be considered more important than achievement. In poverty-stricken families, harsh survival problems may overshadow the implications of having a child with a disability. Socio-economic status is linked to the types of support that parents need, and related to this factor is age, marital status and level of education of

parents. All of these factors may impact on parents' reaction to the diagnosis of deafness and influence their ability to seek support services and benefit from them (Meadow-Orlans & Sass-Lehrer, 1995: 320). Other variables identified by Kampfe (in Schirmer, 2001: 27) are the type, degree and cause of deafness, the resources available to parents for raising a deaf child, and the support they receive from their family, other families with a deaf child, friends, members of the community, and professionals.

When parents are expecting a child they seldom think of the real-life implications of having a deaf child, and usually they have little information to assist them to gain a better understanding of deafness. Some parents, on learning of the diagnosis of their child's deafness, may experience strong negative emotions which they struggle to come to terms with, but many do not respond in this manner. However, most hearing parents are devastated at the birth of a deaf child, as their dream of the 'perfect' child is shattered (Ross *et al.*, 2004: 156; Schirmer, 2001: 27; Krause, 1993: 207). In some families, deafness is regarded as a crisis that can be overcome, while for other families it is seen as a great tragedy. Yet, in other families deafness is seen not as a problem in itself, but as an additional component in their struggle for survival.

According to Gargiulo (in Levitz, 1991: 89) parental responses to the birth of a child with a disability may be analysed according to three phases, namely, primary, secondary and tertiary. The primary stage constitutes the initial reactions of shock, denial, mourning, grief and depression. The secondary phase involves feelings of guilt and self-blame, anger, fear, frustration, embarrassment, confusion and shame. The tertiary stage entails bargaining, adaptation, reorganisation, acceptance and adjustment.

Many researchers agree that the following are some of the emotional responses commonly experienced by parents on discovering that their child is deaf: shock, grief, denial, projection, anger, guilt, fear and depression, despair, frustration, bargaining, and finally acceptance (Ross *et al.*, 2004: 156; Scheetz, 2001: 60-61; Schirmer, 2001: 27; Kricos, 2000: 279; Marschark, 1997: 78-79; Gascoigne, 1995: 13-17; Dysart, 1993: 31-33; Luterman, 1991: 146-147; Vernon & Andrews, 1990: 125-128). Hearing parents of deaf children go through "stages of grieving" similar to the stages of

grieving experience by dying patients, described by Kübler-Ross (in Ross & Deverell, 2004: 36; Ross *et al.*, 2004: 156; Kricos, 2000: 279). These “stages of grieving”, which include denial, anger, bargaining, depression and acceptance, are important for the bereaved to work through in order to help them come to terms with the bad news.

**Shock** is almost always the first response that parents experience on learning that their child has been diagnosed as being deaf. They may initially suspect that something is wrong but when their suspicions are medically confirmed, the reality can be traumatic (Ross *et al.*, 2004: 36; Wall, 2003: 31; Scheetz, 2001: 60; Schirmer, 2001: 27; Gascoigne, 1995: 17). On the other hand, the discovery that their child is deaf may come as a relief to some parents, as they realise that it could have been something worse (Marschark, 1997: 78).

**Grief** is a natural reaction when there is pain, disappointment or loss. Grieving is not an end result but rather, an on-going process. It continues throughout the life of a person whose dreams are shattered or whose aspirations for the future are not realised. In the case of parents whose children are diagnosed as deaf, their grieving usually results from the loss of a dream of a ‘perfect’ child and a ‘normal’ family life (Meadow-Orlans *et al.*, 2003: 47; Scheetz, 2001: 60; Marschark, 1997: 78; Gascoigne, 1995: 16). Grieving and mourning often result in depression. Meadow-Orlans *et al.* (2003: 46) maintain that it is understandable for families to grieve when they learn that the child has a disability with far-reaching consequences.

**Denial** can serve the purpose of a defence mechanism or shock absorber initially, as it allows parents time to stall in order to absorb the shock of the diagnosis of deafness and its implications. Denial is used to “buy time needed” to find inner strength, information and support needed to cope with the situation (Ross *et al.*, 2004: 37). Denial may be regarded as a short-term defence mechanism that is usually soon followed by a certain measure of acceptance. Denial “may serve as an emotional buffer” which allows the grieving individual time to come to grips with the loss and draw on inner strength to come to terms with it (Kricos, 2000: 279). Parents may go through a period of disbelief and may feel that the diagnosis could have been incorrect and that the mistake would be found and rectified. Parents may manifest signs of

denial in various ways. Some may accept the diagnosis but deny the implications of deafness. Others may deny that the ramifications of the diagnosis have any effect on their feelings. Denial is often used as a coping mechanism (Wall: 2003: 31; Scheetz, 2001: 60; Mertens *et al.*, 2000: 140; Marschark, 1997: 78; Gascoigne, 1995: 14; Dysart, 1993: 31; Kapp, 1991: 347).

Kricos (2000: 279) states that it is relatively easy to deny deafness as it is invisible. Moreover, parents may deny the original diagnosis and resort to “shopping” for a more acceptable professional opinion, by taking the child to other professionals and clinics. Denial indicates the unwillingness on the part of the parents to accept the child’s hearing loss. This is frequently the case where the degree of hearing loss is less serious. The parent tries to minimise its effect by disregarding problems that the child might be going through as a result of diminished hearing. The parent may expect the child to perform at the same rate as a child with no hearing loss. This could adversely affect the progress of the deaf child (Kapp, 1991: 347).

**Anger** is an emotion that is probably most destructive in the early stages of diagnosis of deafness. Many parents repress it, which could lead to depression. The loss of control and helplessness parents feel can lead to marital conflict as well as conflict in their interactions with others (Marschark, 1997: 78; Gascoigne, 1995: 16; Luterman, 1991: 146). When the stage of denial can no longer be maintained, feelings of anger, rage, resentment and envy set in (Kricos, 2000: 280). When parents feel that they have been dealt an injustice, they experience intense anger which is sometimes displaced. “They may question what they have done to merit the birth of a less than perfect child” (Scheetz, 2001: 60).

Anger originates from feelings of hurt and inadequacy when parents do not experience the satisfaction of observing the child’s attainment of developmental milestones, or if these are diminished. Anger is also generated from feelings of despair and confusion, bitterness and frustration that parents feel in a situation of helplessness as the realisation of the implications of deafness dawns upon the parents (Gascoigne, 1995: 16). An attitude of continual anger can cause bitterness and strain even in the strongest of relationships (Scheetz, 2001: 61; Marschark, 1997: 78; Dysart, 1993: 32).

**Guilt**, according to Ross *et al.* (2004: 38), is normal and necessary in the grieving process. It usually follows anger, when parents attempt to rationalise the consequence of having a deaf child. At some stage most mothers of deaf children feel responsible for the child's deafness (Meadow-Orlans *et al.*, 2003: 48; Scheetz, 2001: 60; Kricos, 2000: 280; Levine, 1992: 96). Mothers tend to blame themselves and harbour feelings of guilt over their own poor behaviour towards the child and other family members (Marschark, 1997: 78). According to Luterman, (1991: 146) guilt is "potentially destructive to a marriage if it is not recognised and dealt with effectively". Although both parents feel guilt, mothers seem to carry a heavier burden of this emotion (Gascoigne, 1995: 13).

Guilt is an uncomfortable feeling, and so parents may try to blame each other. Dysart (1993: 31) refers to this as projection, which is "the next safety valve after denial, and involves shifting blame on someone else". These accusations can give rise to mixed emotions of anger, guilt or hurt feelings. Parents often try to conceal their emotions, but from time to time these surface, and give rise to explosive situations that can create stress within the family.

Sometimes guilt triggers the search for a family history of deafness in an effort to pinpoint the cause (if unknown) of deafness in their child. In some cases, parents' feelings of guilt can cause them to be overprotective of their deaf child. Overprotection can work against the child becoming independent, as parents feel obliged to do almost everything for the child, thereby depriving him/her of the opportunity to maximise his/her potential. Ross *et al.* (2004: 156) state that parents who are aware of the cause of deafness tend to cope better with feelings of guilt than parents who are not. Parents may find themselves blaming not only themselves or each other for their child's deafness, but also God or fate.

Parents may try taking their child to faith healers and 'negotiating' with God for a miraculous restoration of hearing (Ross *et al.*, 2004: 37; Marschark, 1997: 78). Crowe, as well as Seligman (in Ross & Deverell, 2004: 37), refer to this as "bargaining". Some parents may believe that they are being punished for a sin committed previously, or that they are not good enough to deserve a child without a disability. They may

resort to bargaining with God, health professionals, clinicians or family, and vow to do whatever is requested of them in return for an amelioration of deafness. Prolonged periods of bargaining and parents' false hopes may be detrimental to the physical and emotional well-being of parents "who set unrealistic demands for themselves" (Kricos, 2000: 280).

**Fear and depression** usually set in once the feeling of anger subsides. Moses (in Ross & Deverell, 2004: 38) defines depression as "anger turned inwards towards oneself". Depression is often accompanied by confusion and embarrassment as parents realise how little they know and understand about deafness. The implications of having a deaf child can be frustrating when parents realise the limitations imposed by deafness. People suffering from depression often regard themselves as "impotent, incompetent, incapable, and of little value" (Ross & Deverell, 2004: 38). In some cases, depression can last for years, becoming virtually a life sentence of isolation. "Only after chronic depression is seen for what it is – self-imposed exile from the human race" – can it be overcome (Dysart, 1993: 33). Fear of embarrassment could set in when parents have to take their deaf child out in public. Fears for the future of the child emerge as parents begin to wonder about their child's prospects for employment and marriage. Questions arise as to whether deaf people can work, or marry and start a family, or have normal intellectual capacity to receive an education. Another fear that grips parents pertains to the question of what would happen to the child in the event of their demise (Vernon & Andrews, 1990: 130).

**Acceptance** comes once the depression has abated. Once parents are able to confront their initial suspicions about their child's deafness, they usually begin to resolve their initial negative emotions. While some family members go through the stages of grief as if the child is dead, others never get over the grieving. They remain angry or in denial, burdened with a sense of guilt, or blame someone else, and never reach the stage of acceptance (Ross & Deverell, 2004: 40; Scheetz, 2001: 62). It is only when they reach this acceptance stage that they can deal with the challenges that they can face in life.

The question arises as to how long it takes to arrive at the acceptance stage. The duration between initial diagnosis and the acceptance stage may differ amongst parents for various reasons. It is important to know that it is only when the acceptance stage is reached, that the problems of hearing loss can be handled effectively (Dysart, 1993: 33). Suffice to say, the sooner the parents reach the stage of acceptance of their child's deafness the better, so that preparation for their child's development and education can begin in earnest. Parents who embrace an attitude of wholesome acceptance are realistic about the consequences of their child's deafness. They realise what deafness entails and develop a positive mindset about coping with problems that may arise. "This is the ultimate goal all parents strive to obtain" (Scheetz, 2001: 63). However, parents' grief may resurface each time the child experiences a major milestone such as starting or leaving school, or entering adolescence (Ross & Deverell, 2004: 40).

In conclusion, Luterman (in Ross *et al.*, 2004: 156) states that much of the literature points to the need for parents to go through the "stages of grieving" and "mourn the loss of a normal child" so that they will be able to adapt to the child's disability. The rationale underpinning this is based on the belief that the bereaved will eventually stop grieving and accept the situation. However, Luterman (in Kricos, 2000: 282) cautioned that the "stages of grieving" concept has been oversimplified in many respects and overused in the counselling of those with communicative disorders. Mapp and Hudson (in Kricos, 2000: 282) suggest that there is a likelihood of parents experiencing high levels of stress upon initial diagnosis of deafness, but most parents are able, through various coping strategies, to reduce stress within a short time.

### **2.7.2 Parenting and the family**

The effect of the child's deafness is felt by various members of the hearing family, including not only the parents, but also the child's siblings and grandparents, whose reactions may vary depending on differing circumstances. Research shows that 90% of deaf children are born into hearing families (Storbeck, 2005: 354; Bibby & Foster, 2004: 14; Ross *et al.*, 2004: 155; Calderon & Greenberg, 2003: 180; Traci & Koester, 2003: 190; Marschark, 1997: 9). Many families are unprepared for the consequences of deafness and the adjustments that have to be made to accommodate the deaf child.



Ross *et al.* (2004: 155) and Marschark (1997: 15-16) draw attention to how the birth of a deaf child reshapes the hearing family and point out the need to keep in mind that the entire family is affected by the new situation. Ross *et al.* (2004: 155) maintain that “deafness reverberates throughout the family, with the deaf individual touching and shaping the lives of all family members”. The hearing family’s adjustment to the arrival of a deaf child will have a variety of practical, emotional, and financial ramifications. After a period of adjustment most families with a deaf child function quite adequately, although at the outset, this might seem impossible. Apart from the need to learn and use sign language consistently, life goes on naturally with relatively little disruption to normal family routines (Marschark, 1997: 79).

#### **2.7.2.1 Mother and the deaf child**

In general, mothers take greater responsibility for the upbringing of their children. It would seem that in the case of raising deaf children this responsibility is intensified. This section will focus on hearing mothers and their deaf children, and how their lives are affected as a result of their children’s deafness.

Meadow-Orlans and Sass-Lehrer (1995: 7) draw attention to the effect of the deaf child on the life of the hearing mother. The deaf child invariably becomes more dependent on the mother than on other members of the family which imposes additional responsibilities on her, as she is unable to cut herself off physically or emotionally from the care of the child through outside activities.

Research reveals that mothers of deaf children are more likely than fathers to learn sign language. Therefore, the mother assumes greater responsibility for the care of the deaf child in families that choose to sign (Meadow-Orlans & Sass-Lehrer, 1995: 318). Hadadian and Rose (in Kricos, 2000: 283) found that mothers have far more interaction and contact with deaf children than do fathers, and that hearing mothers play a more active role than fathers in sign language and communication. Research has revealed that mothers who receive practical and emotional support from family and friends are able to cope better with the demands of having a deaf child (Marschark, 1997: 16).

### **2.7.2.2 Father and the deaf child**

The importance of the father's role in the upbringing of the child cannot be sufficiently stressed, more so in the case of the deaf child. Since fathers generally are the main breadwinners, they may be less involved due to their work commitments. Their parental role may take the form of supporting the mother in caring for the deaf child, providing a stable home where the child is made to feel safe, and catering for the material needs of the child. Yet today it is not unusual to find that both parents work outside the home.

Fathers may react differently to the diagnosis of the child's deafness, depending on various factors. Cunningham and Davis (in Levitz, 1991) maintain that a child born with a disability causes greater shock to the self-esteem of fathers because of "socio-cultural values such as manhood, independence, competitiveness and achievement". An alternative explanation, according to these authors, is that mothers are given a greater degree of support from specialists and service providers dealing with handicapped children and are better equipped for child care because of experience. In this regard Herbert and Carpenter (in Wall, 2003: 29) draw attention to the marginalisation of the father, since professional help is focussed on the mother and child, effectively ignoring the father's needs.

Wall (2003: 27), in explaining why fathers may be being less involved, mentions that in most cases, identification, assessment and programmes for intervention of special needs take place during working hours and this may exclude many working men from attending or participating. Therefore, their understanding of discussions regarding the issue are "often second-hand and may lack clarity and/or depth". Once the child's deafness is diagnosed the father generally obtains most of the information from the mother, who plays the primary role, while the father's role diminishes gradually into a secondary one. This can evoke feelings of resentment and anger on the part of the mother who is compelled to take most of the responsibility in caring for the deaf child. The father who feels neglected may vent his anger and frustration on the deaf child or mother (Ross *et al.*, 2004: 160). The father's role is seen as a supportive one and hence he is expected "to be the strong one".

### **2.7.2.3 Siblings and the deaf child**

Siblings are also affected by a deaf child in the family and may respond differently to having a deaf brother or sister. Atkins (in Ross *et al.*, 2004: 160) maintains that from a family system perspective, one can better appreciate the complexity of sibling interactions, since “what happens to one or another of the brothers and sisters reverberates throughout the family”.

Farber (in Ross *et al.*, 2004: 160) found that a child with a disability, irrespective of the ordinal position in the family, was treated as the youngest. Siblings may also be expected to perform better at school, sport, or in their careers to make up for the child with a disability. Sisters of a child with a disability are generally expected to take on more family responsibilities than are brothers, since much of the mothers’ time is taken up in caring for the deaf child. Atkins (in Kricos, 2000: 283) draws attention to some of the reasons to be concerned about siblings of deaf children. These include:

- their parents, because of time demands in caring for the deaf child, being less involved with them
- the fatigue, pre-occupation, and worry of parents detracting from a satisfying relationship with hearing siblings
- the perception that the deaf child is not disciplined by the parents
- possible feelings of guilt and responsibility for their sibling’s deafness
- added responsibilities with regard to house-hold chores, and taking care of the deaf sibling.

Carpenter (in Wall, 2003: 35) identified seven major concerns of siblings of young children who have special needs, which concur with the views of Atkin’s (in Kricos, 2000: 284). These include:

- the need for age-appropriate information about the disability
- feelings of isolation from information given to other members of the family, as well as isolation from siblings from other families with similar problems
- more demands to help care for their sibling

- perceptions of guilt about causing the problem in some way, or not being there to help parents care for the sibling when they leave home
- feelings of resentment since the sibling with special needs receives a greater degree of parents' attention and time
- feelings of being pressurised to achieve highly to make up for the expected low level of achievement of their sibling with special needs
- anxiety about their own as well as their sibling's future.

On the other hand, Schwirian, according to Meadow (in Ross *et al.*, 2004: 160) found that in the case of older siblings of pre-school deaf children, there was little impact on their level of independence, privileges, social activities, or child care responsibilities. However, results of studies by Israelite (in Ross *et al.*, 2004: 160) suggest that some aspects of psychological functioning on the part of siblings may be affected as a result of having a deaf child in the family. Featherstone (in Ross *et al.*, 2004: 160) adds that hearing siblings may be embarrassed and experience feelings of social isolation, while others may feel worried about contracting the disability, or about their own future, and about becoming parents of a child with a disability.

Gregory, as well as Meadow (in Ross *et al.*, 2004: 160) found that the majority of mothers indicated that they were more lenient with their deaf children than with their hearing children, in terms of discipline. Siblings of deaf children were reported to experience more envy, than siblings of other children with other disabilities. They are frequently forgotten and tend to receive relatively less attention than they did before the deaf sibling's diagnosis. It is important for parents and children to maintain normal interactions within the home and for the entire family to work together with patience and understanding.

Research on siblings of children with disabilities other than deafness, shows that they may be positively or negatively affected by the child's disability (Kricos, 2000: 284). Tattersall and Young (2003: 109) point out that much previous literature portrayed a very negative picture of the impact that children with disabilities have on their siblings *e.g.* the extra demands foisted on them with regard to caring for the child, a burden

which they are not prepared for physically or emotionally, and which hinders their social activities outside the home.

However, recent literature paints a more positive image, *e.g.* the enrichment that children with disabilities bring to the lives of their siblings, making them more tolerant, social, and mature in their behaviour and attitude, as well as more understanding, in particular of people with disabilities (Tattersall & Young, 2003: 109; Wall, 2003: 35).

The way in which the parents manage a child with disabilities as well as the siblings will differ from family to family, depending on their unique contexts and circumstances. What is important is that siblings should not be made to feel neglected as a result of parents giving more attention to a deaf sibling.

#### **2.7.2.4 Grandparents and the deaf child**

The role of grandparents cannot be underestimated as a resource in the successful development of the deaf child, even though their reactions to the diagnosis of the grandchild's deafness may vary. Wall (2003: 33) emphasises the critical role played by grandparents in the life of children with disabilities. However, relationships may differ from one family to the next, and parents and grandparents do not always enjoy healthy, supportive relationships.

Like parents, grandparents feel grief, loss and disappointment when a grandchild is diagnosed with deafness, and they need to review their relationships with their deaf grandchild and the child's parents. Further, they need help in reassessing their own role, with a view to "remaining supportive and encouraging while not attempting to shield their children from reality" (Moorton, 2000: 364). A survey conducted by Moorton (2000: 364) showed that parents valued the support of grandparents, and the results can be seen as an indicator that early parental involvement and the inclusion of grandparents in the education of the deaf child "can yield significant benefits", as it can unite families "and provide a solid emotional base for the growth and development of the *whole* deaf child".

Kricos (2000: 285) states that grandparents may become anxious about their own child's ability to cope with the increased responsibilities. Vadasy *et al.* (in Kricos, 2000: 285) found that nearly half of the grandparents in their study continued to experience feelings of sadness long after the initial diagnosis. Meadow (in Ross *et al.*, 2004: 161) states that grandparents may interact with deaf children in a positive or negative manner. If the deaf child is the first grandchild they may experience disappointment and grief, as their attempts to realise their own unfulfilled dreams for their children through their grandchildren become thwarted when the child's deafness is diagnosed. On the other hand, grandparents can be the source of additional support in helping to care for and raise the deaf child. Wall (2003: 33) concurs with this view, adding that some grandparents today play a greater role in their grandchildren's upbringing, "spending the most time with them and supporting them through various key changes and stages" while parents go to work.

## **2.8 THE CHILD'S DEAFNESS AND THE EMOTIONAL WELL-BEING OF HEARING PARENTS**

In this section the concept of emotional well-being and its importance in the lives of hearing parents in successfully establishing interpersonal relationships so as to better manage the upbringing of their deaf children, will be reviewed. Included, will be a discussion of relationships with self, with the deaf child, spouse and others in the family, with educators and members of the community, as well as transcendental relationships.

### **2.8.1 Emotional well-being**

Well-being, according to Cowen (1991: 404) involves "having a sense of control over one's fate, a sense of purpose and belongingness and a basic satisfaction with oneself and one's existence". Six dimensions of psychological (emotional) well-being in adults have been suggested by Ryff and Singer (in Aspinwall & Staudinger, 2003: 277-279). These include:

- self-acceptance – the ability to know and accept one's strengths and weaknesses
- purpose in life – setting goals and objectives that add meaning and direction to life

- personal growth – the realisation of personal talents and potential overtime
- positive relations with others – having close valued relationships with significant others
- environmental mastery – being able to cope with every day life demands
- autonomy – having the courage to follow personal convictions.

These six dimensions of emotional well-being have relevance for hearing parents raising deaf children, and mastery in this regard could lead to better management of their parental role.

Emotional well-being is closely related to emotional intelligence (Goleman, 1998: 317-318) and emotional-social intelligence (Bar-On, 2005a: 2-4; 2003: 4). Daniel Goleman (1998: 317) describes emotional intelligence as the “capacity for recognizing our own feelings and those of others, for motivating ourselves, and for managing emotions well in ourselves and in our relationships”.

In the 1980s Bar-On pioneered a model of emotional intelligence and in 1990, Salovey and Mayor proposed a comprehensive theory of emotional intelligence, which they defined as the ability to monitor and regulate one’s own feelings and those of others, and to use feelings as a guide to thought and actions (Goleman, 1998: 317). Their model was adapted by Goleman (1998: 317-318) to include five basic social and emotional competencies. These include:

- Self-awareness: recognising our feelings and using these to guide our decisions; being self-confident and having a realistic evaluation of our own abilities
- Self-regulation: getting a grip on our emotions so as to facilitate our actions; delaying gratification to achieve goals; and getting over emotional distress
- Motivation: using our deepest feelings to guide us towards achieving our goals, to persevere in the face of adversity, and to strive for improvement
- Empathy: sensing how others are feeling, seeing things from their perspective, and establishing rapport with others

- Social skills: handling emotions in relationships effectively; gaining a good understanding of social situations and interacting with others in an efficient manner to settle disputes, negotiate, persuade and work as a team.

Within the context of this study, hearing parents raising deaf children would be in a better position to manage their parenting role if these competencies are developed. It requires an understanding of their own feelings associated with the diagnosis of deafness, *e.g.* shock, anger, and the ability to overcome these feelings. Amidst the trials and tribulations that confront them, they need to strive towards doing what is best for their deaf child's progress and development, while maintaining sound interpersonal relationships with others in the family, school and community at large.

Emotional intelligence was originally viewed by theorists Salovey and Mayer (1990: 189) as an interrelated component of social intelligence. Bar-On suggested that emotional-social intelligence is a combination of several intrapersonal and interpersonal skills and competencies which determine effective human behaviour (Bar-On, 2005a: 2). According to Bar-On (2005a: 4; 2005b: 47) emotional-social intelligence involves:

a cross-section of interrelated emotional and social competencies, skills and facilitators that determine how effectively we understand and express ourselves, understand others and relate with them, and cope with daily demands.

To be emotionally and socially intelligent means to “effectively manage personal, social and environmental change by realistically and flexibly coping with the immediate situation, solving problems and making decisions” (Bar-On, 2005a: 4).

Contextualising this concept in terms of this study involves hearing parents having to manage the change in their personal and social lives as a result of having a deaf child in the family, coping with the situation in a realistic and flexible manner, solving problems and making decisions that best suit their unique family circumstances and



social contexts, bearing in mind the goal of optimising the deaf child's potential for progress and development.

Freedman (2003: 69-70) states that emotional intelligence grows as we study ourselves and our relationships, and puts forward the following basic assumptions of emotional intelligence: without feeling there is no thinking and without thinking there is no feeling; the potential for self-knowledge increases with greater awareness of experiences; and the greater your degree of self-knowledge, the more likelihood there is of responding positively to yourself and others and making better decisions.

In effect, what this implies for hearing parents of deaf children is that they should understand themselves, their strengths and limitations, learn through their experiences so as to enjoy better intrapersonal and interpersonal relationships and make better decisions.

### **2.8.2 Relationship with the self**

Griessel and Oberholzer (1994: 14) describe a relationship as a particular mode in which there is a mutual link between the person, others, objects and ideas, self, and God. The emotional well-being and formation of relationships on the part of hearing parents raising deaf children will be discussed in terms of relationship with the self, the deaf child, significant others, and God.

The self can be considered as the foundation of all relationships (Hanna, 1991: 1). The parent's self is therefore based on self-concept and self-esteem which form the core of personality development. The development of self-concept is influenced by experience, involvement, and the attribution of meaning (Raath & Jacobs, 1993: 35). The self-concept directs a person's tendencies towards action. Therefore the parent's relationship with self will inevitably influence the way he/she performs. In order to function effectively all parents, and more especially the parents of a deaf child, need to have a good sense of self.

The self is the centre of an individual's world, the point of origin of all behaviour (Hamachek, 1992: 4). The self-concept can be differentiated according to the perceived self (the way individuals see themselves), the real self (the way the person really is), and the ideal self (the way the person would like to be). According to Raath and Jacobs (1993: 28) the realistic self-concept is actualised when a person accepts both the positive and negative aspects of life. The hearing parent can develop a realistic self-concept by acknowledging the challenges and rewards of raising a deaf child. A realistic self-concept leads to self acceptance, mental health, and the accomplishment of realistic goals (Rice, 1992: 246).

Therefore a parent with a positive and realistic self-concept will be better able to come to terms with having a deaf child. This will augur well for the emotional well-being of the parent and help to set realistic goals for the child's development. Such a parent will then be in a better position to assist the child to achieve his maximum potential. Vrey (1993: 167) regards the self-concept as that which comprises the holistic evaluation of all components of an individual's identity. Four characteristics of an adequate personality are a positive self-image, willingness to accept self and others, ability to identify in a positive way with others, and being well-informed (Raath & Jacobs, 1993: 73). The possession of these attributes is likely to contribute to the emotional well-being of hearing parents raising deaf children.

### **2.8.3 Relationship with others**

It is clear that the birth of a deaf child results in a series of adjustments in the lives of parents and the family as a whole. Since each family is unique, different factors will influence the impact of the child's deafness on parents' interpersonal relationships. The family is regarded as a system, and for the system to work effectively various members have to work harmoniously in order to achieve a common goal. Sound family relationships are important for the emotional well-being of its members. Parents play a critical role in maintaining family unity and stability, and ensuring that the family remains functional. Satir (in Luterman, 1991: 144) believes that the parents are the "axis around which all other relationships are formed. The mates are the architects

of the family”. Parents play a pivotal role in influencing the way other family relationships are formed.

The most significant others in the life of a parent are the spouse/partner, as well as the deaf child and other children. Others who could play an important role in the life of hearing parents of deaf children could be the child’s grandparents and educators, extended family members, friends and neighbours and other members of society such as parents’ employers and professionals with whom parents may interact, in the process of raising their deaf children. Hearing parents of deaf children might find that relationships with others are bound to be affected as a result of changed circumstances in the home. The impact of the deaf child on the family can have far-reaching consequences on family, marital and social relationships.

#### **2.8.3.1 Relationship with the deaf child**

Minuchin (in Luterman, 1991: 143) maintains that modern-day parenting is an extremely arduous task which is impossible to accomplish to one’s complete satisfaction, and no parent goes through the processes without conflict. It is not easy to nurture a child without being controlling or imposing certain restrictions from time to time. Children, in testing the limits set by parents, can be seen as hostile and rejecting. Parents are often in conflict not only with their children but also with themselves, as to whether they are exercising too much control and not allowing enough freedom, or being lax. In both premature control and delayed release of control the result is generally the same – “a fearful, low-risk child”. In the case of hearing parents raising deaf children, feelings of guilt may lead to overprotection, delayed or no release, which could be a barrier to the child becoming independent.

Lessenberry and Rehfeldt (2004: 231-232) suggest that the way parents interact with their children with disabilities can seriously impact the child’s educational or therapeutic progress, and that the parents’ level of stress may influence the quality and frequency of interaction with the child. The attitude of hearing parents to the child’s deafness will have important effects on their ability to cope with the responsibilities of raising the child, and on their child’s emotional and social development, and later

school success. The home is the place where any child should feel safe, loved, and understood, and it should provide emotional strength and resources that deaf children need in order to cope in a hearing world. Deaf children need the same kind of parenting and experiences as their hearing peers, if they are to grow up to be just as emotionally stable as hearing children. To achieve this, parents will have to adjust the quantity and quality of interaction they have with their young, deaf child (Marschark, 1997: 79).

In order to create a conducive environment, parents are expected to ensure that the child receives maximum benefit through adopting a loving, caring attitude, taking care of the child's physical needs such as food, shelter, clothing and health, as well as supervising and exercising control over the child's activities at home, thus ensuring a balanced life for the child. A sound mutual understanding between the parents will enable them to come to terms with the problems associated with raising their child. It will help them to maintain a close relationship, which is the basis for providing an effective environment for the education of the child (Griessel, Louw & Swart, 1993: 50-52; Oosthuizen, 1992: 123).

#### **2.8.3.2 Relationship with spouse / partner**

Marital relationships can affect parenting in a positive or negative way, depending on the strength of the bond. The closer the relationship, the better the parents are able to achieve the goal of successful parenting. According to Mendelsohn and Rozek (in Luterman, 1991: 144), when marital bonds are not strong, it could result in the child being "triangulated" into the marriage - the "intrinsic characteristics of the deafness and the caretaking process lend themselves to the child being triangulated into the anxious and conflictual areas in the family life". The child with a disability needs more attention and care, and therefore becomes the focus.

Because of the strong emotions involved in having a deaf child, marital relationships could become strained, and this could disrupt normal family functioning. Featherstone (in Luterman, 1991: 146) noted that the birth of a child with a disability evokes such strong emotions in parents that it becomes a source of conflict and disrupts the

organisation of the family. On a long-term basis, the disabled child is always “a symbol of shared failure”.

A survey of literature tends to support the notion that a child with a disability in the family increases the everyday stresses and strains of married life. Thurman and Widerstrom (in Levitz, 1991: 120) came to the following conclusions regarding the effects of a child with a disability on normal marital relationships and family harmony:

- Disagreement between parents concerning the nature of the child’s disability and the extent to which the needs of the rest of the family should be compromised
- Lack of agreement between parents regarding the management of behaviour problems of the child can result in marital disharmony
- The amount of time and energy spent attending to the child and the resultant neglect of other family members may give rise to feelings of resentment, unresolved conflict and tension in the marriage
- An alliance between one parent and the child may result in feelings of isolation by the other parent, which may cause imbalance in the family system and problems in the marriage.

Cunningham and Davis (in Levitz, 1991: 121), in their survey of literature on how a child with a disability affects family disharmony, concluded that the situation is not as bleak as it might seem judging from the following findings:

- There is inconclusive evidence to link the incidence of marital break-up and family discord to families with children who are severely disabled
- A decrease in marital satisfaction occurs over time in all kinds of families and is not unique to those with disabled children
- In many cases, families of disabled children remain intact
- The existence of a strong family harmony prior to the diagnosis of the disability often tends to strengthen the family bond
- Well-organised, cohesive families with agreed role differentiation are able to withstand the stress and strain of having a child with a disability more effectively.

Gargiulo (in Levitz, 1991: 121) acknowledges that while it appears that a child with a disability may upset marital equilibrium, it is not true in all cases since great diversity exists within individual families as well as within and across disabilities. He states that diminished marital stability is not necessarily an inevitable consequence of having a child with a disability in the family.

Gallagher, Cross and Scharfman (in Luterman, 1991: 144) identified the characteristics of parents of children with disabilities, and who were judged by professionals to have adjusted successfully. The major sources of strength, as suggested by their data, were the personal qualities of the parents and the quality of the relationship between husband and wife.

### **2.8.3.3 Relationship with the deaf child's educator**

International research shows that there is increasing evidence of the advantages of actively involving families and the broader community in the education of children. Such links can promote scholastic achievement and development, improve school attendance and completion of homework, and foster good behaviour, positive attitudes, and self-esteem. If educators see children as *children* with individual needs and unique social backgrounds rather than as *learners* only, the likelihood is that they will regard the family and members of the community as “partners with a shared interest in children’s learning, welfare and development”. The interrelationships between these partners are important in the child’s development. The concept of equal partners in the education of the child is akin to the idea of a “whole village taking responsibility for raising a child” (Swart & Phasha, 2005: 213-214).

Beveridge (in Wall, 2003: 45) comments that since the concept of partnership is based on acknowledging that “parents and teachers have complementary contributions to make to children’s education”, the roles of parents and professionals should support each other. In the case of parents whose children are transported to special schools some distance away, partnerships could be compromised, especially if they themselves do not have transport. However, as pointed out by Hurst (in Wall, 2003: 46), this does not mean that practitioners should not make efforts to establish effective partnerships,

or ignore the need to make regular contact with parents to keep them informed. Wall (2003: 45) maintains that real partnership with parents will depend largely on “the quality of the relationships and the perceived benefits to all parties involved”. What is most important is the practitioner’s awareness of parents’ needs and the willingness to adapt and find ways of meeting these needs. Drifte (in Wall, 2003: 52) concurs with this view, stressing that it is beneficial to all concerned, but more especially to the children.

Warnock (in Armstrong, 1995: 18), in arguing for the collaboration of parents in the education of the child, states that parents’ knowledge of their offspring can assist educators to increase their effectiveness in working with the child in the classroom. However, as Armstrong (1995: 18) points out, this can only apply if the educator is “willing to acknowledge the expert knowledge of the parent”. Vrey (1990: 203) maintains that education is too complex to be managed by educators alone, and therefore stresses the need for cooperation between parents and educator. The educator-parent partnership works together for the ultimate benefit of the learner (Wolfendale, 1992: 5). This process involves collaboration, setting goals, finding solutions, implementing and evaluating shared goals, as well as inspiring and maintaining trust between educator and parents. This relationship is strengthened by openness, honesty, dialogue and frankness.

The basic principles of this partnership are trust, respect and confidence. Parent expectations, as well as educator expectations, greatly influence the relationship between parents and the deaf child’s educator. If these expectations differ confusion can arise, to the detriment of the child. However, shared expectations will be of benefit to parents, educator and the learner (Prinsloo, Vorster & Sibaya, 1996: 56).

Family-school partnerships are described by Christenson and Sheridan (2001: 37-38) as:

- a child-focussed philosophy offering guidance to families and educators to work together to facilitate children’s academic, behavioural, social, and emotional development

- a belief in shared responsibility between families and educators for the education and socialisation of children
- an emphasis on the relationships between schools and families and their collaboration and cooperation in supporting children's learning and development
- a preventative solution-focussed approach whereby schools and families try to provide supportive learning communities that address barriers to learning.

Bardenhorst, Calitz, Van Schalkwyk, Van Wyk, Kruger, Squelch and Lemmer (in Moodley, 2002: 47) describe a sound educator-parent relationship in the following way:

- there is mutual trust, because their intentions are honest, sincere and pure as they cooperate with each other in order to seek the best for the learner
- parents can contribute valuable information about their children's strengths, weaknesses and medical details
- both parents and educator are indispensable partners in the education process, thus underscoring the importance of mutual acceptance, understanding, and collaboration in combating delinquent behaviour
- there is mutual respect and consideration, as educator and parents acknowledge each others' position, situation and expectations.

The principles that promote quality education of deaf children can include acknowledging the parent/caregiver as the child's first educator, and capitalising on the involvement; being flexible and responsive to the needs of individual parents and families; providing opportunities that offer parents/caregivers a range of options that allow them to become active partners in the education of their child; and focussing on the child, parents/caregivers, their families, and their community.

#### **2.8.3.4 Relationships with other professionals in the community**

Parents of young deaf children may have the need to liaise with a range of professionals in the community, such as pediatricians, Ear-Nose-Throat (ENT) specialists, audiologists, psychologists, social workers, guidance counsellors, speech,



language and hearing therapists as well as educators, something quite difficult to achieve due to power relations that exist between professionals and those seeking assistance.

Wall (2003: 28) emphasises the importance of the parent-professional relationship especially in the early stages when parents seek advice about a suspected problem, and the time when diagnosis is confirmed. The confirmation of diagnosis can be a traumatic experience for parents and they often rely on the professional to answer their questions and respond to issues raised. The handling of the early discussions by the professional during this emotional time is crucial as they can facilitate or aggravate the parents' ability to come to terms with the diagnosis. Carpenter (in Wall, 2003: 29) commenting on professionals' initial post-diagnosis discussions with parents, states that very often, at this difficult time, the "professional approaches were insensitive and ill-timed as they did nothing to enhance their quality of life or parenting confidence".

Several issues such as long working hours, poverty, social deprivation, low self-esteem, feelings of inadequacy and the time factor can affect parents' involvement with professionals in the community (Swart & Phasha, 2005: 220-221; Wall, 2003: 45; Christenson & Sheridan, 2001: 84; Wolfendale & Einzig, 1999: 35). Any of these issues can influence the quality of parents' relationships with professionals in the community and may act as barriers to meaningful involvement in their children's progress. Partnership with parents, in the true sense of the word, will depend largely on the quality of the relationship with the professional, and on the envisaged benefits to the parent, professional and child.

Gascoigne (1995: 33) states that most parents of children with special needs carry "emotional and psychological baggage" that can be a hindrance to working in partnership with professionals. They may find it difficult to communicate their views which may be misunderstood by professionals, and when their knowledge or views appear to be trivialised, they feel marginalised. Often they do not fully understand the professionals and are confused by what they hear or read about their child's disability.

Schlesinger (in Meadow-Orlans & Sass-Lehrer, 1995: 316) state that families with deaf children report that sometimes professionals provide selective information about methods of communication, citing the “best interests” of the family to conceal their own bias in this regard. Porter and Edirippulige (2007: 518) concur that parents of deaf children may be provided with information “by professionals who hold strong ideological and methodological viewpoints that can be bewildering and unsettling for families”.

Dunst, Trivette, Boyd and Brookfield (in Meadow-Orlans & Sass-Lehrer, 1995: 316) identified three broad perspectives of professional/family relationships. These include: “the professional as expert” perspective which is based on the assumption that parents/caregivers do not possess skills and knowledge; the “direct guidance” model which assumes that parents/caregivers possess some knowledge, but need skills and services which will be provided by the professional according to his/her discretion; and the “partnership model” in which the family members are accepted as equal partners by the professional. Decision-making abilities are fostered through encouraging active family involvement. Luterman (in Meadow-Orlans & Sass-Lehrer, 1995: 316) views listening as “the most powerful intervention tool for the professional because it tells parents that their views are important and valuable”. It is clear that a sound relationship can only be advantageous.

#### **2.8.4 Relationship with the Transcendental**

The Transcendental relationship is an all-embracing one. It is the basis of human existence and as such, determines man’s relationship with himself and with the world (Landman, Van der Merwe, Pitout, Smith & Windell, 1992: 109). According to Van der Merwe (in Moodley, 2002: 57), the process of becoming is currently influenced by technology, and human judgment is increasingly becoming horizontally rather than vertically measured. As a normative guide to making moral choices, scripture is being replaced with the norm of progress, success and materialism. Religion is essentially a personal experience, search, challenge and commitment and it is fundamental to help individuals understand the meaning and value of life. A strong and honest relationship with God will have a positive effect on life and make individuals happier, add

meaning, purpose and personal depth to life, nurture good mental health and personal maturity, as well as provide a code of conduct that can model their lives.

Meadow-Orlans *et al.* (2003: 128) found a strong association between deafness and religion especially among Black and Hispanic families in the USA who reported that their faith in God and prayer helped them cope with the raising of their deaf children. Further, these writers report that other researchers found that American families attending church regularly indicated that their religious belief was a helpful source of support in coping with disabilities.

It therefore clear that some hearing parents draw on their relationship with the Transcendental, to face the challenges of raising their deaf children in a hearing world.

## **2.9 CHALLENGES FACING HEARING PARENTS OF DEAF CHILDREN**

There are several issues associated with hearing parents raising deaf children, and the ability to cope depends on the way they manage the related stress and strain, and in developing healthy attitudes and relationships.

There is accumulating evidence which suggests that parents of children who have developmental disabilities “often experience deleteriously high levels of stress” (Lessenberry & Rehfeldt, 2004: 231). The diagnosis of deafness is a “critical life event for parents” and it can lead to “high stress experience” (Hintermair, 2006: 495). Stress is defined by Lazarus and Folkman (in Jones & Bright 2001: 20) as “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”.

Lessenberry and Rehfeldt (2004: 232) state that the concept of stress can be subdivided into four domains, including the stressor, strain, coping resources, and coping strategies. The stressor can be an event or situation that is beyond the person’s ability to cope with *e.g.* the initial diagnosis of the child’s deafness. Strain refers to the emotional and physical symptoms related to a stressful event that the person experiences, *e.g.* depression and anxiety. Coping resources include what a person can

make use of to help manage the effects of the stressor, *e.g.* social support networks. Coping strategies are the ways a person uses available coping resources to help minimise or avoid the effects of the stressor, *e.g.* attending a parent-support group. Scorgie, Wilgosh and McDonald (in Hintermair, 2006: 495) summarised the most important variables for understanding parental stress and coping processes in families of children with disabilities under four headings: child variables, parent variables, family variables, and external variables. These variables are linked to the ecosystemic theory explained in 2.2.

Schirmer (2001: 25) draws attention to certain characteristics that play an important role in contributing to healthy family functioning especially in families with a deaf child. These characteristics include communication, flexibility, intimacy, conflict resolution, change and stability, which take on a special meaning in families with a deaf child. “Securing and maintaining these qualities of family life can be a particular challenge for parents who have no prior experience with deafness” (Schirmer, 2001: 26).

A major challenge facing hearing parents of deaf children is coping with stress related to the child’s deafness. Prior to the diagnosis of deafness, strain is common as parents become anxious and apprehensive about the possibility that their child may have a problem. Ross *et al.* (2004: 156) suggest that the “prediagnostic period is apparently a far more difficult time to live through” than the period after the confirmation of the diagnosis.

**Communication with the deaf child** is one of the major challenges for parents of deaf children (Schirmer, 2001: 27; Scheetz, 2001: 61). Deafness is not simply a physical challenge but also a pedagogical one because the deaf child, like the hearing child, has to be educated. Initially, the difficulty of communicating with the deaf child presents a major challenge to hearing parents. Kushalnagar *et al.* (2007: 337) confirm that research shows that parental stress is commonly linked to parent-child communication problems which can result in parents’ feelings of frustration and inadequacy, and that these feelings influence their self-concept. In this regard Mapp and Hudson (in Kushalnagar *et al.*, 2007: 337) concur that parental stress is significantly associated

with the level of communication fluency between parents and their deaf children, while Pipp-Siegel, Sedey and Yoshinaga-Itano (in Kushalnagar *et al.*, 2007: 337) found that increased parental stress was linked to greater language delay of the child. A study by Hadadian and Rose (in Kushalnagar *et al.*, 2007: 337) showed that fathers' resistance to the acceptance of the child's deafness was related to poor communication outcomes in deaf children.

Meadow *et al.* (in Kushalnagar *et al.*, 2007: 335) report that when hearing parents have limited sign language communication with their deaf children, it can result in a lack of signing skills and a lack of language acquisition in deaf children in the early years, and "delays in multiple areas of adaptive functioning". Hintermair (2006: 493) found that the deaf child's communicative competence is a sounder predictor of parental stress than the medium of communication (sign or spoken language). Kotze and Fölscher (in Levitz, 1991: 78) maintain that unless parents find a way of communicating effectively with the deaf child, the quality of parenting becomes compromised. This, in turn, can adversely affect the education of the deaf child as well as the emotional well-being of the parents. Poor parental emotional well-being can contribute significantly to decreased communication effectiveness between parent and child.

Meadow-Orlans *et al.* (2003: 30) state that several studies show that mothers tend to have better communication skills with their deaf children than do fathers, who tend to assume less responsibility for ensuring effective family communication with the deaf child. Those mothers who communicate effectively with their deaf children tend to have more stable and warm relationships with them. Those mothers who do not communicate efficiently with their deaf children tend to have less stable relationships with them, and these children tend to exhibit unacceptable behaviour in preschool or at home. "Generally, hearing parents of deaf children use more physical punishment than hearing parents with hearing children or deaf parents with either deaf or hearing children ... Apparently, when communication fails, punishment is a handy alternative" (Marschark, 1997: 81).

The entire family of the deaf child is faced with a barrier to communication with the child. Unless definite measures are taken to establish an effective means of communication, the child's progress could be severely hampered (Schirmer: 2001: 30). It is important for parents to work through ways of enhancing communication with their deaf child. The lack of effective communication techniques will prevent the deaf child from becoming fully integrated into the family unit; consequently this may threaten family stability (Scheetz, 2001: 61) which can lead to increased levels of parental stress.

**Frequent socio-emotional problems** in deaf children are linked to high parental stress experience, while access to personal and social support is associated with significantly lower parental stress levels; furthermore parents whose deaf children have **additional disabilities** are especially stressed (Hintermair, 2006: 493). Herman (1994: 418) suggests that the **inability of parents to fulfill specific needs of the child** appears to be a potential source of stress for parents. While fathers tend to turn inward towards the family for support, mothers turn outward toward social networks for help in coping with a stressful situation. In order to reduce stress, Dyson (1991: 623-629) suggests that intervention programmes should aim at increasing the child's competence, changing parental perception and caretaking of the child as it seems that these are the major areas that lead to parental stress. The hardships experienced by the family in caring for the deaf child can lead to chronic stress. Bailey, Blasco and Simeonsson (1992: 7) highlight some of these hardships: financial difficulties; stigmatisation from the community; difficulty in liaising with professionals; strained family relationships; changed family lifestyle, and anxiety about the future of the child.

Parents of children with disabilities often experience very intense emotional stress that can strain marital relationships (Scheetz, 2001: 61; Luterman, 1991: 146). A child's disability can evoke such strong emotions in parents that it becomes a source of conflict and disrupts family life. Dysart (1993: 31) states that millions of people go through endless emotional suffering simply because they have not been adequately prepared to face the reality of deafness. If these emotional reactions are not dealt with properly they can be magnified out of proportion, and consequently even lead to increased parental stress.

The coping styles of individual family members will depend on the ability to handle stress and on the attitude towards the deaf child, whose birth demands greater adjustments in family life. Most deaf mothers can recognise whether their children are deaf by at least six months of age simply by the way their babies behave or react to them, whereas the average age of diagnosis of most deaf children of hearing parents is thirty months in the United States (Marschark, 1997: 77). The earlier the diagnosis of deafness, the sooner can intervention programmes begin, and the greater is the advantage for the deaf child's development. Parental stress is likely to be reduced once deafness is accepted and measures are in place to work with it. Stress between parents will dissipate, and there is no evidence that having a deaf child influences the success or failure of marriages in any way. Research has revealed that those mothers who receive emotional and practical support from their family and friends are able to cope more efficiently with the demands of having a deaf child (Marschark, 1997: 16).

## **2.10 SUMMARY**

In this chapter the theoretical framework for understanding deafness and parenting was provided. The prevalence of deafness, the clinical features of deafness, as well as the types of deafness were covered. The three types of deafness included sensorineural, conductive, and mixed hearing loss. The development of the deaf child was discussed, drawing on the ecological framework to highlight the complexity of deafness. Parenthood and parental responsibilities were reviewed through an ecosystemic lens, including a discussion of the family and the deaf child. The child's deafness and the emotional well-being of hearing parents were explored, followed by an overview of some of the issues facing hearing parents raising deaf children.

In chapter 3 the focus will be on research design and methodology. Mixed methods research, incorporating both quantitative and qualitative approaches through the concurrent triangulation design, chosen to answer the research questions, will be discussed.

## CHAPTER 3

### RESEARCH DESIGN AND METHODOLOGY

*“Once you actually realise that your child is deaf, you actually feel alone. There’s nobody who can actually tell you that speech is the best, or that sign language is the best, or a cochlear implant would be the best...I think I would have gone the cochlear implant way, if I only knew then what I know now. So, I think it’s good to have somebody that can actually lead the way.”*

(Frieda, participant: 2006)

#### 3.1 INTRODUCTION

The previous chapter included a survey of literature pertaining to theoretical perspectives on deafness, a discussion of the theoretical framework underpinning the study, and parenting of deaf children. The focus of this chapter is on the research design and methodology. A mixed methods approach has been selected to explore the experiences, from an ecosystemic perspective, of hearing parents raising deaf children. Both qualitative and quantitative methods have been used concurrently in this study, although the qualitative approach is foregrounded. In this chapter the nature of mixed methods research, the research paradigm, and the research design including the mixed methods design, the qualitative and quantitative approaches or strategies of inquiry will be discussed. This will be followed by an outline of the purpose statement and the research questions. Data generation procedures and data analysis for quantitative and qualitative methods will be explained. This will be followed by a discussion of the sampling strategies for both quantitative and qualitative data collection, validation procedures and ethical issues.



## **3.2 THE NATURE OF MIXED METHODS RESEARCH**

### **3.2.1 Introduction**

In this section a brief history of mixed methods research will be traced. Next, a definition of mixed methods research will be provided. This will be followed by a discussion of the purposes of mixed methods research. Thereafter, the growth of interest in mixed methods research, and its strengths will be discussed. Finally, the challenges and limitations of mixed methods will be outlined.

### **3.2.2 A brief historical perspective**

The mixed methods research is relatively new and has become established as a research approach in the past two decades (Creswell & Garrett, 2008: 323). The formative period spanned about three decades from the 1950s to the 1980s. It probably originated in the field of psychology in 1959, when Campbell and Fiske used a “multimethod matrix” of quantitative data collection methods in a study of the validity of psychological traits (Creswell & Plano Clark, 2007: 15; Ivankova, Creswell & Plano Clark, 2007: 262; Creswell, 2009: 204; Teddlie & Tashakkori, 2003: 6; Creswell, 2003: 210; Tashakkori & Teddlie, 1998: 18). This study encouraged other researchers to use a combination of approaches to generate data within a single study, when considering the limitations of the use of a single approach.

Interest in triangulating different sources of quantitative and qualitative data emerged with Jick’s study in 1979, in which he used surveys, observations, documents and semi-structured interviews to triangulate data to develop a better understanding of the research problem (Creswell & Garrett, 2008: 323; Creswell & Plano Clark, 2007: 15; Creswell, 2009: 204; Ivankova *et al.*, 2007: 262; Teddlie & Tashakkori, 2003: 7; Creswell, 2003: 210). However, the conceptualisation of “mixed methods as a distinct approach to inquiry” only took root as late as 1988 in the United States of America when Brewer and

Hunter wrote the first book based on mixed methods research (Creswell & Garrett, 2008: 323).

The period spanning the 1970s to the 1980s saw the emergence of paradigm wars or debates between quantitative and qualitative researchers relating to mixed methods research. The question arose as to whether it was possible to combine quantitative and qualitative data (Creswell & Plano Clark, 2007: 15; Ivankova *et al.*, 2007: 262; Tashakkori & Teddlie, 1998: 3). Some researchers were of the view that mixed methods research was impossible on the grounds of incompatibility, since mixed methods required the mixing of paradigms (Creswell & Plano Clark, 2007: 15; Teddlie & Tashakkori, 2003: 17). Although the paradigm debate is an ongoing one, pragmatism has gained favour as “the best philosophical foundation for mixed methods research” (Creswell & Plano Clark, 2007: 15).

The period of procedural developments regarding mixed methods research gained ground during the 1980s, when attention shifted to the procedures or methods for a mixed methods design. Greene, Caracelli & Graham (1989: 258-260) laid the groundwork for mixed methods research design when they analysed 57 evaluation studies and developed a classification system comprising six types of mixed methods designs. Subsequently, several authors have identified ways of classifying mixed methods designs, and in 1989 Brewer and Hunter (in Creswell & Plano Clark, 2007: 15) linked the combination of research methods to the process of research, *e.g.* the formulation of problems, sampling and data collection.

Since the 1990s authors have advocated the establishment of a mixed methods approach as “a distinct approach to research with its own designs and a set of procedures” (Ivankova *et al.*, 2007: 262). In 1991 Morse (in Creswell & Plano Clark, 2007: 15) designed a notation system as a guide to researchers for the implementation of the quantitative and qualitative components of mixed methods research. Since then, authors have engaged in formulating specific types of mixed methods designs, and books have

been written about mixed methods research. In section 3.2.5 recent growth and interest in mixed methods research will be outlined.

### **3.2.3 Defining mixed methods research**

Various terms have been used in the literature to refer to the mixing of research methods, for example, multimethod spread convergence, integrated, combined, multiple methods, mixed methods, triangulation of methods, methodological mixes, mixed methodology, quantitative and qualitative methods, synthesis, and integrating (Creswell, 2009: 205; Creswell, 2003: 16; Tashakkori & Teddlie, 1998: 14). In this study, the term mixed methods will be used for combining quantitative and qualitative methods. Mixed methods research combines quantitative and qualitative methods (Creswell, 2009: 203; Creswell & Plano Clark, 2007: 6; Creswell, Ivankova & Plano Clark, 2007: 260; Greene, Kreider & Mayer, 2005: 274; Tashakkori & Teddlie, 2003: p. x; Tashakkori & Teddlie, 1998: 17). When researchers mix both qualitative and quantitative approaches “the strengths of both approaches are combined, leading to, it can be assumed, a better understanding of research problems than either approach alone” (Creswell & Garret, 2008: 322).

Creswell and Plano Clark (2007: 5) define mixed methods research as an approach to inquiry that connects or combines both qualitative and quantitative data to provide a more thorough understanding of a research problem. It involves philosophical assumptions and the linking of both approaches in a study. Thus it involves more than simply the collection and analysis of both kinds of data. Mixed methods research is defined as “a procedure for collecting, analysing and ‘mixing’ both quantitative and qualitative at some stage of the research process within a single study to understand a research problem more completely” (Ivankova *et al.*, 2007: 261).

Greene *et al.* (1989: 255-256) define mixed-methods designs as those that include at least one quantitative method (to collect numerical data) and one qualitative method (to collect text data) where neither type of method is directly linked to any particular inquiry paradigm. On the other hand, Tashakkori and Teddlie (1998: 19) define mixed methods

studies as “studies that are products of the pragmatist paradigm and that combine both quantitative and qualitative approaches within different phases of the research process”.

A mixed method approach can therefore be described as one in which the researcher makes use of mixed methods of data collection and analysis for pragmatic purposes. Pragmatism is the overarching paradigm in mixed methods studies. It involves drawing on both quantitative and qualitative data collection procedures, for example, a survey, as well as in-depth interviews which, according to De Vos (2005: 357), involves mixing “between methods”.

#### **3.2.4 Purposes of mixed methods research**

Researchers recognising that all methods have limitations felt that convergence of data sources across quantitative and qualitative methods was a means of neutralising the biases inherent in any single method (Flick, 2006: 37; Creswell, 2003: 15; Tashakkori & Teddlie, 1998: 42; Greene *et al.*, 1989: 256). This gave rise to the concept of triangulation from which emerged other reasons for using mixed methods. Methodological triangulation is used to ensure that the most comprehensive approach is adopted to solve a problem when a single research method is inadequate.

Greene *et al.* (2005: 275) state that mixed method approaches to social inquiry were initially viewed as an opportunity to “generate a better understanding” than studies restricted to a single approach. Over time other purposes evolved for the use of the mixed methods approaches.

Greene *et al.* (1989: 258) on reviewing 57 mixed methods studies from the 1980’s, listed five purposes for choosing a mixed methods approach: (a) Triangulation, or seeking convergence of results; (b) Complementarity, or examining overlapping or different facets of a phenomenon; (c) Initiation, or discovering fresh perspectives, paradoxes and contradictions; (d) Development, or using the methods sequentially, so that results from the first method inform the use of the second method; (e) Expansion, or adding breadth and scope to a project.

In this study (a), (b), and (e) are relevant as the purpose of choosing mixed methods research was to seek convergence of results of quantitative and qualitative data, as well as complementarity, to get a broader understanding of the different facets of hearing parents raising deaf children, from an ecosystemic perspective.

Mertens (in Creswell, 2003: 16) holds the view that the use of a mixed methods approach can serve the purpose of transformation and advocacy for marginalised groups, such as people with disabilities. Initially mixed method design was defined by authors from different fields under the general heading of method triangulation. Denzin (in De Vos *et al.*, 2005: 362) who originally coined the term triangulation in terms of research described four types of triangulation: data triangulation, investigator triangulation, theory triangulation and methodological triangulation.

However, Creswell (2003: 14) noted that mixed method design serves purposes beyond triangulation, to include the convergence of results across qualitative and quantitative methods. It involves strategies for collecting and analysing both forms of data in a single study. Creswell, Plano Clark, Gutmann & Hanson (2003a: 223-229) provide four main reasons for combining both qualitative and quantitative methods within a study. These include:

- elaborating on or explaining quantitative findings with qualitative data
- using qualitative data for developing a theory, or a new instrument for measurement
- comparing both qualitative and quantitative data to come up with well-validated conclusions
- enhancing a study with a set of supplemental data, either quantitative or qualitative.

In this study the use of the mixed method approach serves the purpose of gaining a broader perspective of the research questions through the use of both qualitative and quantitative methods. It enhances the study with the advantages of both quantitative and qualitative data, as different perspectives can be gained from the different types of data.

The use of a mixed methods approach will chiefly serve the purpose of gaining an in-depth understanding of an ecosystemic perspective on hearing parents' experiences of raising deaf children, and how the ecosystem influences their attitudes, opinions, and trends with regard to the way they manage their parenting role.

### **3.2.5 Recent growth of interest in and strengths of mixed methods research**

Recently there has been much growth and interest in mixed methods research, with many writers advocating that it should be recognised as a separate research design alongside qualitative and quantitative approaches (Creswell & Garrett, 2008: 323; Creswell & Plano Clark, 2007: 16). Referring to mixed methods research as the “third methodological movement”, Teddlie and Tashakkori (2003: 44-45) state that the time has come for acknowledgement of the need to teach mixed method research courses, and that it will be the way most educators will approach research. Prior to 2003 there were very few text books on mixed methods research. However, Creswell, Tashakkori, Jensen and Shapley (2003b: 620) listed more than 20 books, chapters and articles recently written on mixed methods research. This is indicative of the recent and growing development of “the wide range of available high-quality sources for a mixed methods course” (Tashakkori & Teddlie, 2003: 44).

Creswell (2003: 208) draws attention to the increasing frequency with which journal articles on mixed methods research are being published in diverse fields such as occupational therapy, interpersonal communication, dementia care-giving, middle school science and AIDS prevention. Since 2003 several workshops in various fields have highlighted increased interest in mixed methods research, and over 60 journal articles employing mixed methods research in social and human sciences between 1995 and 2005 were published (Creswell & Plano Clark, 2007: 16-17).

In 2005 a new journal, called the *Journal of Mixed Methods Research*, devoted exclusively to the publication of mixed methods studies and matters pertaining to mixed methods research, was started by Sage publications. The first issue was available in

January 2007. International interest in mixed methods research became evident with two international conferences held in Cambridge University and in Switzerland in 2005 (Creswell & Plano Clark, 2007: 18).

With regard to the strengths of mixed methods research, Creswell and Garret (2008: 325) draw attention to the emergence of views regarding “the value-added by mixed methods research”, and state that sixteen reasons were put forward by Brewer and Hunter in 2006 for mixing quantitative and qualitative approaches. Neuman (2006: 149) and Brewer and Hunter (in Tashakkori & Teddlie, 1998: 42) suggest that, since a combination of quantitative and qualitative approaches allows for data triangulation, it is therefore superior to single method research.

Flick (2006: 37) holds the view that the combining of qualitative and quantitative methods in a single study complement each other and this is viewed as the “complementary compensation of the weaknesses and blind spots of each single method”, while Denzin and Lincoln (2003: 8) state that the use of mixed methods indicates an attempt to gain “an in-depth understanding of the phenomenon in question”. Likewise, Morse (2003: 195) holds the view that the major strength of mixed methods designs lies in the fact that “they allow for research to develop as comprehensively and completely as possible”. Creswell (2005: 22) suggests that a mixed method design is beneficial in capturing the advantages of both quantitative and qualitative approaches, especially if a researcher wants to generalise the findings to a population as well as develop a deeper insight into the meaning of a phenomenon being studied.

Jick (in De Vos, 2005: 362) identifies the following “opportunities” or advantages of triangulation in the mixed methods approach for research:

- It gives researchers greater confidence regarding the results. This is the overall strength of mixed methods design
- Triangulation may stimulate the creation of new ways of capturing a problem, to balance conventional data collection methods

- It may lead to the discovery of different dimensions of a phenomenon. Divergent results from mixed methods can lead to a better understanding and enriched explanation of the research problem
- Methodological triangulation can lead to a synthesis or integration of theories, as it closely parallels theoretical triangulation, *i.e.*: attempts to bring different theories to bear on a common problem. Triangulation, by virtue of its comprehensiveness, may serve as a critical test of competing theories.

Methodological triangulation is a means of obtaining complementary findings that add strength to research results and contribute to the development of knowledge. “Smart researchers are versatile and have a balanced and extensive repertoire of methods at their disposal” (Morse, 1991: 122). Mouton and Marais (1990: 169-170) put forward the view that the phenomena which are investigated in the social sciences are so enmeshed that it is not possible to succeed in understanding the full complexity of human nature through a single approach. It would therefore be futile to behave as though any one approach has precedence over the other.

Accordingly, if one adopts the point of view of convergence and complementarity it may help one to gain a deeper insight into human nature and social reality. However, De Vos (2005: 360) points out that these authors offer little advice or practical guidelines on how to combine qualitative and quantitative methods. This leads to the next aspect, namely, the challenges and limitations of mixed methods research.

### **3.2.6 Challenges and limitations of mixed methods research**

Despite the many strengths and advantages of the mixed methods approach, there are also some challenges and limitations. De Vos (2005: 359) and Creswell (2003: 218), draw attention to the limitations that need to be considered when combining both methods in a single study, as the different sets of data have to be transformed in such a way that they can be integrated within the analysis phase of the research. This is an expensive, time-



consuming and lengthy task. As pointed out by Creswell (2003: 218-219) there is currently limited literature to guide a researcher through this process.

Moreover, there is not much advice to be found for the resolution of discrepancies that may occur between the two types of data. Morse (2003: 195) points out that the study may be challenged on the grounds that it may not be considered to be rigorous enough, and that “the supplemental data may be considered thin and therefore suspect”.

De Vos (2005: 360) points out a further limitation in that most researchers (and university departments) are often not trained in the skills needed to conduct research from more than one paradigm. Researchers are more familiar with one paradigm, which then tends to dominate their study. Mitchel (in Morse, 1991: 120) states that guidelines for the use of methodological triangulation are lacking, and notes five areas of concern, namely:

- the difficulty of merging textual and numerical data
- the interpretation of divergent results obtained from the use of quantitative and qualitative methods
- the lack of delineation of concepts and the merging of concepts
- the weighing of information from different sources of data
- the problem of ascertaining the contribution of each method when the results are being assimilated.

According to Morse (1991: 122), Mitchel’s problem of weighing the results from different data sources can be resolved if “findings are interpreted within the context of present knowledge”, and that “each component should fit like pieces of a puzzle”. She explains further that this type of interpretation cannot be accomplished through the application of a mathematical formula. Instead, it is an informed thought process that involves wisdom, creativity, judgement and insight. Triangulating different methods can be exciting.

### 3.3 RESEARCH PARADIGM

The term paradigm is used to describe “an approach to research which provides a unifying framework of understandings of knowledge, truth, values and the nature of being (Somekh & Lewin, 2005: 347). Creswell and Plano Clark (2007: 21) explain that a paradigm or worldview is the view we have of our world which ultimately influences how we design and conduct research. Neuman (2006: 81) describes a paradigm as a “general organizing framework for theory and research that includes basic assumptions, key issues, models of quality research, and methods for seeking answers”. A paradigm is a worldview which is a “basic set of beliefs that guide action” in terms of research (Guba, 1990: 17).

These beliefs have been referred to by different writers as paradigms and philosophical assumptions which include epistemology (the relationship between the researcher and the researched), ontology (the nature of reality), axiology (the role of values), rhetoric (the language of research), and broadly conceived research methodologies (Creswell, 2007: 17; Creswell & Plano Clark, 2007: 24). Creswell (2003: 6) refers to these beliefs as “alternate knowledge claims”.

The ontological assumption related to this study, since its purpose is to investigate the nature of reality with reference to the way hearing parents manage their role of parenting deaf children, is that reality can be viewed in different ways. Creswell *et al.* (2003a: 231-232) are of the view that multiple paradigms may serve as the foundation for doing mixed methods research, and that from a qualitative philosophical perspective, multiple realities exist. Moreover, several paradigms may be used as a framework for a study which uses a triangulation design.

Neuman (2006: 81), Cohen *et al.* (2007: 33), Henning, Van Rensburg & Smit (2004: 16) and Terre Blanche and Durrheim (1999: 6) identify three theoretical frameworks or paradigms. These include the positivist, interpretive and critical frameworks. On the other hand, others have identified four world views used in research, namely, postpositivism, constructivism, advocacy/participatory, and pragmatism (Creswell, 2009: 6; Creswell,

2007: 19; Creswell & Plano Clark, 2007: 22; Tashakkori & Teddlie, 1998: 22; Creswell, 2003: 6).

The positivist paradigm is adopted by researchers who believe that what is to be studied consists of an unchanging, stable reality, and that a detached, unbiased epistemological stance towards reality can be adopted through the use of a methodology that can control and manipulate reality in order to “provide an accurate description of the laws and mechanisms that operate in social life” (Terre Blanche & Durrheim, 1999: 6). Somekh and Lewin (2005: 347) describe a positivist paradigm as an approach to research based on the assumption that the researcher can discover knowledge by generating data through observation and measurement, and analyzing the data to establish truth.

The interpretivist paradigm is used to describe research which aims to discover meaning and to gain a deeper understanding of the implications revealed in the data about people (Somekh & Lewin, 2005: 346). Researchers who believe that the reality to be explored involves the subjective experiences of social reality may adopt an interactive epistemological stance towards studying that reality, and may use interviewing or participant observation techniques that call for a subjective relationship between the participant and researcher.

Advocacy and participatory paradigms are associated with political concerns and are adopted by researchers who see the need to address issues such as social injustice, patriarchy and marginalization, to bring about social improvement, for example, through empowerment of marginalized groups (Creswell, 2009: 9; 2007: 21-22; Creswell & Plano Clark, 2007: 22-23) .

The overarching paradigm for mixed methods research suggested by current researchers is that of pragmatism (Creswell & Plano Clark, 2007: 173) which underpins this mixed methods study. Several authors advocate that “pragmatism serve as the foundation for mixed methods research” (Teddlie & Tashakkori, 2003: 18). Pragmatists generally combine different kinds of methods because the complex way in which they work

demands the use of mixed methods in order to “get the job done” (Greene & Caracelli, 2003: 101).

Pragmatists focus on the research problem and the outcomes of the research, rather than the research method used or the paradigm that underlies the method, and are of the view that different methods can be used to find answers to the research question (Creswell & Garret, 2008: 327; Creswell, 2007: 22; Creswell & Plano Clark, 2007: 173; Teddlie & Tashakkori, 2003: 21). Tashakkori and Teddlie (1998: 29) propose that “pragmatism is the best paradigm for justifying the use of mixed methods research”, and that pragmatism presents a very practical and applied philosophy of research. Teddlie and Tashakkori (2003: 20) note the concurrent view of several authors that pragmatism is thought to be the most suitable philosophical foundation to justify the mixing of different methods within a single study. Morgan (2007: 70) avers that pragmatism is not new to social science and that it provides alternate options for addressing methods of conducting research in the social sciences. Maxcy (2003: 85-86) states that there are several good reviews of pragmatism as a justification for the combination of quantitative and qualitative methods. Drawing from the views of Morgan (2007) and Cherryholmes (1992), Creswell (2009: 10-11) suggests the following reasons for pragmatism being a sound philosophical foundation for mixed methods research:

- Pragmatism is not restricted to any single system of philosophy and reality; it also applies to mixed methods research as researchers draw from qualitative as well as quantitative assumptions
- Individual researchers have freedom of choice with regard to methods, procedures and techniques to suit their needs and purposes; mixed methods researchers draw from both qualitative and quantitative data to gain the best possible understanding of a research problem
- Just as pragmatists do not view the world as an absolute unity, so too do mixed methods inquirers, who prefer not to be confined only to one approach to collect and analyse data

- Pragmatism unlocks the door to different world views, assumptions, and methods of research.

The rationale for choosing a mixed methods approach for this study is the compatibility of qualitative and quantitative methods. Besides, corroboration of results from both data sets provides a better understanding of the research questions. The mixed method research design chosen for this study will be discussed more fully in the next section.

### **3.4 RESEARCH DESIGN**

#### **3.4.1 Introduction**

In this section the mixed method design, classification of mixed method designs, including the criteria for selecting a mixed method design for this study, will be discussed. This is followed by a discussion of the qualitative and quantitative strategies of inquiry that are used in this study.

#### **3.4.2 Mixed methods design**

Mixed methods designs have been classified in numerous ways by various authors from different disciplines. Tashakkori and Teddlie (2003: 672), in a survey of literature, found approximately forty different types of mixed methods designs. Creswell *et al.* (2003a: 224), identified six major types of mixed methods designs. These include the sequential explanatory design, the sequential exploratory design, the sequential transformative design, the concurrent triangulation design, the concurrent nested design, and the concurrent transformative design. Creswell (2009: 209; 2003: 213-214) refer to these designs as strategies. A functional classification including four major types of mixed-method designs, with variants within each type, have more recently been advanced by Creswell and Plano Clark (2007: 59) and Ivankova *et al.* (2007: 263). These include the explanatory design, the exploratory design, the embedded design, and the triangulation design.

Creswell (2009: 206; 2003: 211-213) suggests four criteria for selecting a mixed method design. These include implementation, priority, integration, and theoretical perspective. Implementation refers to the collection of quantitative and qualitative data in phases (sequentially) at the same time (concurrently). Priority refers to the weight given to the quantitative or the qualitative approach. The priority may be equal, or greater emphasis may be given to either one of the approaches. Integration is the stage in the research process when the qualitative and quantitative data and findings will be integrated. Theoretical perspective refers to whether the study is guided by a larger theoretical perspective (such as gender, ethnicity, lifestyle, class).

In this study the concurrent triangulation design was used and this, as well as the reason for choosing this design, will be discussed in 3.4.2.1 below. Briefly, the other three major designs are as follows:

The **explanatory design** is the most straightforward of all the mixed methods designs (Creswell *et al.*, 2003a: 264). It is a two-phase design, the purpose of which is to use the qualitative data collected and analysed in the second phase to build upon, refine or clarify the initial quantitative results. The name suggests that the findings from the qualitative data help explain the results obtained from the quantitative data in the first phase (Creswell & Plano Clark, 2007: 71; Ivankova *et al.*, 2007: 264; Creswell *et al.*, 2003a: 223).

The **exploratory design** is also a two-phase design in which the researcher first explores a topic qualitatively, before measuring or testing it quantitatively. This design is useful for the researcher who needs to test a theory or design a measurement instrument using the qualitative results obtained from the first phase (Creswell & Plano Clark, 2007: 75; Ivankova *et al.*, 2007: 265; Creswell *et al.*, 2003a: 227).

The **embedded design** involves the embedding of qualitative data within a quantitative experimental design, or quantitative data could be embedded within a qualitative methodology, depending on the purpose of the research. In this one-phase design one set

of data “provides a supportive, secondary role in a study based primarily on the other data type” (Creswell & Plano Clark, 2007: 67). This design is selected when a researcher needs answers to a secondary research question that is related to, but different from, the primary research question, where both qualitative and quantitative data sets are required (Ivankova *et al.*, 2007: 267). Both sets of data are collected simultaneously.

#### **3.4.2.1 Triangulation design**

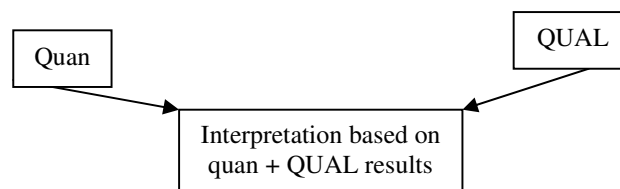
The triangulation mixed methods design chosen for this research inquiry is the most popular and well known of the four mixed methods designs (Creswell & Plano Clark, 2007: 62; Ivankova *et al.*, 2007: 266). Morse (1991: 122) suggests that the purpose of this design is to “obtain different but complementary data on the same topic” so as to gain a more comprehensive understanding of the research problem. This one-phase design is also known as “parallel” or “concurrent” mixed method design, since both sets of data are collected concurrently (Ivankova *et al.*, 2007: 266).

The triangulation design is considered to be a traditional mixed methods design which a researcher uses in order to generate both quantitative and qualitative data simultaneously, to study a single phenomenon with a view to comparing and contrasting the two sets of findings, in order to determine whether there are similarities, differences or some combination to produce well-validated findings (Creswell, 2009: 213; Creswell *et al.*, 2003a: 229; Creswell, 2003: 217).

Initially, triangulation was conceptualised as a means of validating results within individual methods. However, the focus has shifted more towards complementing and enriching knowledge, and overcoming the limited potential of a single method inquiry (Flick, 2006: 390). This design is selected when the researcher, in attempting to seek convergence, or corroboration of results, uses two different methods within a single study (Greene *et al.*, 1989: 259). Both qualitative and quantitative methods are used as a means of offsetting the limitations inherent within one method with the strengths of the other method (Creswell, 2009: 213; Creswell *et al.*, 2003a: 229; Creswell, 2003: 217). In this

design priority may be given to either the qualitative or the quantitative approach, although priority is usually equal and the two sets of results are integrated during the interpretation or discussion phase (Creswell, 2009: 213; Creswell *et al.*, 2003a: 229).

In this study the triangulation design was used to generate quantitative and qualitative data concurrently to explore the experiences of hearing parents raising deaf children from an ecosystemic perspective. The integration of these methods took place during the analysis and interpretation stage of the study, to integrate the quantitative and qualitative findings side-by-side in a discussion so as to provide a comprehensive analysis of the research problem. For the sake of representation the quantitative results from the survey are presented first to provide an overview of the trends, opinions and attitudes, followed by the qualitative data and quotations from the transcripts of interviews. The triangulation design (Figure 3.1) illustrated below is adapted from Creswell and Plano Clark (2007: 63). The uppercase letters (QUAL) indicate priority of weight or emphasis on the qualitative method, while the lowercase letters (quan) denote less priority or emphasis on the quantitative method.



**Figure 3.1**      **Triangulation Design**  
(adapted from Creswell & Plano Clark, 2007: 63)

#### **3.4.2.2 Strategy of inquiry (quantitative approach): survey**

In the late 19<sup>th</sup> and 20<sup>th</sup> century quantitative strategies of inquiry invoked the postpositivist worldview and involved experimental designs such as true experiments, and less rigorous experiments as well as specific single-study experiments. Recently, quantitative strategies of inquiry have included complex experiments and structural equation models. In addition the collective strength of multiple variables has been



identified. Moreover, non-experimental designs such as surveys are used. Survey research provides a numeric or quantitative description of attitudes, trends, or opinions of a population through a study of a sample of that population (Creswell, 2009: 12). Babbie (in Creswell, 2009: 12) states that questionnaires or structured interviews are used to generate data for the purpose of generalizing from a sample to a population.

In this study the quantitative strategy chosen is survey research to collect numeric data using a questionnaire to provide a quantitative description of opinions, trends, and attitudes of hearing parents raising deaf children in South Africa. The purpose of the survey was to complement the qualitative data in order to gain a broader perspective of the issues surrounding the parenting of deaf children by hearing parents.

#### **3.4.2.3 Strategy of inquiry (qualitative approach): phenomenology**

Creswell (2009: 176; 2007: 184) as well as Creswell and Plano Clark (2007: 169) identify five approaches or strategies of qualitative inquiry. These include narrative, phenomenology, grounded theory, ethnography, and case study. Phenomenology, “the study of lived, human phenomena within the everyday social contexts in which the phenomena occur from the perspective of those who experience them” (Titchen & Hobson, 2005: 121), is used in this study.

Phenomenological research focuses on the study of human experience, in order to get a deeper understanding of its essence, and to make meaning of the lived experiences of a phenomenon as described by the participants (Creswell, 2007: 58; Creswell, 2009: 13; Fouché, 2005: 270). The purpose of phenomenological research is to “grasp the very nature of the thing” (Van Manen, 1990: 177). The term “hermeneutical phenomenology” is used by Van Manen (1990: 4) to describe “lived experience” and the interpretation of the “texts” of human life. Phenomenology is an interpretive process in which the researcher “mediates” between different meanings of lived experience (Van Manen, 1990: 26). The intent of this study is to explore the phenomenon of hearing parents raising deaf children, and to research the experiences of these parents who are a subset of all possible

parents. This is best undertaken using mixed methods, which combine the qualitative and quantitative approaches, giving priority to the qualitative approach.

One of the characteristics of the qualitative approach entails that the researcher gains a first-hand and holistic understanding of phenomena through the use of a flexible strategy such as unstructured interviewing to gain an in-depth knowledge of how participants construct their social worlds (Fortune & Reid, 1999: 94). Qualitative research, in its broadest sense, allows participants to give accounts of meaning, experience and perceptions in their own words. In order to understand fully the values linked to people's experiences, the researcher needs access to in-depth knowledge and understanding of the participants' life worlds as well as to qualitative and subjective interpretations. The researcher is therefore concerned with a subjective exploration of social reality in a natural setting, from the perspective of an insider (Terre Blanche & Durrheim, 1999: 215).

Qualitative research entails the use of small samples that are often selected for a specific purpose (Flick, 2006: 19). Several writers concur that the purpose of qualitative research is to construct detailed descriptions of social reality, using participants' natural language to gain a genuine understanding of their social worlds (Neuman, 2006: 157; Flick, 2006: 12; Fouché & Delport, 2005: 75; Mc Intyre, 2005: 209; Henning *et al.*, 2004: 5; Terre Blanche & Durrheim, 1999: 215; Creswell, 2003: 181; Denzin & Lincoln, 2003: 5). In qualitative research the researcher cannot escape the personal interpretation brought to the analysis of data (Henning *et al.*, 2004: 7; Creswell, 2003: 182).

Fouché and Delport (2005: 74) point out that a qualitative approach allows a researcher to elicit participants' accounts of experiences, perceptions or meaning. It also gives rise to rich descriptive data that incorporates the participants' own natural language, and entails understanding the participants' values and beliefs underpinning the phenomenon under study. Marshall and Rossman (1999: 46) concur and add that a qualitative approach is the preferred one for research that delves deeply into complexities, while Fortune and Reid (1999: 94) aver that through a qualitative approach, the researcher can gain valid

understanding through first hand acquisition of accumulated knowledge. Therefore the aim of a qualitative approach is to elicit accounts of participants' experiences, perceptions and meaning in order to investigate social reality. Qualitative research involves the use of empirical methods and materials that provide insight into "routine and problematic moments and meanings in individuals' lives" (Denzin & Lincoln, 2003: 5). This could result in a more accurate understanding of the meanings people attach to their lived experiences.

In this study the researcher, in a quest to explore and understand the phenomenon of hearing parents' experiences of raising deaf children, became personally involved in the research, through in-depth, one-on-one interviews of twenty hearing parents raising deaf children. A composite description of the phenomenon, using participants' actual words to make better sense of their social reality, is given.

Moustakas (in Fouché, 2005: 270) and Van Manen (1990: 177) suggest that the basic purpose of phenomenological research is to reduce the accounts of participants' experiences to a central meaning to derive the essence of the experience. In order to describe the essence of the experience being studied the researcher should gain entry into the participants' life world or life setting, through naturalistic methods of study whereby conversations and interactions with participants can be analysed. This will result in what Geertz (in Henning *et al.*, 2004: 6) refers to as "thick description", which not only goes beyond facts and empirical context, but may also allow for interpretation of the information in the light of other empirical information that emerges from the study. Moustakas (in Creswell, 2007: 58; Fouché, 2005: 270) explains that the researcher collects data from individuals who have experienced the phenomenon being studied (in the case of this study, hearing parents raising deaf children), which then leads to the development of a composite description to capture the essence of all of the participants' experiences.

### **3.5 PURPOSE STATEMENT**

This mixed methods study addresses, from an ecosystemic perspective, the way hearing parents experience and manage their parental role of raising deaf children. A concurrent triangulation mixed methods design was used, a type of design in which different but complementary data was collected on the same phenomenon. In this study, a survey instrument was used to collect data about how various ecosystemic variables influence the experiences of hearing parents raising their deaf children in three provinces (KwaZulu-Natal, Gauteng, and Western Cape) in South Africa. Concurrent with this data collection, qualitative interviews explored the phenomenon of hearing parents raising deaf children. The reason for collecting both quantitative and qualitative data was to bring together the strengths of both forms of research to corroborate results, in order to gain a better understanding of the research problem, and to find answers to the research questions outlined in the next section.

### **3.6 RESEARCH QUESTIONS**

The primary research questions in this study are:

- To what extent do various ecosystemic variables influence the experiences of hearing parents raising their deaf children in this country?
- What are the experiences of hearing parents in the raising of deaf children?

Based on the findings of the above questions, a secondary research question can be posed:

- How might hearing parents be supported in their unique role of raising deaf children, so as to facilitate their own emotional well-being and in turn, provide an enabling environment for the holistic development of their deaf children?

### **3.7 SAMPLING**

In this section general information about sampling, including probability, non- probability (purposive), and mixed methods sampling, will be outlined. This will be followed by a discussion of the quantitative and qualitative sampling strategies selected for this study.

Strydom (2005: 194) states that sampling is perhaps the most important action in the entire research process. The reason why a sample is studied is to try to understand the population from which it is drawn. It also helps to explain some aspects of the population. Besides, it is not practical and seldom possible to include an entire relevant population in order to study a phenomenon. The main reason for sampling is therefore feasibility, taking into consideration factors such as cost, effort and time. Likewise, it would be difficult to process, analyse and interpret the huge amount of data produced if the population is too large, in which case it would be more feasible to study only a portion of the population. Somekh and Lewin (2005: 348) state that a sample comprises the individuals who are included in data collection, and who are selected from the entire population.

Sampling procedures for qualitative and quantitative research differ and are generally divided into two broad groups, namely, probability, and non-probability (purposive) categories. While probability sampling aims at achieving greater breadth of information from a larger sample, purposive sampling aims at achieving greater depth of information from a smaller sample. Both probability and non-probability sampling have a variety of sample types and procedures, and although some of these sampling procedures are associated with either the quantitative or the qualitative method, most of them can be used interchangeably (Tashakkori & Teddlie, 1998: 74).

However, Teddlie and Yu (2007: 77) claim that there are actually four categories, the two additional ones being, convenience sampling, and mixed methods sampling. Convenience sampling entails selecting samples that are easily accessible and willing to participate in a research study. Mixed methods sampling involves selecting samples for research drawing

on “both probability sampling (to increase external validity) and purposive sampling strategies (to increase transferability)” (Teddlie & Yu, 2007: 78).

Probability sampling techniques are used mainly in quantitative studies, the aim being to achieve representativeness, that is, the degree to which the sample is representative of the entire population. It involves “selecting a relatively large number of units from a population, or from specific subgroups (strata) of population, in a random manner where the probability of inclusion for every member of the population is determinable” (Tashakkori & Teddlie, 2003: 713). Probability sampling techniques include three basic types, namely, random, stratified and cluster sampling, to which another category can be added, that is, “multiple probability techniques” (Teddlie & Yu, 2007: 78).

Purposive/non-probability sampling techniques are used mainly in qualitative studies and involve deliberately choosing individuals, groups, or institutions for specific purposes linked to research questions. They are defined as sampling whereby “particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices” (Maxwell, 1997: 87). In non-probability sampling, the researcher has limited knowledge about the larger population from which the sample is taken, and cannot be certain that the sample is representative of the wider population (Neuman, 2006: 220; Strydom, 2005: 201). There are three broad categories of purposive sampling techniques, namely, sampling to achieve representativeness or comparability, sampling special or unique cases (including among others, criterion sampling), and sequential sampling (including among others, snowball or chain sampling). Each of these categories encompasses various specific types of procedures. In addition, there is a fourth category, that is, multiple purposive techniques, which involves the use of two or more purposive sampling techniques combined (Teddlie & Yu, 2007: 80-81).

### **3.7.1 Mixed methods sampling**

Mixed methods sampling, employed in this study, involving both probability and purposive sampling techniques, allows researchers to collect complementary sets of data that can give both depth and breadth of information pertaining to the phenomenon being explored. Both numeric and narrative data are usually generated through mixed method sampling. Teddlie and Yu (2007: 89) suggest the following provisional typology of mixed methods sampling strategies: basic, sequential, concurrent, and multilevel mixed methods sampling, as well as a combination of these sampling strategies.

Mixed methods sampling sometimes involves a compromise between the requirements of quantitative and qualitative samples, which Teddlie and Yu (2007: 87) refer to as “representativeness/saturation trade-off”. This means that when more emphasis is placed on the representativeness of the quantitative sample, less emphasis is placed on the saturation of the qualitative sample, and vice versa. The term saturation is used “to describe the point when you have heard the range of ideas and aren’t getting new information” (Kreuger & Casey, 2000: 26). In this mixed methods study where a combination of probability and purposive sampling techniques was used, more emphasis was brought to bear on the saturation of the qualitative sample, while less emphasis was placed on the representativeness of the quantitative sample.

### **3.7.2 Quantitative sampling**

Probability sampling, often used in quantitative studies, involves random, stratified, cluster, and multiple probability sampling techniques (Teddlie & Yu, 2007: 87). In quantitative sampling, the purpose of sampling is to select individuals who are representative of the target population so that the results can be generalised to the population.

Graziano and Raulin (in Strydom, 2005: 193) state that the concept of representativeness has important implications for generalisability, since findings of a study can only be

generalised on the assumption that what was observed in the sample would also be observed in any other group of participants from the population. Lewin (2005: 217) concurs with this view and adds that informed choices have to be made to ensure that the sample is as representative as possible, using one of a number of sampling strategies, to try and overcome potential limitations. An example of probability sampling is the random sampling procedure. However, random sampling, in which each individual in the population has an equal chance of being selected, is not always workable (Creswell & Plano Clark, 2007: 112).

Multi-stage cluster sampling is an example of a probability sampling procedure (Tashakkori & Teddlie, 1998: 75). Lewin (2005: 217), as well as Creswell (2003: 156) explain that multi-stage sampling involves the researcher first sampling clusters or organisations (such as schools for the Deaf), obtaining names of individuals within the organisations or clusters and then sampling within the cluster (*e.g.* only hearing parents, not deaf parents, raising deaf children). Babbie (in Creswell, 2003: 156) states that this type of sampling is ideal when it is “impossible or impractical to compile a list of the elements composing the population”.

In this study multi-stage cluster sampling was used to select the sample for the survey. It included 157 hearing parents of deaf children who were enrolled at any of the six schools for the Deaf in three provinces in South Africa, namely, KwaZulu-Natal, Western Cape and Gauteng. These provinces were chosen since they have the largest number of schools for the Deaf. The schools were randomly chosen. The assistance of the principals was enlisted to identify those hearing parents whose deaf children were attending these schools. These participants were chosen to maximise the possibility of obtaining background information about their experience of the parenting role, as their experiences of raising deaf children would contribute to and provide an added perspective to the phenomenon under investigation. Table 3.1 reflects the biographical details of the 157 participants who completed the questionnaire.



**Table 3.1 Biographical information of participants who completed the questionnaire**

	Number	%
Sample size of questionnaire disseminated to:	250	
Total number of questionnaires responses returned:	157	
% of sample size returned:		63
<u>Participant's relationship to deaf child:</u>		
Number of mothers	120	76
Number of fathers	24	15
Number of guardians	5	3
Number of grandparents	5	3
Other relationship	2	1
<u>Participant's home language:</u>		
English	99	63
Afrikaans	30	19
IsiZulu	23	15
Other	4	2
<u>Age of deaf child:</u>		
1 – 5 years	27	17
6 – 13 years	99	63
14 years +	27	17
No response	4	3
<u>Age of child on diagnosis of deafness:</u>		
Before 2 ½ years	120	76
After 2 ½ years	28	18
No response	9	6

Of the 250 questionnaires that were disseminated 157 were returned, which constitutes a response rate of 63%. With regard to the participants' relationship to the deaf child, 120 were mothers, 24 were fathers, 5 were guardians, 5 were grandparents, and 2 indicated that their relationship to the deaf child did not fall into any of these categories.

Regarding the participants' home language, 99 were English speaking, 30 were Afrikaans speaking, 23 were IsiZulu speaking, and 4 indicated "other" as their home language. With regard to the age of the deaf child, 27 fell into the category 1-5 years, 99 were between 6 and 13 years of age and 27 were older than 13 years. 4 participants did not indicate the age of the deaf child.

Regarding the age of the child when deafness was diagnosed, 120 children were diagnosed as deaf before thirty months of age, 28 were over thirty months old when diagnosis of deafness was confirmed, while 9 participants did not indicate the age at which the child's deafness was diagnosed.

### **3.7.3 Qualitative sampling**

Non-probability sampling which is often used in qualitative studies comprises a variety of techniques, such as purposive or judgmental sampling, in which the participants are chosen with a specific purpose in mind, based on the researcher's judgment; snowball or chain sampling, in which potential participants are identified by other persons who know such participants; and criterion sampling, whereby all participants have to meet some criterion which contributes to quality assurance (Creswell, 2007: 127; Neuman, 2006: 220).

In purposive sampling the sample consists of participants who have the most typical or representative attributes of the population based on the researcher's judgment (Neuman, 2006: 222; Strydom, 2005: 202; Lewin, 2005: 218; McIntyre, 2005: 105; Cohen, Manion & Morrison, 2000: 104, Tashakkori & Teddlie, 1998: 76). Cohen *et al.* (2000: 102) state that non-probability sampling can be perfectly adequate for a study where the researcher does not intend to generalise findings from the sample to the population.

In qualitative research, purposeful decisions rather than random sampling are preferable, since sampling decisions determine the way the reality under study is constructed, what becomes empirical material in the form of text, what is taken from the text material and

the way it is used to construct meaning (Flick, 2003: 133-134). Qualitative researchers adopt the position that “no individual or group is ever only an individual or group”, and that each case must be studied in context, taking into account the background of more universal social experiences and influences (Strydom & Delport, 2005: 328). This view concurs with Bronfenbrenner’s (1992; 1998) ecological systems theory which was revised and later became known as the bioecological model of human development (*c.f.* 2.2).

Creswell (2003: 220) states that criteria for the selection of participants need to be clearly identified and formulated. Morse (1998: 73) specifies several general criteria for a “good informant” especially for interviews. Those who fulfill all the criteria are regarded as a “primary selection”, whereas those who do not, are considered “secondary selection”. These criteria comprise the following: they should be knowledgeable and have experience for answering the questions about the issue being investigated; they should be capable of reflecting and articulating; they should be able to give of their time for the interview, and they should be ready to participate in the study. In the case of this study I am confident that the participants have met all these criteria.

The non-probability sampling procedure involving a combination of techniques was used in this study. These included snowball or chain sampling (in which potential participants were identified by the principals of six schools for the Deaf in Gauteng, Western Cape, and KwaZulu-Natal who knew the participants); criterion sampling (participants had to fit the criterion of being hearing parents of deaf children attending one of the six schools for the Deaf so that they could contribute to the understanding of the research problem through their parenting experience); as well as convenience sampling (involving participants who were accessible and willing to participate in the study), which according to Creswell (2007: 127), “saves time, money and effort, but at the expense of information and credibility”.

However, Strydom and Delport (2005: 329) state that it is important for the researcher to think critically about the parameters of the population when choosing the purposive sampling technique. Creswell (2003: 220) makes the point that in qualitative data

collection purposeful sampling involves the selection of individuals who have experienced the central phenomenon under investigation, and that the “purposeful selection of participants represents a key decision point in a qualitative study” (Creswell, 1998: 118). The purpose of conducting semi-structured, one-to-one interviews with 20 hearing parents of deaf children was aimed at finding answers to the main research questions.

For this reason the chairpersons of the governing bodies of the six school’s were contacted for permission to conduct research at the school, and the principals were requested to provide names of hearing parents who would be willing to participate in interviews, and share their experiences of raising deaf children who had attended, or were currently enrolled at a school for the Deaf. The biographical details of the 20 interview participants follow:

**Table 3.2 Biographical information of participants interviewed**

NO.	CODE NAME	RACE	GENDER	MARITAL STATUS	EMPLOYED	RELOCATED	NO. OF CHILDREN	NO. OF DEAF CHILDREN	GENDER OF DEAF CHILD	POSITION OF DEAF CHILD IN FAMILY	AGE OF DEAF CHILD	AGE AT WHICH DEAFNESS DIAGNOSED	GEOGRAPHIC LOCATION
1	Amy	W	F	M	Yes	No	2	1	M	1	14	6 months	Gauteng
2	Barbara	W	F	M	Yes	Yes	2	1	M	1	20	2 weeks	Gauteng
3	Constance	B	F	M	Yes	Yes	1	1	M	1	8	6 months	Gauteng
4	Devi	I	F	M	No	Yes	1	1	F	1	7	6 months	Gauteng
5	Edna	W	F	M	Yes	No	2	1	F	1	13	6 months	KZN
6	Frieda	W	F	M	Yes	Yes	3	1	F	2	8	24 months	KZN
7	Grace	W	F	M	Yes	Yes	4	1	F	4	3	6 months	KZN
8	Hemma	I	F	M	Yes	No	2	1	M	1	8	30 months	KZN
9	Indrani	I	F	M	Yes	No	1	1	M	1	9	24 months	KZN
10	Judy	W	F	M	No	Yes	2	1	F	1	7	24 months	KZN
11	Kate	W	F	M	Yes	No	3	1	M	3	8	18 months	W Cape
12	Lydia	W	F	M	Yes	No	1	1	F	1	8	24 months	W Cape
13	Marie	W	F	M	Yes	No	2	1	F	2	20	18 months	W Cape
14	Nico	C	M	M	Yes	No	2	1	F	1	14	18 months	W Cape
15	Olivia	W	F	M	Yes	No	4	1	F	1	13	11 months	W Cape
16	Patricia	W	F	M	Yes	Yes	2	1	F	2	15	8 months	W Cape
17	Queenie	W	F	D	Yes	Yes	2	2	M	1	13	42 months	W Cape
18	Rene	W	F	D	No	No	1	1	M	1	16	18 months	W Cape
19	Stefan	W	M	M	Yes	Yes	3	1	F	1	18	14 months	W Cape
20	Tanya	W	F	M	Yes	Yes	3	1	M	3	4	6 months	W Cape

The names assigned to participants are pseudonyms, to protect their identity. In terms of race, 15 participants were White, 1 was Black, 1 was Coloured, and 3 were Indian. 18 participants were female while 2 were male. With regard to marital status, 18 were married, and 2 were divorced. 3 participants were unemployed while 17 were employed. 10 of the participants resided in Western Cape, 4 in Gauteng and 6 in KwaZulu-Natal. The number of children per participant ranged from 1 to 4, with an average of two children per participant. Each participant had one deaf child, with the exception of one, who had deaf twins. Of the participants' deaf children 9 were male and 11 were female. Their ages ranged from 4 years to 20 years, the average age being approximately 10 years. The ages at which deafness was diagnosed ranged from 2 weeks to 42 months, with the average age being approximately 20 months. 10 of the 20 participants relocated to another province or within the same province for the sake of the deaf child's education.

In concluding this section on sampling, suffice to say that Erlandson, Harris, Skipper and Allen (1993: 118) emphasise the need for the search for data to be guided by processes that will maximise the range of information and provide rich detail regarding the specific context being studied. Therefore, a combination of probability and non-probability sampling techniques were used in this mixed methods study, namely, multi-stage cluster sampling, purposive sampling, snowball sampling, criterion sampling, as well as convenience sampling techniques, in order to generate rich data which would provide an in-depth understanding of the phenomenon of hearing parents raising deaf children.

### **3.8 DATA GENERATION**

The concurrent triangulation design that is employed in this mixed methods study necessitates the simultaneous generation of quantitative (less dominant) and qualitative (dominant) data, to provide a better informed understanding of the phenomenon of hearing parents raising deaf children. Both quantitative and qualitative data generation will be discussed below.

### **3.8.1 Quantitative data generation**

The selected quantitative approach to inquiry comprised survey research mainly to provide a background to the life worlds of hearing parents raising deaf children. The data generation instrument used in my study was a structured questionnaire. The use of the term ‘participants’ (which is generally associated with qualitative research) rather than the term ‘respondents’ (which is usually linked to quantitative research) is preferred for this study given the fact that the qualitative approach to inquiry is dominant and given priority. What follows is a brief discussion about the questionnaire as a quantitative data collection instrument, including its advantages and limitations, after which the quantitative data generation procedures of this study will be explained.

#### **3.8.1.1 The questionnaire as a quantitative data generation instrument**

The questionnaire is a data generation instrument generally used to collect survey information. There are three different types of questionnaires, including structured, unstructured, and semi-structured types. A structured questionnaire comprises closed questions, and enables the researcher to identify patterns and make comparisons. An unstructured questionnaire comprises open-ended questions that allow participants the freedom to write what they want, and are more word-based. The semi-structured questionnaire is a “powerful tool” with a clear focus and structure, but is open-ended and comprises a series of statements, items or questions which participants respond to or comment on in their own words (Cohen *et al.*, 2007: 321).

In this study a structured questionnaire was administered. It was developed on the basis of discussions with relevant stakeholders, namely, psychologists, social workers, educators and hearing parents of deaf children, as well as through a survey of literature pertaining to the parenting of deaf children. A Likert-type scale questionnaire with three response categories, namely agree, disagree, uncertain was constructed. The three response categories facilitated the placement of responses into one of the three categories, thereby enabling the researcher to determine the direction of their responses. The main purpose of

the questionnaire in this study was to obtain background information about the life worlds of hearing parents of deaf children, and to address the research question: *To what extent do various ecosystemic variables influence the experiences of hearing parents raising their deaf children in this country?*

The first section of the questionnaire called for biographical information and comprised five items, pertaining to participants' relationship to the deaf child, their gender, home language, age of deaf child, and age of the child when deafness was diagnosed. To protect the identity of the participants they were not required to provide their names. The next section comprised 25 questions in the form of statements relating *inter alia* to the diagnosis of deafness, as well as issues related to family, school and community that influence their experiences as hearing parents raising deaf children. The findings from the quantitative data were used to complement support to the qualitative enquiry which was the dominant research method used.

#### **3.8.1.2 Advantages and limitations of questionnaires**

Questionnaires have their strengths as well as their limitations. According to Wilson and McLean (1994: 21) the questionnaire is a useful and widely used instrument for the generation of survey information. It provides structured data and can be administered in the absence of the researcher. Neuman (2006: 299), as well as Lewin (2005: 219), claim that it is often relatively straightforward to analyse, and that this type of survey is by far the cheapest and can be sent to a vast geographical area, and conducted by a single researcher. Delport (2005: 167) concurs in that data can be obtained from a large number of participants within a short time, and adds that the participants enjoy freedom in completing the questionnaire, since they are shielded from the possible influence of bias from the field worker. Beside the low cost, a distinct advantage of a self-administered questionnaire is that of anonymity, as participants are more likely to give valid answers when answering questions of a sensitive nature (McIntyre, 2005: 167). Structured questionnaires containing closed questions can be quick and easy to code, and participants



are not unduly discriminated against on the basis of how articulate they are (Wilson & McLean, 1994: 21).

However, there are certain limitations to the use of the structured questionnaire as a survey instrument. It is time-consuming to develop, pilot and refine the questionnaire. Oppenheim (1992: 115) states that the scope of the data to be collected as well as the flexibility of response can be limited, as the participants cannot add any remarks, or explanations for the categories, and that the categories might not be exhaustive. Some of these limitations also applied to this study as flexibility of responses was restricted, and some categories were not exhaustive.

With regard to questionnaires that are posted, Cohen *et al.* (2007: 345) claim that often, “the postal questionnaire is the best form of survey in an educational inquiry”, and that it has several distinct advantages, especially in terms of time, and resources. However, Delport (2005: 167) and Neuman (2006: 299) state that one of the biggest problems with posted questionnaires is that people do not always complete, respond to, or return the questionnaires. Neuman (2006: 299) adds that the conditions under which a questionnaire is completed cannot be controlled by the researcher, and that incomplete questionnaires can also be a major problem. Delport (2005: 167) adds that if the questionnaire is long and if questions are unclear, or complex and require in-depth thought, the non-response rate may be very high. However, with regard to this study the response rate to the questionnaire was acceptable as 63% of the questionnaires were completed and returned.

### **3.8.1.3 Quantitative data generation process**

The questionnaire was piloted amongst parents of two deaf children attending a school for the deaf and a few minor amendments were effected. In the biographical section the question pertaining to family income was omitted as the pilot participants felt that it was confidential information that would not affect their responses to the rest of the questionnaire. After gaining permission to conduct research at schools for the Deaf, the questionnaires were posted to the principals of three schools in Gauteng and the Western

Cape. Questionnaires were personally delivered to the principals of three schools in KwaZulu-Natal, and their assistance was enlisted to distribute them to hearing parents of deaf children who were currently enrolled at their schools. School administrators and participants were informed of the reasons for conducting research among hearing parents of deaf children, via written communication. A total of 250 questionnaires were disseminated, of which 157 (63%) were returned. This is a high response rate, considering the claim by Cohen *et al.* (2007: 345-346) that a well-planned postal survey is expected to yield at least a 40% response rate. The high return rate may be indicative of the perceived need of the participants for an inquiry into their particular experiences and their need for assistance.

A covering letter, in which ethical issues were also addressed, accompanied the questionnaire. This informed participants of the purpose of the research, and the potential benefits of the research. Participants were assured of confidentiality and anonymity. Simple instructions were given regarding the answering of the questionnaire. The estimated time for completion of the questionnaire was half an hour to forty five minutes (See Annexure 1: Questionnaire).

### **3.8.2 Qualitative data generation**

The qualitative approach helped provide valuable answers to the main research question: *What are the experiences of hearing parents in the raising of deaf children?* Since the qualitative data generation instrument used in this study was interviews, this section will include a brief, general discussion of interviews, including the advantages and limitations of interviews, followed by a discussion of qualitative data generation procedures used in this study, as well as an outline of field notes made pertaining to the interviews. A table showing the biographical information of participants in the interviews will be provided.

### **3.8.2.1 Interviews as a qualitative data generation instrument**

Several data generation instruments are used in qualitative research, and the basic types include interviews, observation, document analysis, and visual participation instruments (Creswell, 2009: 179-180; Creswell, 2007: 130; Flick, 2006: 273). Since the qualitative approach to inquiry in this study is located in phenomenology, the data generation instrument deemed most appropriate was interviews. Interviews are social interactions whereby meaning is negotiated between interviewer and interviewees. Interviews are conducted to find out about other people's stories because these are a source of information. Additionally, story telling is a meaning-making process. Both interviewer and interviewee are unavoidably and deeply involved in meaning-making (Seidman, 1998: 1).

The purpose of interviews in this study focussed on the generation of "thick descriptions" of hearing parents' subjective experiences of raising deaf children. Denzin (in Creswell, 2007: 194) describes this process as extending beyond surface experiences and just facts, as it takes into account details, emotionality, as well as networks of social relationships, and contextualises experience so that the participants' feelings, actions and meanings are understood and their voices are heard. In a similar vein, Geertz (in Henning *et al.*, 2004: 37; Denzin & Lincoln, 2003: 25; Van Manen, 1992: 178) suggests the use of interpretive, open-ended approaches as means of gathering "thick descriptions" of particular events, so as to make sense out of a local situation, is valuable.

There are several types of interviews identified by various authors. LeCompt and Priessel (in Cohen *et al.*, 2007: 353), for example, refer to standardised, in-depth, ethnographic, elite, focus group and life history interviews. Creswell (2007: 130) identifies unstructured, semi-structured, and focus group interviews with variations in terms of the way these are conducted, *e.g.* face-to-face, e-mail, on line focus group and telephone interviews. Likewise, Greeff (2005: 292-299) identifies one-to-one unstructured and semi-structured interviews, ethnographic interviews, and focus group interviews. Wilkinson and

Birmingham (2003: 45), as well as Terre Blanche and Durrheim (1999: 128), state that three types of interviews exist, namely, unstructured, structured and semi-structured.

The unstructured interview is very flexible, and although the areas of interest are set by the interviewer, the participant generally guides the discussion which can be difficult to channel and to analyse if it goes off track (Wilkinson & Birmingham, 2003: 45). The unstructured interview “merely extends and formalises conversation, and is also referred to as a “conversation with a purpose” (Greeff, 2005: 292). Its chief purpose is to understand the experiences of other people and to make meaning of that experience. Terre Blanche and Durrheim (1999: 128) hold the view that if the researcher wants participants to talk in some depth about their experiences and feelings regarding an area of interest, then the unstructured interview is the mode to use.

The structured interview, according to Wilkinson and Birmingham (2003: 45), is regarded by some as “no more than a questionnaire that is completed face to face”. All the questions are pre-determined and the interviewer has control over the order of the questions. According to Terre Blanche and Durrheim (1999: 128), if all that is required is straightforward information, a structured interview – “essentially just a list of standard questions” – would suffice.

The semi-structured interview is less flexible than the unstructured interview as the interviewer guides the interview more closely, although the participant has sufficient opportunity to “shape the flow of information” (Wilkinson & Birmingham, 2003: 45). May (in Greeff, 2005: 292) defines semi-structured interviews as those that focus on areas of particular interest, while still allowing sufficient flexibility in scope and depth. The interviewer controls the direction of the interview more closely, and questions are pre-planned. Greeff (2005: 269) states that semi-structured interviews are generally used to gain a detailed account of participants’ beliefs, or perceptions about a particular topic, adding that they are particularly suitable for researching issues that are complex, personal or controversial. Terre Blanche and Durrheim (1999: 128) state that the semi-structured interview is the most popular kind of interview, where the researcher develops a list of

key topics and perhaps subtopics in advance. This interview schedule is useful to steer the interview in the desired direction.

The one-to-one semi-structured interview was used in my study to explore the phenomenon of hearing parents raising deaf children. The main question participants were asked was: *What is it like to be a hearing parent raising a deaf child?*

### **3.8.2.2 Advantages and limitations of interviews**

Although interviewing is the primary mode of data generation in qualitative research and has gained much popularity with researchers (Flick, 2006: 149; Barbour & Schostak, 2005: 41; Greeff, 2005: 287; Atkinson & Silverman, in Henning *et al.*, 2004: 51; Wilkinson & Birmingham 2003: 43), interviews have their advantages as well as limitations. One of the advantages of interviews is that they are a more natural way of interacting with people than getting them to fill out a questionnaire, take a test, or participate in an experiment. It affords the researcher the opportunity to get to know the participants better so as to gain a deeper understanding of their views and emotions (Terre Blanche & Durrheim, 1999: 128).

Another advantage of interviews is that they can be tape-recorded. Sacks (1992: 26) strongly recommends the use of the tape recorder to record interviews on the grounds that it is impossible to remember every detail such as “pauses, overlaps, and inbreaths”, and that by studying the tape recordings of conversations the researcher is able to focus on “actual details of actual events”. However, tape recording has its disadvantages in that the participant may feel uncomfortable and may even withdraw from the interview (Greeff, 2005: 298). Fortunately this did not happen in this study as the participants stated that they were comfortable with having the interview audio-taped. Participants were made to feel at ease to enable them to speak freely as the researcher explained the purpose of tape-recording the interviews. Besides, it was made clear at the outset that if the participants were not comfortable with the tape recorder it would be switched off.

The advantage of the unstructured interview for the qualitative researcher is that it “apparently offers the opportunity for an authentic gaze into the soul of another” (Denzin & Lincoln, 2003: 343). The disadvantage is that it is difficult for the researcher to channel the discussion if the participant steers away from the main subject matter. In addition, the analysis of the unstructured interview can prove extremely difficult (Wilkinson & Birmingham 2003: 45).

The advantages of the semi-structured face-to-face interview are that the interviewer knows when to use contingency questions to probe further, and can control the sequence of questions. Additionally, the interviewer can also observe the setting and the use of non-verbal communication cues and visual aids such as body language (Neuman, 2006: 301; McIntyre, 2005: 167). Greeff (2005: 294) adds that the researcher and participant have some degree of flexibility, and the researcher is able to follow up interesting areas that emerge from the responses. Furthermore, participants are able to provide greater detail, thereby furnishing an in-depth account of their life experiences, as questions are open-ended.

A major disadvantage of face-to-face interviews is the high cost factor. It is also the most labour-intensive type of interview because of the time spent travelling and interviewing participants in different places (Greeff, 2005: 299; McIntyre, 2005: 167). In this study the cost factor was something to contend with, as the researcher travelled to schools in three different provinces in South Africa in order to interview participants. This was time-consuming and required much patience.

Field and Morse (1994: 67-73) point out the several limitations of interviews, some of which are listed below:

- *Interruptions and competing distractions:* The most common interrupter is the telephone. Interruptions distract the participant and break the trend of thought. It takes time to regain the level of intimacy that was established. A high quality interview requires concentration on the part of the researcher and participant.

- *Stage fright*: Participants may feel intimidated by the use of a tape recorder and open-ended questions may make them feel vulnerable.
- *Awkward questions*: Some questions may make participants feel uncomfortable
- *Teaching and preaching*: This could occur if participants trap the researcher into this mode by asking questions or by giving responses which reveal misinformation on their part.
- *Jumping*: This occurs when the researcher asks questions in an illogical sequence.
- *Counselling*: If this happens early in the interview it leads to premature closure of the topic and inhibits in-depth inquiry.
- *Superficial interviews*: Often interviews are shallow as the researcher hurries the participant along without giving any attention to non-verbal cues, and not spending enough time getting to know the participant.
- *The use of translators*: The interview process can be slowed down as the translator first has to translate before the participant and researcher understand each other. Moreover, the translator may not give an accurate translation of the participants' affective meaning and expression.

Of these limitations, the one relating to interruptions applied to this study, when the telephone rang twice during the interview in a participant's office. The interview had to be paused while the participant took the call. However, the rest of the interviews were conducted in designated venues at the schools, where the possibility of interruptions was minimised. There was no need to use translators as all the interviews were conducted in English which participants were familiar with, even though for some, English was not their mother tongue. Two participants (one Afrikaans-speaking and the other Xhosa-speaking) did code-switch very occasionally, but this did not present a problem as I enlisted the help of colleagues to translate these utterances.

In this study, the participants were very willing and happy to participate, and their responses to questions were relevant and insightful. Seidman (1998: 91) raises an interesting point that in-depth interviewing can threaten the limits of intimacy that can develop, causing the participant to become emotionally troubled. In this study, some

participants became emotional and wept as they relived their early experiences of the pain and trauma they felt at the time of diagnosis of deafness, and as they recalled the painful experiences and the challenges they faced along the journey of raising their deaf children. In these cases the interviews were temporarily stopped, participants were comforted, and they were reminded that they need not continue if they did not wish to, or if they felt uncomfortable with any question of a sensitive nature. However, after regaining their composure they chose to continue with the interview, rather than stop. Their willingness to continue was indicative of their need to speak to someone who would listen to them about their unique experiences, however painful those could have been.

### **3.8.2.3 Qualitative data generation process**

In this study, semi-structured one-to-one interviews were conducted with twenty hearing parents of deaf children who had attended, or were currently enrolled at one of six schools for the Deaf in KwaZulu-Natal, Gauteng and Western Cape. With the permission of participants the interviews were tape-recorded. The audio-tapes were subsequently transcribed for close analysis. Each interview lasted approximately 45minutes to one hour.

Field notes were kept of observations pertaining to the settings in which interviews took place and the participants themselves. Salient points were noted regarding personal information about participants such as those relating to their family, home, employment, marital status and contact details, where available. Table 3.2 which reflects the biographical information of interviewed participants captures some of these details. During the interviews key words were jotted down, where necessary, for example, of the emotional state of the participants, some of whom broke down and wept, while others held back their tears and tried to stop their voices from quivering when recalling sensitive issues relating to their parenting experiences. Observations of participants' non-verbal communication cues such as facial expressions, gestures, and body language were noted, and the field notes were useful for analysing and interpreting the data.



### **3.9 DATA ANALYSIS**

In this section an overview of quantitative and qualitative data analysis procedures will be presented. This will be followed by a discussion of mixed methods data analysis procedures relating to my study. In mixed methods research, data analysis comprises the analysis of both qualitative and quantitative data using qualitative and quantitative methods respectively, to address the mixed methods question. The type of data analysis procedures varies depending on the type of mixed method design chosen for the study (Creswell & Plano Clark, 2007: 128).

Data analysis is the process whereby the researcher brings structure and order to the vast amount of data collected, and looks for patterns in the data in order to make sense of it, leading to interpretation and meaning-making (Neuman, 2006: 458; De Vos, 2005: 333; Somekh, Stronach, Lewin, Nolan and Stake, 2005: 337; Creswell, 2003: 190). For data analysis in both quantitative and qualitative approaches researchers draw inferences from the data to look for meaning and to reach a conclusion based on evidence and reasoning after simplifying the complexity of the data. Comparison is central to the process of all data analysis, and all social researchers compare the evidence they have collected with related evidence, in an attempt to find similarities and differences, and look for more authentic, valid or worthy descriptions and explanations (Neuman, 2006: 458).

The processes for both qualitative and quantitative data analysis are similar, and these steps entail: preparing the data for analysis, exploring the data, analysing the data, representing the analysis, and validating the data (Creswell & Plano Clark, 2007: 129). These steps are explained briefly as follows:

- Preparing the data for analysis involves converting the raw data into a form that can be used for data analysis
- Exploring the data comprises an examination of the data with a view to developing broad trends and shaping the distribution, as well as reading through the data, making memos, and developing a general understanding of the data

- Analysing the data involves an examination of the data to address the hypotheses or the research questions
- Representing the data analysis involves presenting the results of the analysis in the form of a summary, *e.g.* tables, figures, or statements summarising the results
- Validating the data means checking on the quality of the data and results.

### **3.9.1 Mixed methods data analysis**

In mixed methods research data analysis occurs both within and often between the quantitative and qualitative data, and data analysis relates to the type of design chosen for the procedures (Creswell & Plano Clark, 2007: 135; Creswell, 2009: 218; 2003: 220). In this study the concurrent triangulation design was used, which involved conducting a separate initial data analysis of both quantitative and qualitative data, and comparing the findings from both sets of data during the discussion of findings in the interpretation stage. Creswell (2009: 213) refers to this as “side-by-side integration”. Tashakkori and Teddlie (2003: 35) maintain that the main advantage of using mixed methods lies in the quality of inferences that are made at the end of the study. The term ‘inferences’ can be used by both qualitative and quantitative researchers as it refers to the conclusions that are derived inductively or deductively from the study. Inferences are based on the researcher’s interpretations of the results or outcomes of data collection and analysis.

#### **3.9.1.1 Quantitative data analysis**

The quantitative data analysis involved descriptive analysis (Creswell & Plano Clark, 2007: 129) of responses from the Likert-type questionnaire administered. This was effected according to a scale that reflected whether participants agreed, disagreed, or were uncertain with regard to each of the questions (in the form of statements), in order to check for trends and distributions. The data from the 157 questionnaires returned was captured on Microsoft Excel in rows and columns.

Prior to capturing any data, the hard copies of questionnaires returned were numerically marked at the top right hand corner, and this number (for example, 1, 2, 3, 4, 5 *etc.*) corresponded with (and hence identified) the number of the participant. The number assigned to each questionnaire and the corresponding responses of participants to each of the questions on the questionnaire were captured in rows. The recording of the responses to the questions on the questionnaire was indicated in columns. Responses fell into Y (yes), N (no), U (uncertain) categories. Through a formula selected on Excel the number of responses in each category for each question was calculated.

Bar graphs indicating responses to each of the 25 questions were drawn up. These graphs were labelled according to the number of the question on the questionnaire and the corresponding question (statement) was inserted into the graph. The quantitative data on each graph were interpreted descriptively as the main purpose of the questionnaire was to gain background information into the life worlds of hearing parents raising deaf children, so that broad trends may be identified. Thus, the analysis of the questionnaire data was used for descriptive purposes, to complement the qualitative analysis in order to gain a better understanding of the meaning attached to participants' verbal accounts of their parenting experiences. This made it possible to compare and integrate the two sets of data side by side.

#### **3.9.1.2 Qualitative data analysis**

Wilkinson and Birmingham (2003: 76) state that qualitative analysis is aimed at capturing the richness and describing the unique complexities of data. De Vos (2005: 334) states that qualitative data analysis "is a search for general statements about relationships among categories of data". This entails transforming the data by reducing the amount of raw data, sifting out relevant information, identifying significant patterns and developing a framework for conveying the essence of what is revealed in the data (De Vos, 2005: 341; Flick, 2004: 104; Creswell, 2003: 190; Wilkinson and Birmingham, 2003: 147).

In this study the process of qualitative data analysis involved transcribing the recordings of the twenty one-to-one interviews which were audio-taped, and carefully scrutinising the transcripts for the purpose of coding, in order to generate categories and themes. Transcription in itself is a phase of analysis which involves getting closer to the data. Flick (2006: 288) suggests that if a technical device (such as the audio-tape recorder) has been used to record data then transcription is an essential step towards interpretation. Several writers (Cohen *et al.*, 2007: 267-268; Flick, 2006: 291; Henning *et al.*, 2004: 162) provide guidelines for researchers with regard to the process of transcribing audio-taped data.

Coding helped to reduce the massive amount of raw data collected, and to focus on the meaning attached to participants' experiences as hearing parents raising deaf children. Coding is a process of organising the data into small units or segments of text in order to attach meaning to each segment (Creswell & Plano Clark, 2007: 131; Creswell, 2009: 186; 2003: 192). It entails taking the text data, segmenting sentences and paragraphs, identifying units of meaning, categorizing them and labelling these categories with an appropriate term, and finally putting together similar categories into themes (Neuman, 2006: 460; De Vos, 2005: 338; McIntyre, 2005: 294; Corbin & Holt, 2005: 50; Henning *et al.*, 2004: 105). The aim of open coding is "to express data and phenomena in the form of concepts" (Flick, 2006: 297). Open coding is that part of the data analysis process which entails close examination of the data collected, and assigning of codes which are used for the naming and categorising of phenomena (Neuman, 2006: 461; De Vos, 2005: 340; Corbin & Holt, 2005: 50; Henning *et al.*, 2004: 105). It is the initial basic analytic step to condense the mass of information into categories, which will then inform the rest of the analysis process. The open coding process was used to generate a description of the participants' experiences, according to categories and themes which are discussed in detail in the next chapter.

In this study the coding process suggested by Tesch (1990: 142-145) was followed in the analysis of the qualitative data. All the transcripts were read carefully to get a sense of the life worlds of hearing parents raising deaf children. Thereafter, one interview transcript

was selected for closer scrutiny, to obtain an impression of the underlying meaning of the participant's parenting experience, and points were written in the margin to flag certain thoughts. This procedure was repeated for other interview transcripts, and a list of all the topics was made. Similar topics were clustered together. The topics were abbreviated as codes which were written next to the relevant section in the text. Descriptive words were assigned to topics, which were turned into categories. The list of categories was reduced by grouping together related topics, and labels were assigned to the categories. The different categories were also colour-coded on the transcripts for easy identification. The categories were organised into themes which reflect the major findings. These themes and categories, which appear in table form in the next chapter, enabled the researcher to make sense of the data and attach meaning to participants' experiences.

### **3.9.1.3 Concurrent data analysis for the triangulation design**

The following general guidelines applied to the concurrent data analysis for the triangulation design (Creswell & Plano Clark, 2007: 136-137):

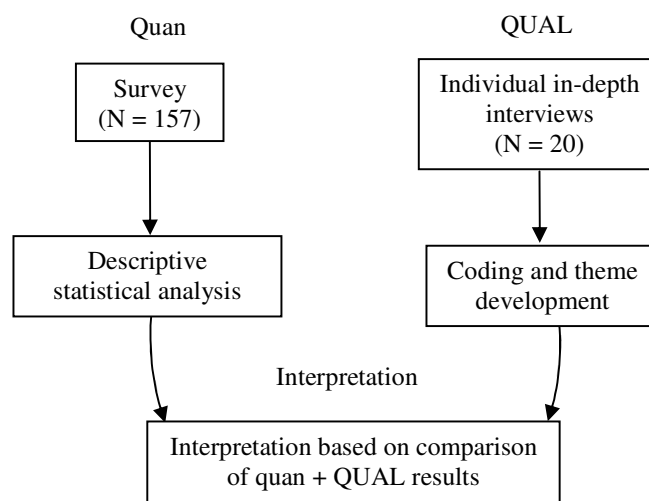
- Stage 1 involved conducting separate data analysis initially for the quantitative and qualitative sets of data (this was discussed in 3.9.2.1 and 3.9.2.2)
- Stage 2 involved merging the quantitative dataset into the qualitative dataset for the sake of comparison
- The merging of databases enabled the researcher to answer the mixed methods research questions related to the concurrent triangulation design and find answers to the following questions: To what extent do similar types of data confirm each other? To what extent do the survey results complement the themes emanating from the qualitative interview data? What similarities and differences exist across levels of analysis?

In this study the quantitative data are first presented (*c.f.* 4.2) followed by the qualitative data (*c.f.* 4.3). The technique used for merging the quantitative and qualitative data was through a discussion of the findings, and the answers to questions relating to the mixed

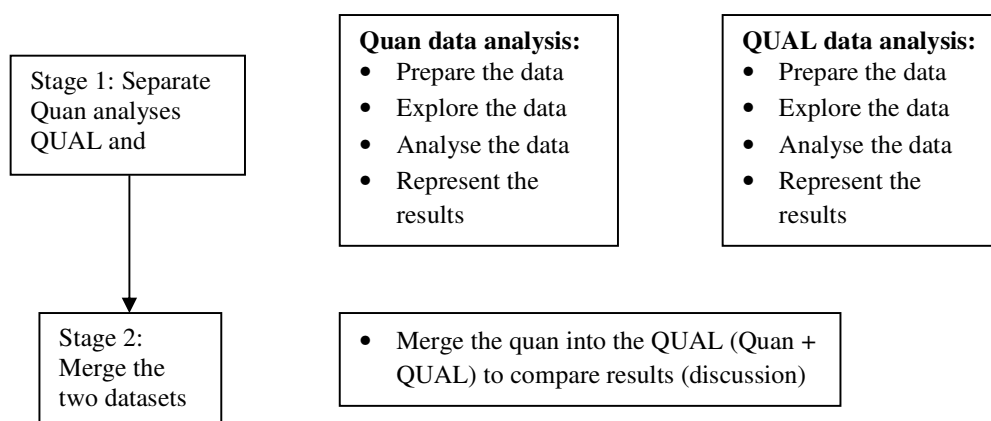
methods concurrent triangulation design are found in the next chapter, under the section dealing with findings and discussion of findings (*c.f.* 4.3.3). Specific quotations or information about a theme will be followed up by a descriptive statistical result for comparison to either confirm or disconfirm results. Creswell and Plano Clark (2007: 140) state that this approach is used frequently by mixed methods researchers. Two adapted visual models of the triangulation mixed methods design are provided below. The plus sign denotes the concurrent nature of the design. Uppercase letters indicate the dominant method, while lowercase denotes the less dominant.

**Figure 3.2 Visual model of Triangulation mixed methods design procedures**

(Adapted from a 2005 study by Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzerler & Bradley, in Ivankova *et al.*, 2007: 272)



**Figure 3.3 Visual model of Concurrent Data Analysis Procedures in Triangulation Design** (Adapted from Creswell & Plano Clark, 2007: 137)



### **3.10 VALIDATION PROCEDURES**

Proponents of mixed methods research advocate the use of both quantitative and qualitative validation procedures to ensure the validity of quantitative results and the accuracy of qualitative findings (Creswell, 2009: 219; Creswell & Plano Clark, 2007: 146). What follows is a discussion of quantitative validation procedures, qualitative validation procedures, and mixed methods design validation procedures.

#### **3.10.1 Quantitative validation procedures**

Creswell (2009: 162) draws attention to potential threats to validity which must be identified, so that steps can be taken to minimise these threats. Measurement validity is the degree to which a measure does what it is intended to do (Babbie, 2004: 143; Gravetter & Forzano, 2003: 87). Terre Blanche and Durrheim (1999: 83) concur, adding that in order to establish measurement validity the researcher must determine whether the instrument is suited to the purposes for which it is to be used. In this study the researcher remains confident that the instrument used, namely, the Likert-type questionnaire, was suited to the purpose of the investigation, since it fulfilled the purpose of providing a more comprehensive understanding of the research problem.

Delpont (2005:160-161) identifies content validity as an aspect of an instrument's validity, and this refers to the representativeness or sampling adequacy of the items or topics of an instrument. A measurement instrument would be considered valid if it provides "an adequate or representative *sample* of all *content*, or elements or instances of the phenomenon being measured", and if it really measures the concept it intended to measure. According to Rubin and Babbie (2001: 194), content validity is determined on the basis of the judgements of the researcher or other experts, as to whether the instrument covers all the aspects of the concept being measured. In this study, the questionnaire used was considered valid according to the judgements of the researcher as well as two psychologists and two social workers employed at two of the sample schools.

Concerning the issue of reliability, Terre Blanche and Durrheim (1999: 64) state that quantitative researchers attach great importance to the criterion of reliability, as an indication of the accuracy and conclusivity of their findings. Since reliability addresses the issue of objectivity, it is a key concept in quantitative research (Cohen *et al.*, 2000: 105). Reliability refers to the extent to which results can be repeated, and the dependability of a measurement instrument, that is, the extent to which the same results can be arrived at using the measurement instrument on repeated trials (Terre Blanche & Durrheim, 1999: 88). A similar survey conducted on a national scale in the USA by Meadow-Orlans *et al.*, 2003: 1-2) showed similarities to the findings of the survey conducted in this study.

### **3.10.2 Qualitative validation procedures**

Creswell (2009: 190) states that validity has different connotations in qualitative studies compared to quantitative studies, and is not the same as reliability or generalisability. While qualitative validity refers to the procedures employed by the researcher to check for the accuracy of findings, qualitative reliability is an indication of the consistency of the researcher's approach when applied by other researchers across different projects. Gibbs (in Creswell, 2009: 190-191) suggests several reliability procedures that researchers can follow to ensure that their research is consistent and reliable. Some of these include:

- Checking transcripts for mistakes
- Ensuring that the coding of data is consistent
- Cross checking codes developed by different researchers in a team by comparing results
- Communicating with members of the research team through regular meetings, and sharing analysis

The first two procedures were followed, whilst the third and fourth were achieved through discussion with my supervisor.



Validity in qualitative research is based on determining whether the findings are accurate from the point of view of the researcher, participant, or the readers of an account. According to Marshall and Rossman (1995: 143) all research must meet criteria against which the trustworthiness of the project can be evaluated. Krefting (1991: 217-221) suggests twenty-three strategies to establish the trustworthiness of qualitative research, and eleven different methods of determining the trustworthiness of qualitative findings are presented by Tashakkori and Teddlie (1998: 90-93), while Creswell (2009: 191) also recommends the use of multiple validity strategies to ensure the accuracy of findings. Some of these strategies (a few of which were used in this study,) include:

- Triangulation of different sources of information and converging sources to develop a sound justification for themes
- Member checking to determine accuracy of qualitative findings through taking the final report, or themes revealed to participants, to ascertain whether they think that these are accurate
- Spending prolonged time in the field to develop in-depth understanding of the phenomenon being explored
- Presenting negative or discrepant information that goes against the flow of the themes since real life comprises different perspectives
- Peer debriefing, which involves interpretation by another person who reviews the account and asks questions about it
- External auditing by someone not familiar with the researcher to provide an objective assessment of the project
- The use of rich, thick descriptions of the setting or themes to convey findings so as to “transport readers to the setting” and give them a sense of “shared experiences” (Creswell, 2009: 192).

The validation procedures with regard to this study involved triangulating quantitative and qualitative datasets, presenting negative or discrepant information that went against the flow of the themes, peer debriefing, external auditing by someone not familiar with the

researcher, as well as the use of rich, thick descriptions of the setting or themes to convey findings.

While Cohen *et al.* (2000: 105) state that the terms *validity* and *reliability* apply to quantitative and qualitative research, Lincoln and Guba (in Krefting, 1991: 215) suggest that these terms are relevant for quantitative inquiry, but are inappropriate for qualitative research. Alternate terms such as accuracy of representation, credibility, and authority of the writer are suggested by Agar (in Krefting, 1991: 215).

The global qualitative concept of trustworthiness was introduced by Lincoln and Guba (in Tashakkori & Teddlie, 1998: 90; Marshall & Rossman, 1995: 143-145; Krefting, 1991: 214-216) as an alternative for many of the issues associated with quantitative design and measurement. Four general criteria are suggested, which, when combined, can determine the trustworthiness of an enquiry. These include:

- The credibility of findings of the study, and the criteria by which it can be judged
- The transferability and applicability of the findings in another context
- The consistency of the findings in the event that the study is replicated
- The neutrality of findings, *i.e.*: freedom from bias or prejudice.

Lincoln and Guba (in De Vos, 2005: 346) advocate the use of alternate terms *credibility*, *transferability*, *dependability* and *conformability* to evaluate qualitative research, rather than the terms *internal validity*, *external validity*, *reliability* and *objectivity* which are terms appropriate to describe quantitative inquiry.

Each of these alternative terms is described as follows:

1. *Credibility* is the alternative to internal validity, in which the goal is to show that the study was conducted in a manner that ensures that the participants were appropriately identified, and that the pattern of interactions, setting and research process were accurately described. “The strength of the qualitative study that aims to explore a

problem or describe a setting, a process, a social group or a pattern of interaction will be its validity” (De Vos, 2005: 346). Based on this statement, my research can be considered valid.

Linked to credibility is the establishing of truth value of the study. According to Lincoln and Guba (in Krefting, 1991: 215), truth value establishes whether the researcher has demonstrated confidence in the truth of the findings for the participants, and the context in which the research was undertaken. The truth value is usually obtained from the study of human experiences as they are lived and the meanings attached to these experiences. Sandelowski (in Krefting, 1991: 216) states that truth value is perhaps the most important criterion for evaluating qualitative research, and suggests that when the researcher presents accurate descriptions or interpretations of human experience, which can be immediately recognised by the people who share that experience, then the qualitative research is deemed credible.

In this study credibility was ensured by the use of the non-probability sampling strategy, involving the purposive sampling technique, to select the participants for the one-to-one interviews. The interviews were conducted in contexts where the participants were comfortable, that is, at the schools where their deaf children were attending, or where they themselves were employed. The participants were apprised of the purpose of the interviews and were asked for permission to audio-tape the conversations, after they were ensured of confidentiality. The transcripts are an accurate representation of the interviews. The researcher is confident that the descriptions and interpretations of the participants’ lived experiences have been accurately presented.

2. *Transferability* is the alternative term suggested by Lincoln and Guba (in De Vos, 2005: 346) for external validity or generalisability which entails “demonstrating the applicability of one set of findings to another context”, and this may be problematic in a qualitative study. Lincoln and Guba’s (in Krefting, 1991: 216) perspective on the applicability of findings is determined by the “degree of similarity or goodness of fit

between two contexts”. Sandelowski (in Krefting, 1991: 216) argues that generalisation is not relevant in qualitative research and it is an illusion since each research situation is unique in terms of the researcher, participants and interactions. Tashakkori and Teddlie (1998: 65) also maintain that for most qualitative studies, generalisability or “transferability of results” to other individuals, situations and times is considered irrelevant.

Nonetheless, as long as the original investigator presents sufficient descriptive data, shows how the data collection and analysis has been guided by the original theoretical framework, and states the theoretical parameters of the research, the problem of applicability or transferability can be addressed (De Vos, 2005: 346; Lincoln & Guba, in Krefting, 1991: 216). Another way of enhancing the generalisability of a study is through the triangulation of multiple data sources, “to corroborate, elaborate or illuminate” the research project (De Vos, 2005: 346). Research design that involves multiple participants, using more than one data collection method, can strengthen the transferability of the findings of a study.

In this study, transferability was ensured through sufficient descriptive data. The parameters of the research problem, the setting, the population and pattern of interactions, as well as the theoretical framework have been clearly identified.

3. *Dependability* or consistency is the alternative to reliability. Consistency, according to Guba (in Krefting, 1991: 216), is defined in terms of dependability, and this criterion considers whether the findings would be consistent if the study were to be replicated with the same participants or in a similar setting. While quantitative inquiry is based on the assumption of a single unchanging reality, qualitative research on the other hand may be complicated by external and unexpected variables. The positivist concept of an unchanging social context is in direct contrast to the qualitative research, where the social context is constantly being constructed and transformed. Therefore, the concept of replication is itself problematic, and variability is expected in qualitative research (De Vos, 2005: 346).

Field and Morse (in Krefting, 1991: 216) assert that the emphasis in qualitative research is the uniqueness of human experience, so rather than evaluating for identical repetition, variation in human experience is sought. Duffy (in Krefting, 1991: 216) maintains that the main aim of qualitative research is to learn from the participants rather than to control them. Thus, in my mixed methods study the main purpose of conducting in-depth, one-to-one semi-structured interviews with hearing parents of deaf children was to investigate their lived experiences and to attach meaning to these experiences, so as to gain a deeper insight into the way they manage their parenting role, and to learn from their unique experiences.

4. *Confirmability*, suggested by Lincoln and Guba (in De Vos, 2005: 346) is the alternative to objectivity. Sandelowski (in Krefting, 1991: 216) proposed the term “neutrality” which like conformability, refers to freedom from bias in the research procedure. This criterion is appropriate to evaluate the confirmability aspect of trustworthiness in qualitative research, since it seeks to assess whether the findings of the study could be confirmed by another, and whether the data help to confirm the general findings that culminate in the presentation of implications. In this study, the validity of the research project rests on the use of the mixed method research design, the triangulation of data sources, and the accurate descriptions and interpretations of participants’ experiences. The interview data was coded following the guidelines suggested by Tesch (in Creswell, 2003: 192). Furthermore, the interview data were submitted for scrutiny to an independent coder, who confirmed that there was saturation in the data after conducting an audit of the transcripts of the interviews. The researcher is confident that in the presentation of the findings, a true reflection of the phenomenon of hearing parents raising deaf children has been captured.

### **3.10.3 Mixed methods design validation procedures**

There are potential threats to validity associated with quantitative research as well as qualitative research, and the act of combining the two approaches presents additional threats to validity (Creswell & Plano Clark, 2007: 145). Validity has been identified as one of the six major issues in mixed methods research (Tashakkori & Teddlie, 2003: 4). Creswell and Plano Clark (2007: 146-147) recommend the following procedures to address the issue of validity in mixed methods research:

- Discuss both quantitative and qualitative validation procedures, to avoid minimising traditional approaches to validity in mixed methods research. This has been done in section 3.9.1 and 3.9.2 above.
- Use the term “inference quality” in addition to the term validity to refer to mixed methods research validation procedures. The term “inference quality” (Tashakkori & Teddlie, 2003: 35), which pertains to issues such as internal validity and credibility, is used to refer to the accuracy of conclusions derived inductively and deductively from mixed methods research. Mixed methods writers, Onwuegbuzie and Johnson (in Creswell & Plano Clark, 2007: 146) prefer the term “legitimation” to refer to validity in mixed methods research.
- Validity in mixed methods research is the ability of the researcher to draw accurate and meaningful inferences from all the data in the study.
- From the standpoint of triangulating mixed methods design, it might be problematic to forge accurate conclusions. However, Onwuegbuzie and Johnson (in Creswell & Plano Clark, 2007: 146) suggest that, through the combining of the two datasets, certain “metainferences” can emanate from the analysis; for instance, if the triangulation design is guided by the pragmatic paradigm, it can result in “triangulation validity” or “consequential validity”. This is explained as an “overarching validity” where the researcher is able to draw evidence from different sets of data to provide better results than either quantitative or qualitative data alone. Since the pragmatic paradigm guided the concurrent triangulation design in my study, I can confidently claim that triangulation validity is evident in my study, as inferences

were drawn from both quantitative and qualitative datasets to provide a better understanding of the research problem.

- The discussion of potential threats to the establishment of meaningful conclusions that arise during data collection and analysis, as well as ways of addressing them, can enhance validity in mixed methods research. In my study one of the potential threats was the selection of different individuals for the quantitative and qualitative data collection. To minimise this threat, quantitative and qualitative samples were drawn from the same population. With regard to data analysis, inadequate data approaches to converge the data posed a threat. This threat was minimised through analysing both sets of data separately, and comparing the data.

### **3.11 ETHICAL ISSUES**

Terre Blanche and Durrheim (1999: 66) designate three ethical principles of autonomy, nonmaleficence and beneficence that should guide all research. The principle of autonomy requires the researcher to respect the autonomy of the participants in the study. It requires the researcher to obtain voluntary and informed consent from the participants, allowing them the freedom to withdraw from the research at any time, while at the same time ensuring the participants' right to autonomy in any publication that may emanate from the research. The principle of nonmaleficence means that there should be no harm to the participants in the research. The researcher is required to consider potential risks, such as physical, emotional, social or any other form of harm that may be inflicted upon those who participate in the study. Consideration of this principle may lead to changes in the research design of the study to avoid any harm or to minimise risk to subjects. The principle of beneficence requires that the researcher designs research that will be of benefit to other researchers and to society at large, even if the participants do not benefit directly from the research.

According to Denzin and Lincoln (2003: 89-90), ethical concerns traditionally focussed on three topics, namely, informed consent (*i.e.* receiving the participants' consent after carefully and truthfully informing them about the purpose of the research), right to

privacy (*i.e.* protecting the identity of the participant), and protection from harm (*i.e.* emotional, physical or any other type of harm). These authors point out that there are other ethical issues, such as surreptitious use of tape-recording devices, manipulating the participants while interviewing them, and breach of confidentiality.

Punch (in Denzin & Lincoln, 2003: 90) suggests that researchers doing fieldwork need to exercise common sense and a responsibility firstly to their participants, secondly to the text, and thirdly to themselves. The essential purpose of ethical concerns in research is the protection of the welfare and rights of the participants. To this end ethical clearance forms from the university were obtained and duly completed for submission.

Permission was sought from the Department of Education, principals and governing body chairpersons of schools for the Deaf, to conduct research and interview hearing parents of deaf learners at the school. In this study every effort was made to conform to the requirements of the ethical guidelines outlined above. Participants were made aware of the purpose of the research before informed consent was obtained. They were informed that no harm would be inflicted on them, and that their identities would not be revealed. They were assured that their responses would be treated in a confidential manner. Participants were also informed that they could withdraw from the investigation at any time without fear of recrimination.

The nature and purpose of the research, as well as the benefits of the research to hearing parents raising deaf children, and to the Deaf community at large were clearly and truthfully explained to the participants. The identity and institutional association of the researcher and supervisor, together with their contact details were made available to participants. Permission was sought from the participants to tape-record the interviews. All participants were asked, at the beginning, whether they would be comfortable having the interview tape-recorded. All participants were willing to be tape-recorded. All documents and audio tapes are stored safely in a cupboard in an office at the university. These will be kept for a period of five years, after which time they will be destroyed.



In order to protect the identity of participants actual names were not used. Instead, pseudonyms were used. The decision to use pseudonyms rather than numerical or alphabetic symbols was based on the fact that it is more personalised to refer to participants by names. The close bond made with the participants was of such a personal nature that it would be an injustice to deny the reader personal connections, by referring to the participants by symbols, as though they were inanimate objects. The use of pseudonyms rather than symbols also helps to transport the reader to the setting, and create a sense of virtual reality, as if the reader had been present during the interviews.

Many participants became emotional during the course of the interview. When this happened, the interview was suspended and participants were comforted. It is possible that there was therapeutic value for participants in giving vent to their emotions, and being given a chance to talk about their painful experiences and sensitive issues to someone who was prepared to listen patiently. Although they were given the option of withdrawing from the interview, none chose to withdraw. Instead, they were apologetic for allowing their emotions to “disrupt” the interview, and displayed an eagerness to continue after they regained their composure, for which the researcher was grateful.

### **3.12 CONCLUSION**

This chapter discussed the nature of mixed methods research and explained the research paradigm and mixed methods concurrent triangulation research design that was employed in this study. It also included a presentation of the purpose statement and the research questions. The approach was chosen to gain insight into the experiences of hearing parents raising deaf children, and the factors that influence their parenting role. Sampling techniques and data collection procedures for both quantitative and qualitative approaches were discussed. This was followed by a discussion of data analysis and validation procedures for quantitative and qualitative approaches, as well as mixed methods design. Finally, ethical guidelines were discussed.

In the next chapter (Chapter 4) the findings for both quantitative and qualitative data, and the discussion of findings, will be addressed.

## CHAPTER 4

### FINDINGS AND DISCUSSION OF FINDINGS

*“By talking to people who have a deaf child, you are able to share your experience, and they share theirs’ with you, and you feel like this whole burden lifts off your shoulder, because you’ve got somebody to share it with, who will understand exactly what you’re going through, who will give you feedback on what worked with them, and what didn’t.”*

(Hemma, participant: 2006)

#### 4.1 INTRODUCTION

In the previous chapter the research design and methodology were discussed. This chapter focusses on the analysis and interpretation of data generated through a mixed-method approach, to investigate the experiences of hearing parents raising deaf children, and how parents manage this responsibility. Both quantitative and qualitative methods were employed in this study for the purpose of triangulation. The 157 questionnaires completed by hearing parents of deaf children constitute the quantitative survey. The qualitative data generation entailed conducting individual semi-structured interviews with 20 hearing parents of deaf children. The findings emanating from the data will be discussed, with more emphasis being placed on the discussion of the qualitative data which is the dominant data generation method (See Chapter 3). The quantitative and the qualitative data, as well as literature control, will be integrated in the analysis and interpretation of the findings. The quantitative data analysis will be presented first.

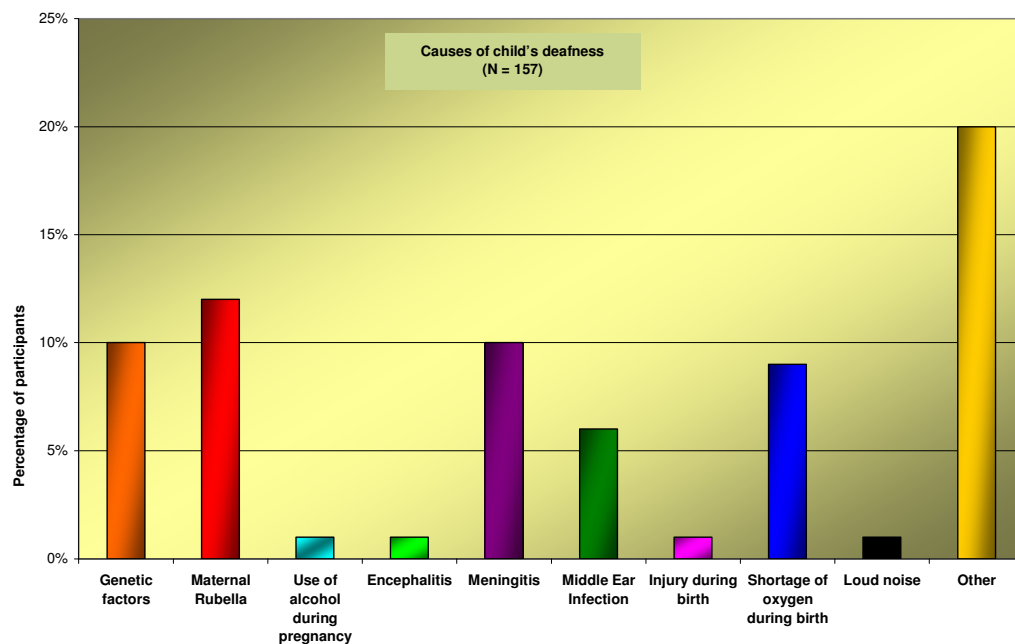
## **4.2 EXPERIENCES OF HEARING PARENTS RAISING DEAF CHILDREN: WHAT DO THE QUANTITATIVE DATA REVEAL?**

The findings from the questionnaire sent to hearing parents of deaf children served to explore various ecosystemic variables influencing the experiences of hearing parents raising deaf children. The descriptive statistics, as explained in chapter three, and represented in the form of bar graphs, complement the qualitative data. Each of these bar graphs is followed by a description of the quantitative data, as well as an interpretation thereof, also drawing on relevant literature. These findings provide answers to the quantitative research question in this study.

### **4.2.1 Representation of quantitative data in the form of bar graphs**

(Each bar graph appears on a new page.)

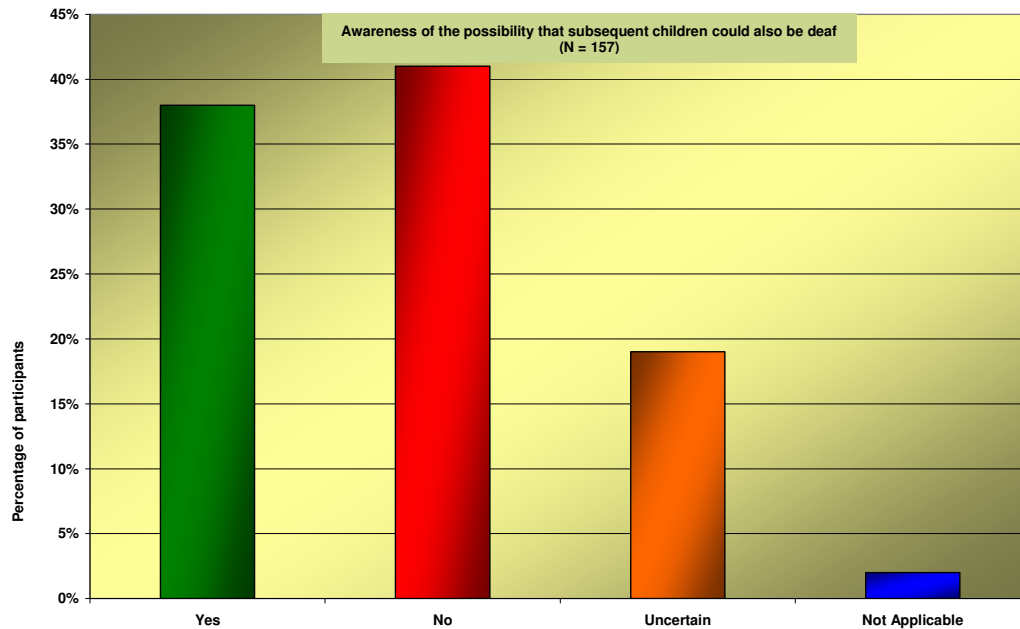
**Graph 4.2.1.1: Causes of child's deafness**



The quantitative data, in response to question one of the questionnaire, shows that 12% of participants indicated that maternal rubella was the cause of their children's deafness, (*c.f.* 4.3.3.1 of qualitative findings), while meningitis and genetic factors each accounted for 10% of cases. Asphyxia (shortage of oxygen at birth) was the cause of deafness reported by 9% of participants. Middle ear infection was the cause of deafness among 6% of the cases, while use of alcohol during pregnancy was the cause of deafness in 1% of cases. Encephalitis, injury at birth, and loud noise each accounted for 1% of cases, while 20% of participants indicated that other factors led to their children's deafness. This questionnaire included causes identified in the literature, but did not include all the possible causes of deafness, which could account for the indication by 20% of participants that other factors caused their children's deafness.

Interpreting the quantitative data descriptively, the fact that middle ear infection, the use of alcohol during pregnancy, loud noise, and rubella are preventable causes of deafness, implies that some participants were possibly not aware of these factors, and therefore did not take sufficient preventative measures. Maternal rubella ranked as the primary cause of deafness, which is in keeping with what the literature reveals, even though the rubella vaccine was developed to bring the epidemic under control (Scheetz, 2001: 45; Schirmer, 2001: 7; Marschark, 1997: 29). As the vaccine is not mandatory in South Africa, it could account for rubella being the main cause of deafness.

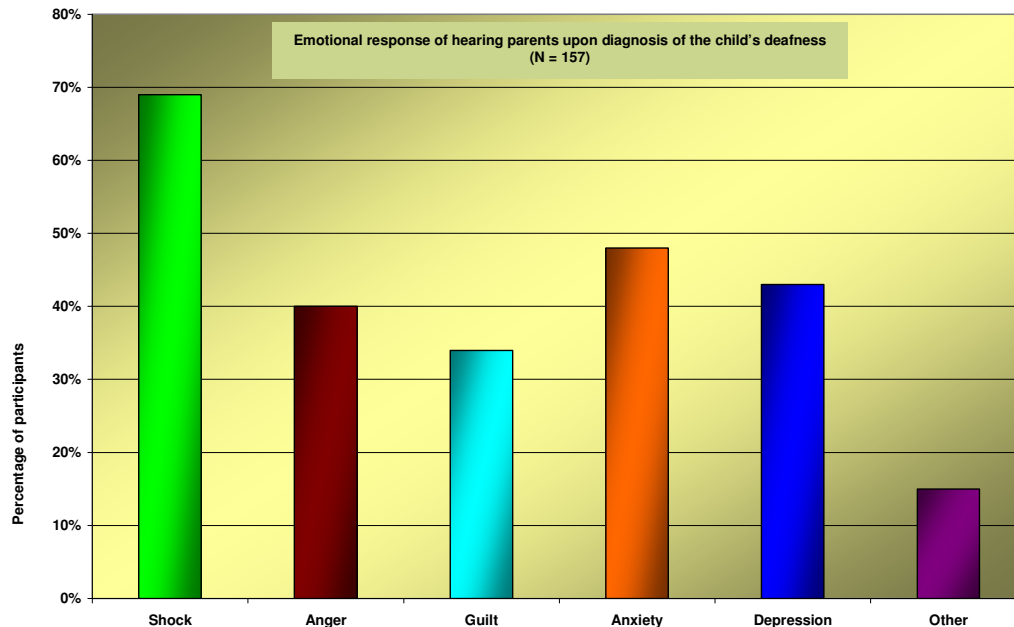
**Graph 4.2.1.2: Awareness of the possibility that subsequent children could also be deaf**



The quantitative data, in response to question two of the questionnaire, reveals that 38% of participants were aware that if their child's deafness was due to genetic factors, children born subsequently could also be deaf. 41% of participants were not aware of the possibility that if they were to have more children they could also be deaf while 19 % were uncertain and 2% of participants indicated that the question was not applicable to them.

One needs to interpret the quantitative data descriptively, since this item on the questionnaire is linked to genetics as the cause of deafness. In that case the fact that a large number of participants were not aware of the possibility that subsequent children could also be deaf, implies that they possibly had not been exposed to genetic counselling after their child had been diagnosed with deafness. The fact that 41% of participants indicated that they were unaware of the possibility of subsequent children being born deaf, while 19% were uncertain in this regard implies that they could possibly benefit from genetic counselling before they plan to have more children. This however, raises the importance of information and education. In the case of those who indicated that the question was not applicable, the reason for this could possibly be that some of the participants were guardians or grandparents, and not the biological parents of deaf children. Alternatively, the cause of their child's deafness was due to external factors and not genetically linked.

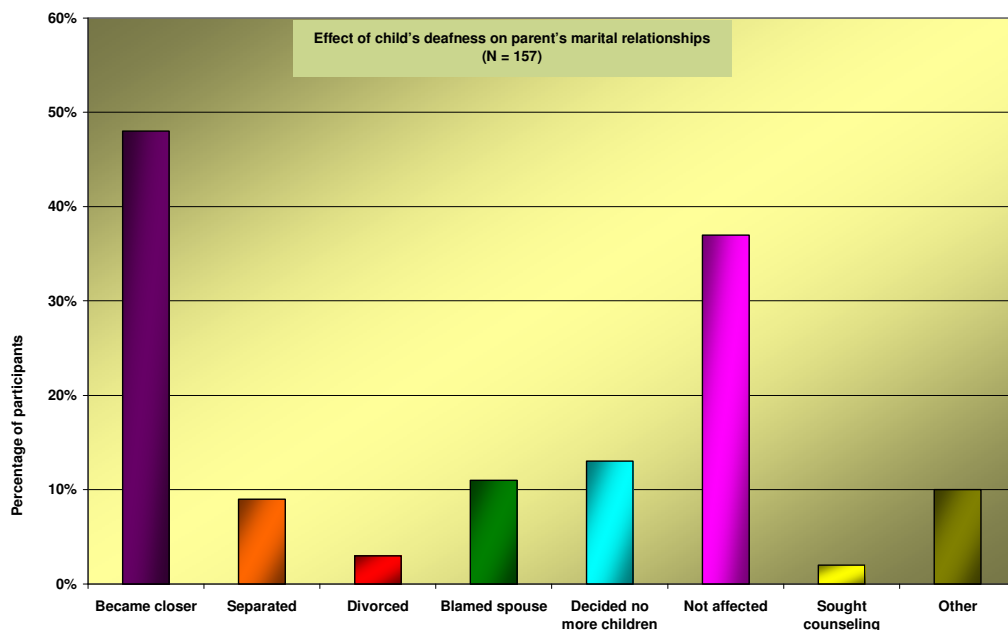
**Graph 4.2.1.3: Emotional response of hearing parents upon diagnosis of the child's deafness**



The quantitative data, in response to question 3 of the questionnaire, shows that 69% of participants experienced shock upon the diagnosis of their children's deafness; 40% experienced anger; 34% had feelings of guilt; 48% experienced anxiety; 43% went through depression, while 15% experienced 'other' emotional responses which were not included in the questionnaire (*c.f.* 4.3.3.1 of qualitative findings).

Interpreting the quantitative data descriptively, the finding that most of participants experienced shock upon the diagnosis of their children's deafness is in keeping with what Scheetz (2001: 60), Schirmer (2001: 27) and Marschark (1997: 78) found. Most hearing parents' initial emotional response to the diagnosis of deafness is that of shock, because their dreams of having a 'normal' child are shattered, and they experience feelings of anxiety. Grieving is also a natural response because of the loss of a dream of a 'perfect' child and a 'normal' family life, and this can be followed by anger and depression and feelings of guilt. Hintermair (2006: 495) and Bloom (in Weisel, Most & Michael, 2007: 56) concur that the diagnosis of deafness is a critical life event for parents and can lead to high levels of parental stress, which could threaten family adjustment and cohesion. The findings are supported by that of Weisel and Zandberg (in Weisel *et al.*, 2007: 56) since initial reactions to the diagnosis of deafness often include sadness, anger, shame and helplessness. According to Feher-Prout (in Weisel *et al.*, 2007: 56) this is especially the case in families where there is no knowledge of deafness or no previous contact with deaf people.

**Graph 4.2.1.4: Effect of child's deafness on parents' marital relationships**

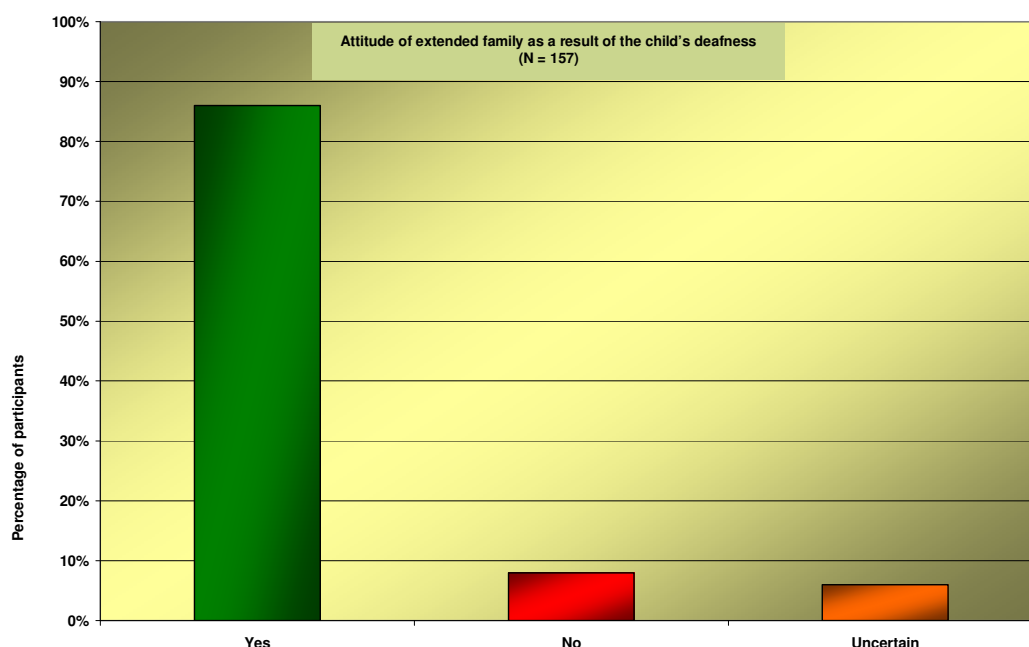


The quantitative data, in response to question 4 of the questionnaire, shows that 48% of participants became closer to their spouses as a result of having a deaf child; 9% were separated and 3% got divorced; 37% of marriages were not affected as a result of having a deaf child; 2% sought counselling to save their marriages; 11% blamed their spouses for their children's deafness; 13% decided not to have any more children, while 10 % indicated that the diagnosis of their children's deafness had other effects on their marital relationships, indicating that the questionnaire did not cover all the possible effects on marital relationships (*c.f.* 4.3.3.2 of qualitative findings).

If one interprets the quantitative data descriptively, the fact that many participants grew closer to their spouses could be indicative of their belief that difficulties could draw people closer together but also their belief in the joint responsibility for raising their children. Levy-Schiff (in Britner, Morog, Pianta & Marvin, 2003: 336) proffers the claim that fathers' involvement in caring for the child greatly influences marital stability. It is interesting to note Kazak and Clark's statement (in Britner *et al.*, 2003: 336) that parents of children with severe disabilities tend to report greater marital satisfaction than do parents of children with milder disabilities. Freeman (in Ross *et al.*, 2004: 159) found that being parents of deaf children does not affect the divorce rate. In this study only a few marriages were adversely affected, yet some participants decided not to have more children. Britner *et al.* (2003: 335-336) and Scheetz (2001: 61) maintain that parents of children with disabilities often report high levels of stress which could affect marital relationships, yet couples respond differently in times of stress possibly because of differences in the quality of their marital and spiritual relationships (*c.f.* Graph 4.2.1.7).



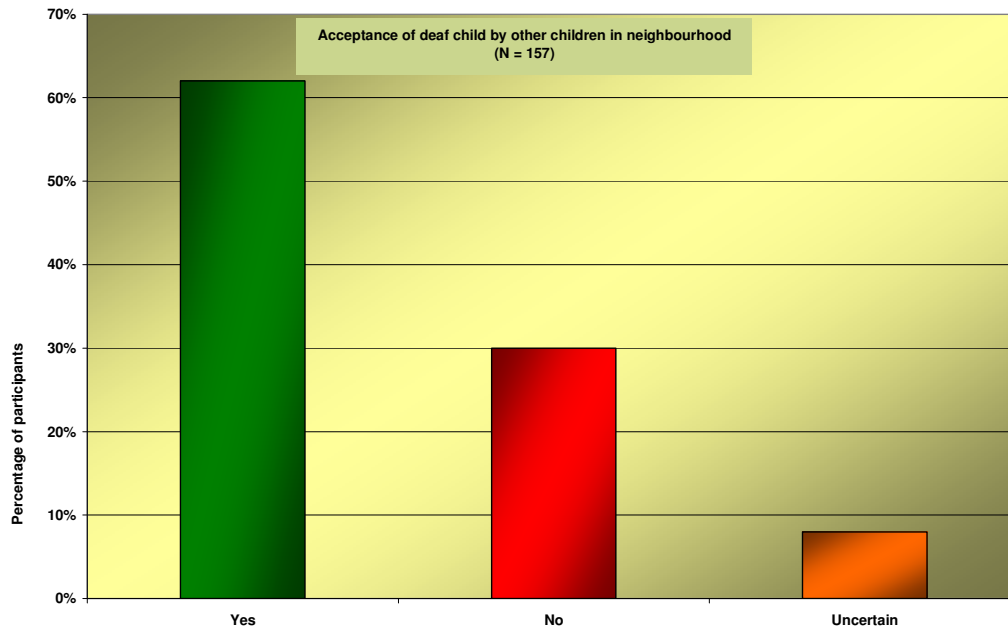
**Graph 4.2.1.5: Attitude of extended family as a result of the child's deafness**



The quantitative data, in response to question five of the questionnaire, shows that 86% of participants experienced a positive attitude from the extended family towards their children's deafness; 8% did not; 6% were uncertain in this regard (*c.f.* 4.3.3.2 of qualitative findings).

Since the vast majority of participants experienced a positive attitude from the extended family, a descriptive interpretation of the data could indicate the general predisposition of acceptance of deafness on the part of extended family, and willingness to reach out and support the family. This augurs well for deaf children as well as their parents, and is in keeping with Zaidman-Zait's (2007: 221) finding that the consistent involvement of family and friends contributes to parents' coping experience. This view is corroborated by Hintermair (2006: 495) who summed up the main factors influencing parents' coping process from several studies which reveal how, above all, the availability of personal and social resources, that is, the support parents receive from family, relatives, friends and acquaintances, influences their ability to cope with raising their deaf children. As stated by Gallagher *et al.* and Kazak and Marvin (in Britner *et al.*, 2003: 337), familial and informal support may perhaps be more important to families with children with special needs than professional support since these parents often face the added stress caused by social isolation, when the demands of raising the child lead to decrease in the family's social contacts. Marschark (1997: 16) concurs that parents who receive support from their family cope better with having a deaf child.

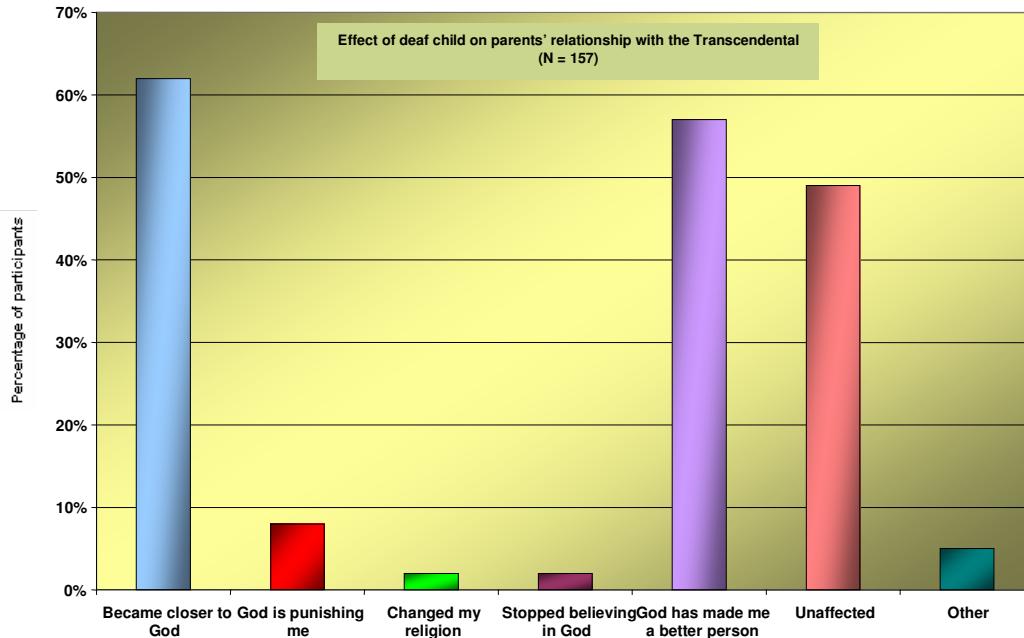
**Graph 4.2.1.6: Acceptance of deaf child by other children in the neighbourhood**



In response to question six of the questionnaire the quantitative data reveal the following: 63% of participants indicated their deaf children were fully accepted by other children in the neighbourhood, while 30% indicated otherwise, and 8% were uncertain in this regard (*c.f.* 4.3.3.2 of qualitative findings).

The implication of these findings following a descriptive interpretation of the quantitative data could be that most parents of hearing children encourage their children to accept deaf children as part of the community, and it is possible that the parents' attitudes influence the behaviour of their hearing children towards deaf children. This is encouraging, especially in the context of inclusive education, which aims to promote human rights, social justice, integration, equal access to education and participation of all learners irrespective of any differences they may have (DoE, 2001: 5). The fact that some children in the neighbourhood do not accept deaf children could be an indication that negative attitudes persist, and that these could possibly be passed on by parents who might have reservations about the impact of deaf children on the progress of their hearing children. Negative attitudes may also arise from lack of knowledge about deafness. As stated by Knoors (2007: 245), many parents of hearing children in the Netherlands are actively opposed to inclusive education, the chief reason being their fear that it will result in loss of quality of education for their own children.

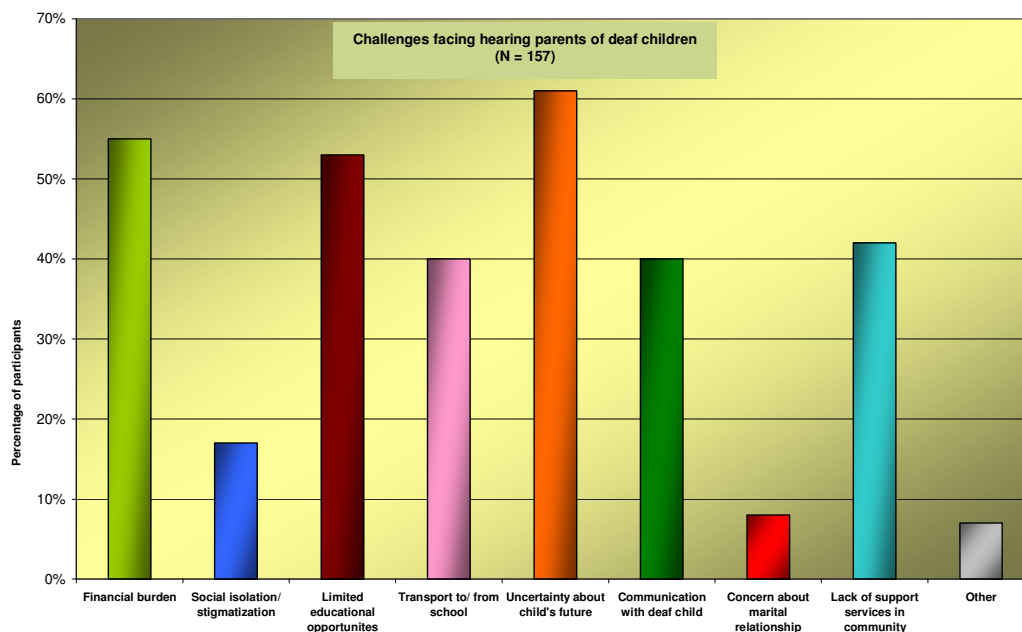
**Graph 4.2.1.7: Effect of deaf child on parents' relationship with the Transcendental**



The quantitative data, in response to question seven of the questionnaire, show that 62% of participants indicated that they grew closer to God as a result of having a deaf child, and 57% indicated that God had made them become better people in the process of raising their deaf child. However, 8% felt that they were being punished by God; 2% changed their religion; 2% stopped believing in God; 49% of participants' relationship with God was unaffected, while 5% indicated that their relationship with God was affected in other ways (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, it would seem that the experience of having a deaf child has a profound influence on participants' spirituality. It deepened the faith of the majority, and gave them a sense of self-worth. This is in keeping with the finding by Mapp and Hudon (in Weisel *et al.*, 2007: 56) that deaf children's parents who are regular churchgoers experience low levels of stress. Shea and Bauer (in Levitz, 1991: 103) maintain that strong religious beliefs and self-confidence increase self-acceptance, which contributes to parents' feeling more accepting of the deaf child. A few participants indicated that their relationship with God was affected in a negative way. As Scheetz (2001: 60) and Dysart (1993: 31) state, some parents may feel that they are being punished and may experience feelings of anger towards God for giving them a deaf child. A few participants changed their religion as a result of having a deaf child, possibly hoping that another religion might provide better answers to their questions and prayers. Parents who are in denial about their child's deafness often negotiate with God for a miracle to happen so that their child's hearing may be restored (Marschark 1997: 78).

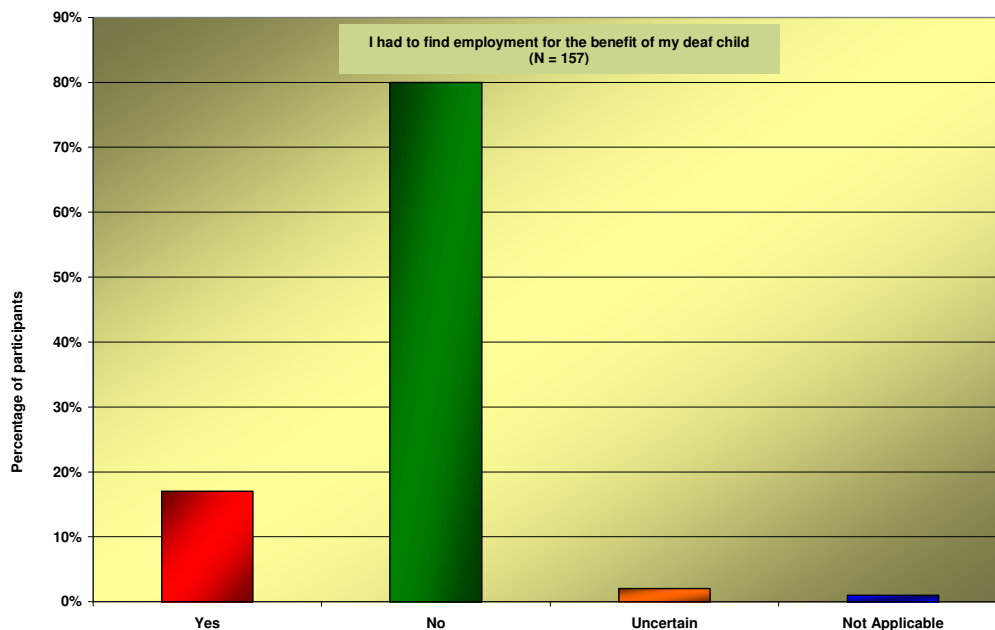
**Graph 4.2.1.8: Challenges facing hearing parents of deaf children**



The quantitative data, in response to question eight of the questionnaire, show that uncertainty about their deaf children's future was a major challenge facing 61% of the participants; 55% flagged financial burden as another major challenge; 53% indicated that limited educational opportunities presented a challenge to them; 42% found the lack of support services in the community challenging; 40% indicated that communication was a challenge; 40% found transport to and from school to be challenging; 17% indicated social isolation/ stigmatisation as a challenge; 8% indicated that their marital relationships were challenging; 7% indicated that there were other challenges that they faced as hearing parents of deaf children, indicating that the questionnaire did not include all the possible challenges facing them (*c.f.* 4.3.3.1 ; 4.3.3.2 and 4.3.3.3 of qualitative findings).

If one interprets the quantitative data descriptively, it is clear that many of the participants face several challenges in their situation as hearing parents raising deaf children. These are likely to increase parents' stress levels and affect their emotional well-being. This is in keeping with Zaidman-Zait's (2007: 221) findings in a recent study, that parents reported various challenges that they face in conjunction with caring for their deaf child, and that these multiple parenting challenges lead to increased parental stress. As Lessenberry and Rehfeldt (2004: 232) point out, parents of children with developmental disabilities often experience very high levels of stress as a result of several challenges associated with child rearing, which may affect the quality and frequency of interactions with the child as well as the child's development and progress.

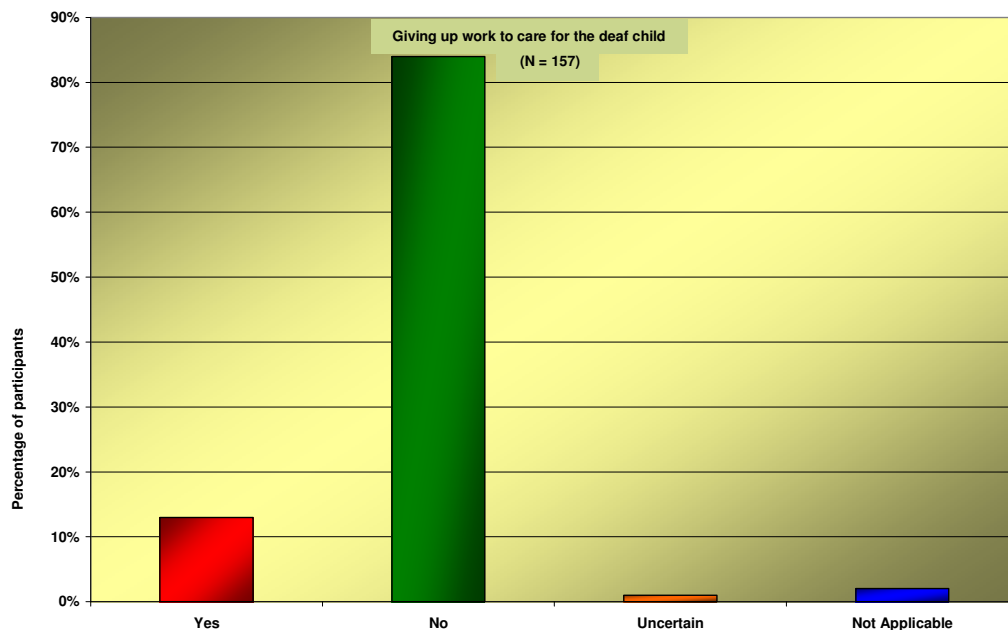
**Graph 4.2.1.9: I had to find employment for the benefit of my deaf child**



The quantitative data, in response to question nine of the questionnaire, show that 80% of participants indicated that they were not forced to find employment as a result of having a deaf child; 17% were forced to find employment; 2% were uncertain in this regard while 1% indicated that the question was not applicable to them.

If one interprets the quantitative data descriptively, the majority of participants, mostly stay-at-home mothers (*c.f.* Table 3.1 biographical information: questionnaire), were not forced to seek employment for the sake of their deaf children. It is possible that staying at home to care for their deaf children took priority over seeking employment, as the family income might have been sufficient to cater for their needs. In the case of some of the participants who were forced to find employment, it is possible that this was due to economic and financial circumstances brought about by the extra expenses associated with raising a deaf child. The reason for a small number of participants indicating that the question was not applicable to them could possibly be that they are stay-at-home grandparents or guardians of the deaf children (*c.f.* Table 3.1 biographical information: questionnaire). Alternatively, they could have been fathers who were already employed and were therefore not forced to seek employment as a result of having a deaf child.

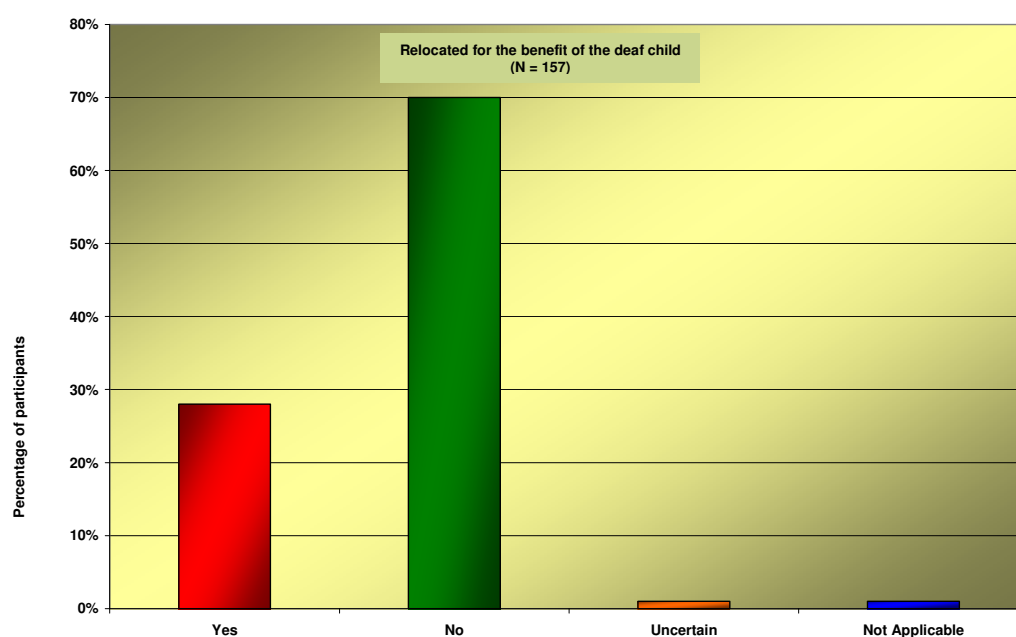
**Graph 4.2.1.10: Giving up work to care for the deaf child**



The quantitative data, in response to question ten of the questionnaire, show that 13% of the participants indicated that they were compelled to give up work to care for their deaf children; 84% were not compelled to give up work for this reason; 1% of participants indicated that they were uncertain in this regard; 2% indicated that the question was not applicable to them (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, it is possible that the majority of participants were already housewives and were therefore not compelled to give up work to care for the deaf child (*c.f.* Table 3.1 biographical information of participants who responded to the questionnaire - the majority of participants were mothers). Alternatively, since some of these participants were fathers (*c.f.* Table 3.1 biographical information of participants who responded to the questionnaire) who were compelled to work in order to support their families, the question was not applicable. In the case of the participants who were forced to leave work for the sake of their deaf children, it is possible that they had no one else to care for their deaf children. For these participants the financial burden resulting from having to give up work could have been stressful.

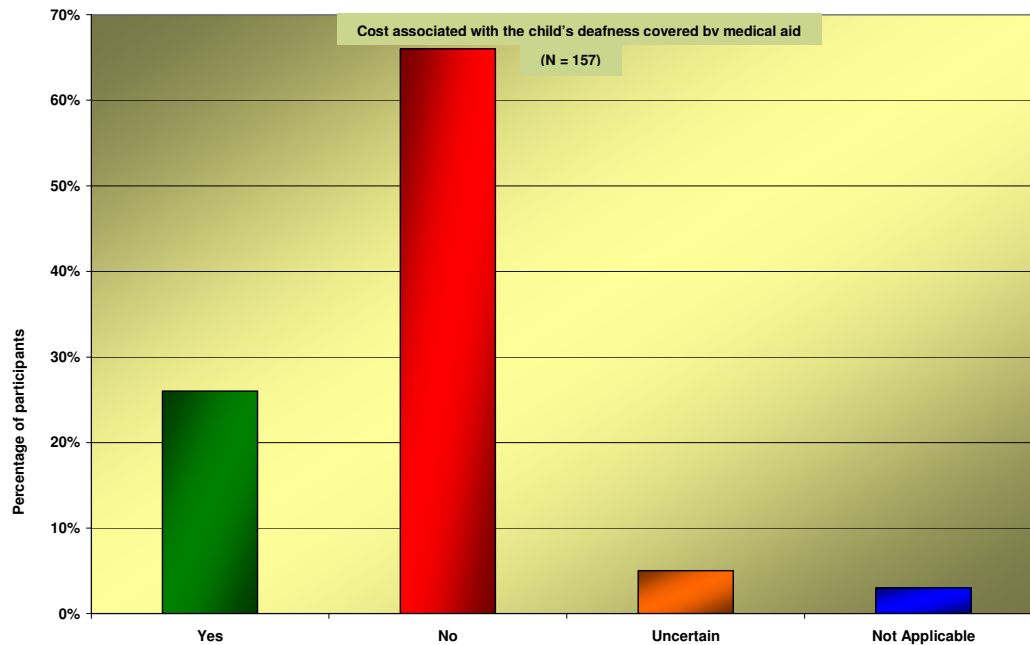
**Graph 4.2.1.11: Relocated for the benefit of the deaf child**



Describing the quantitative data, in response to question eleven of the questionnaire: 28% of participants were had to relocate for the sake of their deaf children; 70% were not compelled to move home as a result of having deaf children; 1% indicated that they were uncertain while 1% indicated that the question was not applicable (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, a number of participants had to relocate in order to provide better opportunities for the education and development of their deaf children. This meant, among other consequences, giving up their jobs and homes, leaving behind family and friends, and finding alternate accommodation and employment in a new environment. This is likely to have increased their stress levels and affected their emotional well-being on the one hand, but might have provided the necessary educational support on the other hand, thereby reducing concern in this regard. The fact that the majority did not have to relocate as a result of having a deaf child could possibly be an indication that these participants could not afford to give up their jobs and homes, and had to make the most of the facilities such as schools and other services in their own residential area. As Knoors (2007: 244) states, Dutch parents, in principle, tend to choose a school for their child based on educational quality. However, in practice, proximity between home and school seems to be the decisive factor, and most parents tend to choose a school in the area where they reside or choose to move closer to the school.

**Graph 4.2.1.12: Cost associated with the child's deafness covered by medical aid**

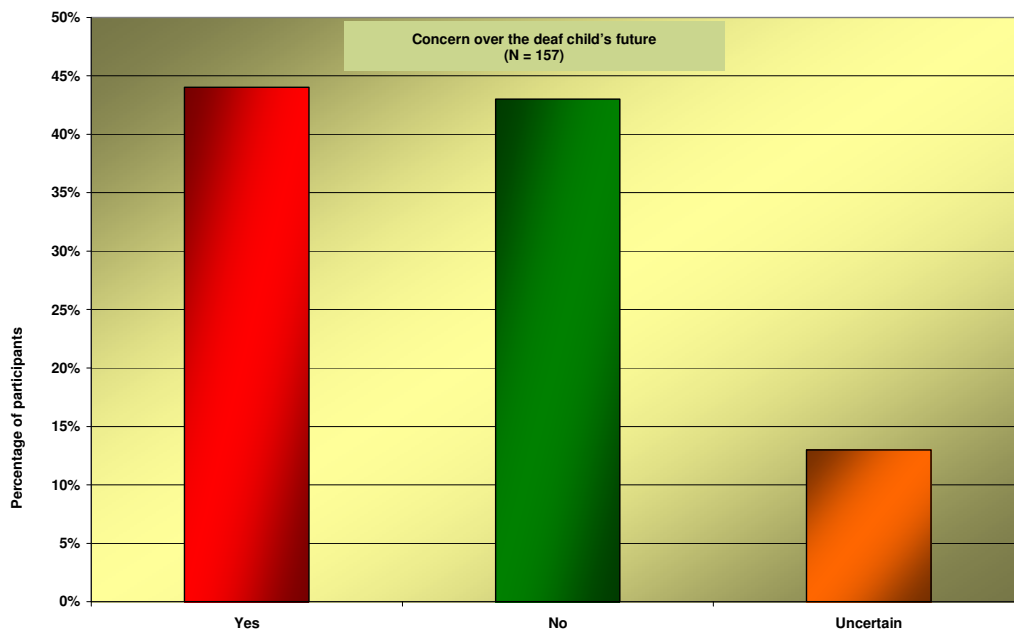


The quantitative data reveal in response to question twelve of the questionnaire that 26% of participants indicated that their medical aid covered the costs associated with their children's deafness; 66% indicated that their medical aid did not cover the costs; 5% were uncertain in this regard; 3% indicated that the question did not apply to them (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, the majority of participants must have incurred financial expenses as the costs associated with raising deaf children are high, including medical tests, audiological screening, hearing aids, cochlear implants, and other services. An overview of the cost associated with deafness reveals "a potentially enormous financial obligation" for the deaf child's parents (Northern & Downs, 2002: 28). These costs could be covered by medical insurance, if parents have it, and if the insurance company is willing to do so. Some participants were fortunate in that their medical insurance covered the costs associated with their children's deafness and eased their financial strain. In the case where the medical insurance did not cover the costs, the financial burden was likely to add to the stress experienced by hearing parents raising deaf children. Ross and Deverell (2004: 15) hold the view that financial constraints and the absence of resources may exacerbate family tensions. The few who indicated that the question did not apply to them may possibly not be members of a medical aid scheme.



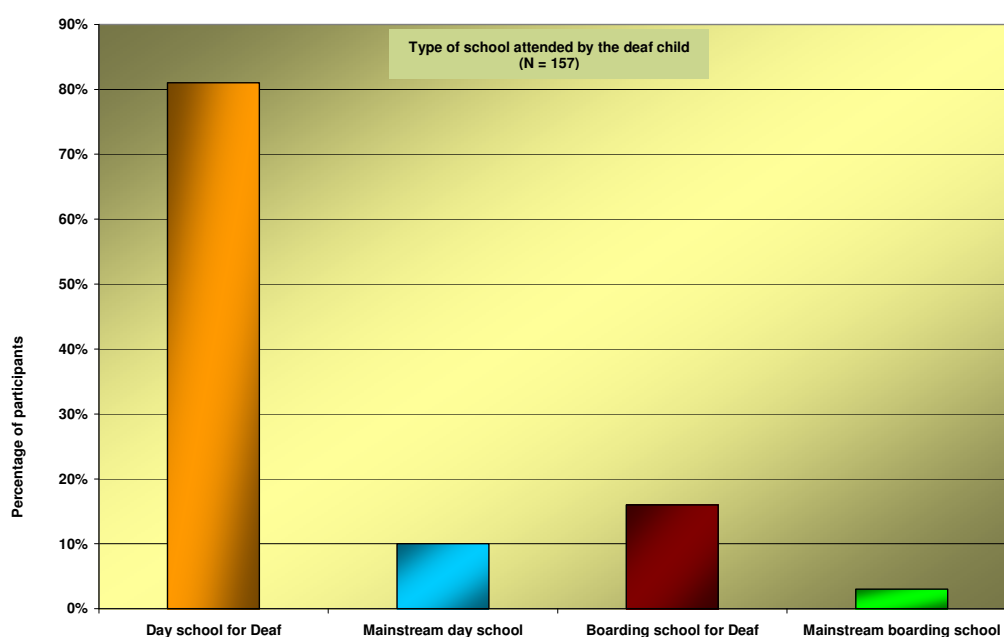
**Graph 4.2.1.13: Concern over the deaf child's future**



The quantitative data reveal in response to question thirteen of the questionnaire that 44% of participants indicated that the future of their deaf children was of concern to them; 43% did not regard their deaf children's future as particularly problematic, while 13% were uncertain (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, there seems to be somewhat of a balance with regard to the number of participants who see their deaf children's future as particularly problematic, and those who do not. The likely reason is that the coping mechanisms of participants differ. This could also be linked to the age of the child, as an eighteen year old's future prospects in terms of work and finding a partner will be of more immediate concern than that of a five year old. Those participants who indicated that the future of their deaf children was not of particular concern to them probably adopt a policy of taking one day at a time, rather than worrying about what might, or might not happen in the future. They possibly viewed the "education" that their children were receiving as preparing them sufficiently for the future. The view of those who indicated that the future of their deaf children was a particular problem resonates with the findings of Vernon and Andrews (1990: 130) in that fears for the child's future emerge as parents begin to think about the child's prospects for employment, marriage and starting a family. Meadow-Orlans *et al.* (2003: 124) also highlights hearing parents' concerns about their deaf children being unable to accomplish their aspirations in life.

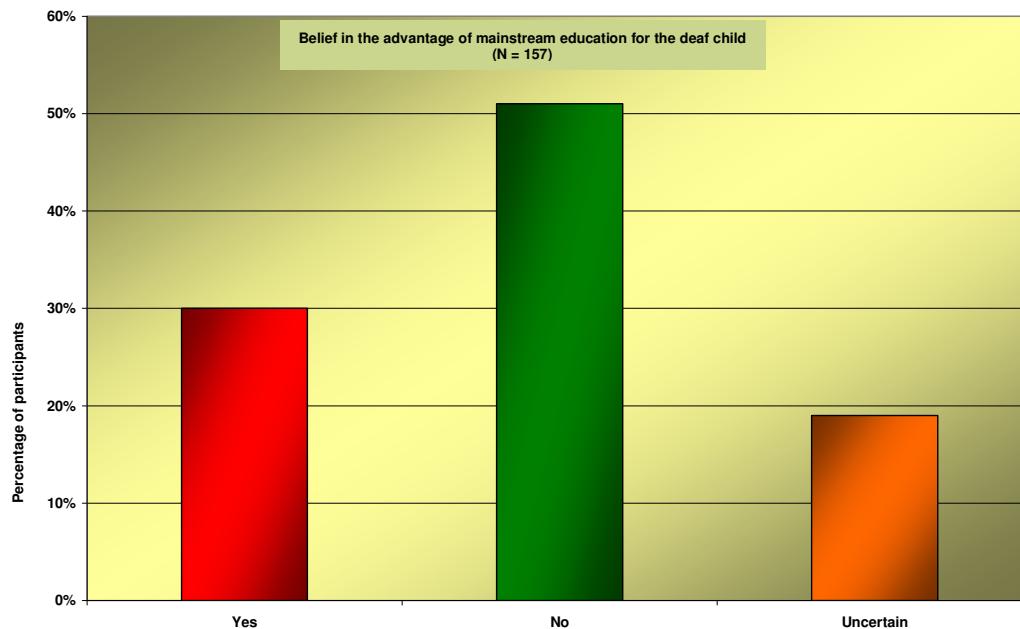
**Graph 4.2.1.14: Type of school attended by the deaf child**



The quantitative data, in response to question fourteen of the questionnaire, show that 81% of the participants' deaf children attended day schools for the Deaf; 10% went to mainstream day schools; 16% were in boarding schools for the Deaf, while 3% were at mainstream boarding school.

If one interprets the quantitative data descriptively, some participants seem to have tried different educational options for their deaf children in view of the fact that the figures do not tally. Most participants chose to send their deaf children to schools for the Deaf possibly because of possible marginalisation in a mainstream school, where larger numbers in classrooms make individual attention difficult. Fear of social isolation and ridicule from hearing learners could be a further reason for their choice of special schools for the Deaf. Moreover, their choice could have been influenced by their belief that their deaf children would receive quality education from specially trained educators for the Deaf. Another reason for their choice of special schools could be based on the use of sign language as the medium of instruction, rather than the oral mode of communication used in mainstream schools. The findings are in keeping with those of Herweijer and Yogels (in Knoors, 2007: 244) who state that the issue of choosing the right educational option for deaf children can be a dilemma, and that in principle Dutch parents usually choose a school based on its educational quality. However, in practice most parents tend to choose a school in their own area unless there is one in another area where the quality of education is considerably better.

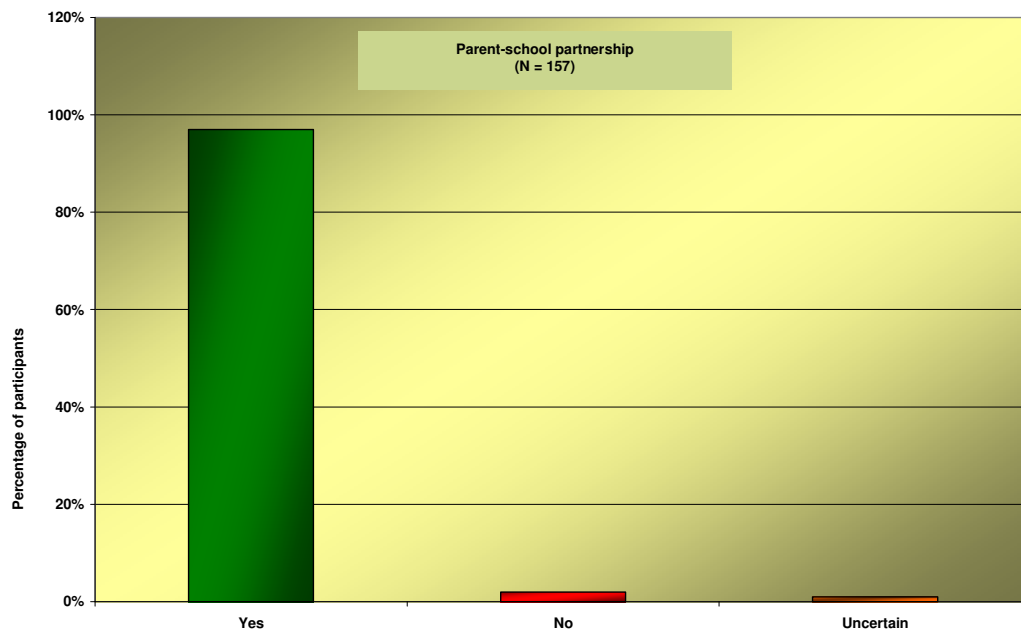
**Graph 4.2.1.15: Belief in the advantage of mainstream education for the deaf child**



The quantitative data reveal in response to question fifteen of the questionnaire that 30% of participants indicated that it would be to the advantage of their deaf children to attend a mainstream school; 51% felt that it would not be to the advantage for their deaf children to attend a mainstream school; 19% were uncertain in this regard (c.f. 4.3.3.2 of the qualitative findings).

If one interprets the quantitative data descriptively, it is clear that most participants believe that it would not be advantageous for their deaf children to be at a mainstream school. This finding is linked with the finding in graph number 4.2.1.14 and could be the reason why the vast majority of participants chose to send their deaf children to special schools for the deaf. The reason could possibly be based on the fear that their children might not cope with the oral medium of instruction, or in large classes which make it difficult for specially trained educators to provide individualised instruction to learners. Other reasons could be fear of social isolation and stigmatisation of deaf learners by hearing learners. A number of participants indicated that their deaf children would benefit from mainstream education possibly because they subscribe to the philosophy underpinning inclusive education, which has as its goal human rights, social justice, equity and integration of all learners in an education system that respects and caters for the diverse learning needs of every learner (DoE, 2001: 5). It is possible that these participants believe that deaf children should be integrated with hearing children so as to make it easier for them to take their place in a hearing society. Knoors (2007: 243) also raises this as a dilemma in deaf education, namely, how to reconcile "a best model approach" with parents' educational objectives and choices.

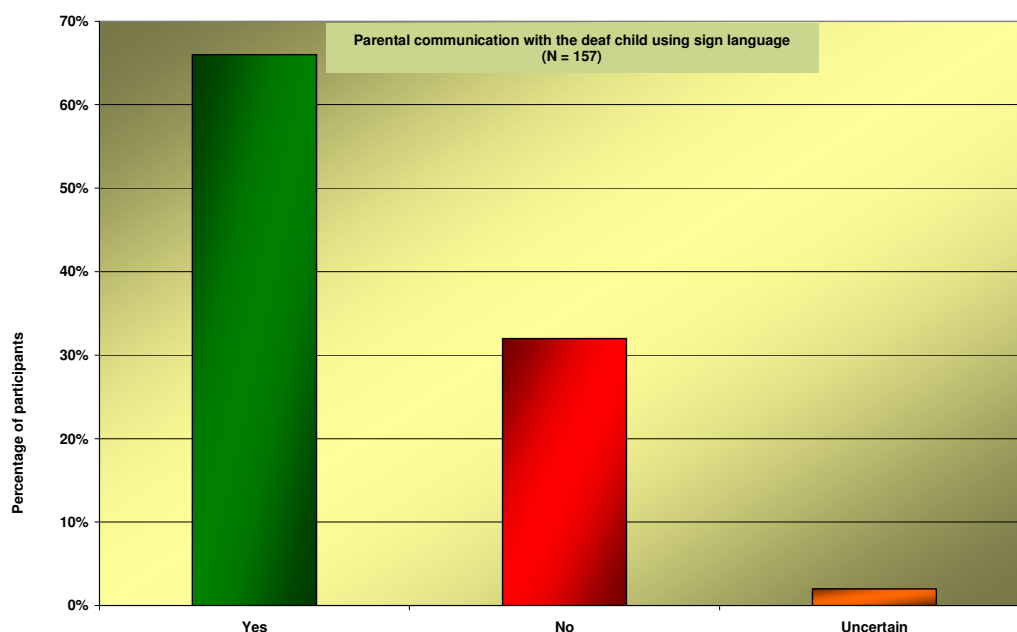
**Graph 4.2.1.16: Parent-school partnership**



The quantitative data, in response to question sixteen of the questionnaire, show that 97% of participants agreed that parents and educators should take joint responsibility for the education of their children; 2% did not agree, while 1% were uncertain in this regard (*c.f.* 4.3.3.2 of qualitative findings).

If one interprets the quantitative data descriptively, it is clear that the majority of participants acknowledge the importance of parents and educators taking joint responsibility for the education of their deaf children in order to actualise their potential. Research shows that active parental and community involvement in the child's education is fundamental to the scholastic progress and development of the child (Swart & Phasha, 2005: 213). The DoE (2001: 6) supports the view that all parents have the right to access and participation in the education of their children. With increasing emphasis on parental involvement in the education of their children, it is clear that most parents realise the value of a parent-school partnership approach to education. This is in keeping with Bronfenbrenner's bioecological model of human development, which emphasises that the reciprocal intervention between different systems in the environment (such as family, school and community) contributes to the child's development (Bronfenbrenner & Morris, 1998: 996). The few participants who did not agree that parents and educators should be joint partners probably still espouse the view that education is the domain of the school and qualified educators rather than the parents.

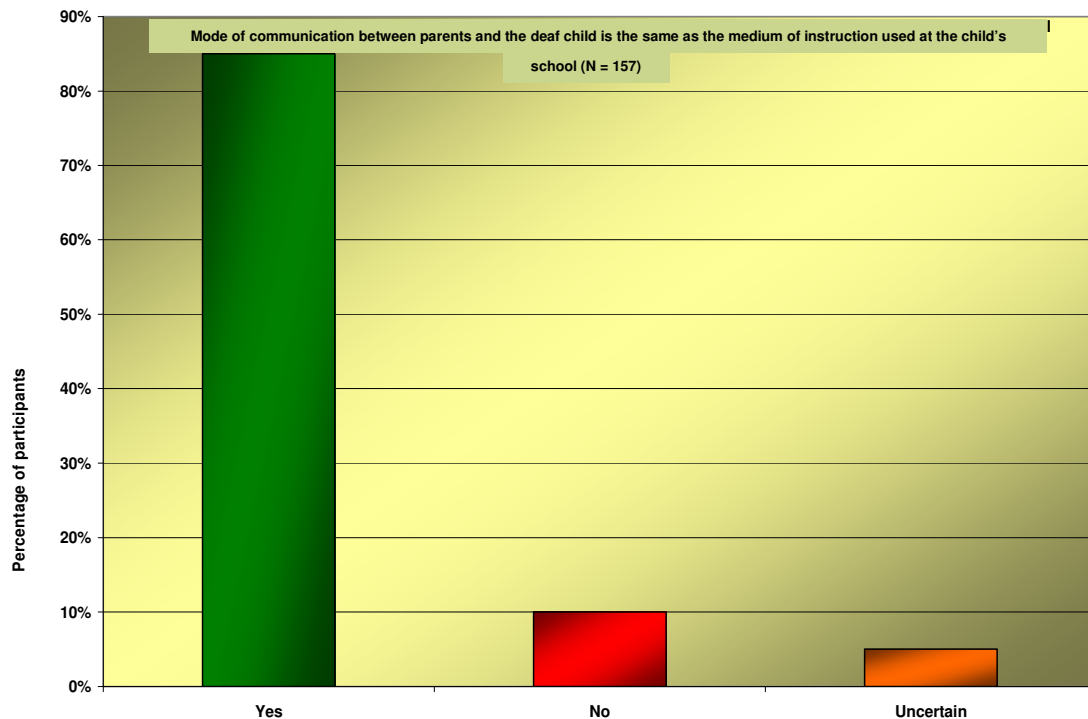
**Graph 4.2.1.17: Parental communication with the deaf child using sign language**



The quantitative data, in response to question seventeen of the questionnaire, show that 66% of participants communicated effectively with their deaf children through sign language; 32% indicated that they did not, and 2% were uncertain (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, the fact that the majority of participants communicated effectively with their deaf children through sign language, is possibly an indication that these participants made a choice to learn and use what is regarded as the natural language of the deaf. Those parents who indicated that they did not communicate effectively with their deaf children through sign language perhaps deliberately chose to communicate through the oral mode. Their belief, one assumes, is that, if their deaf children could develop verbal communication skills they would adjust more easily, and not be marginalised in a hearing world, and that opportunities for socialisation and employment would be increased. On the other hand, it could be that these participants did not have the opportunity to become competent in the use of sign language, possibly because facilities in this regard were not readily available in their community at that time. Meadow-Orlans *et al.* (2003: 12-27) found that hearing parents of deaf children struggle to establish effective communication within their families, and that one third of the parents they surveyed communicated through speech alone with their deaf children. It is clear that ineffective parent-child communication could cause feelings of inadequacy, frustration and depression on the part of parents, and this is in keeping with the findings of Kushalnagar *et al.* (2007: 335).

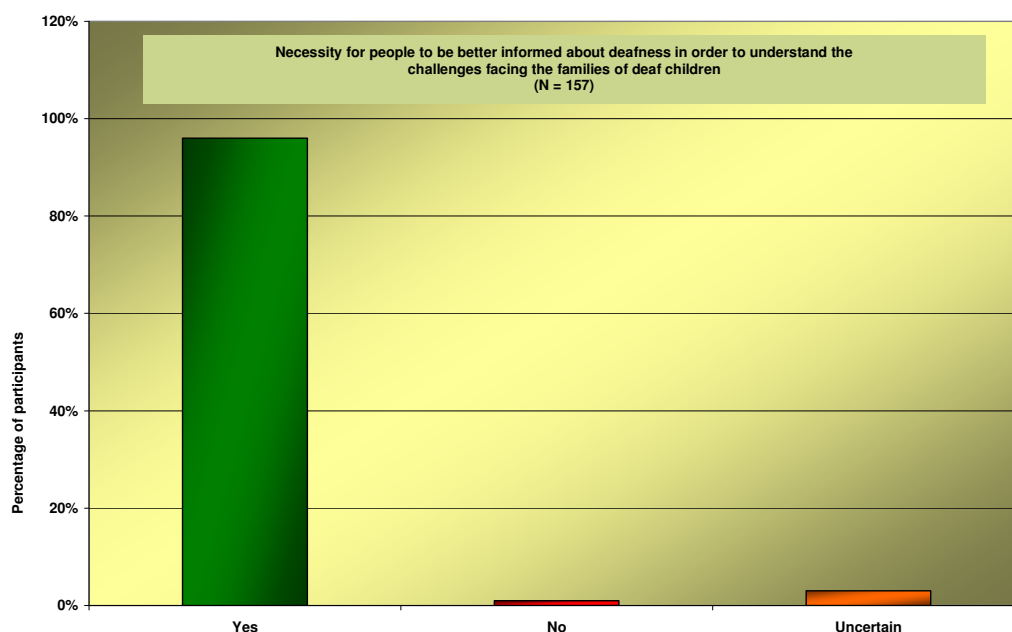
**Graph 4.2.1.18: Mode of communication between parents and the deaf child is the same as the medium of instruction used at the child's school**



The quantitative data reveal in response to question eighteen of the questionnaire that 85% of participants indicated that the mode of communication between themselves and their deaf children corresponded with the medium of instruction used at the child's school while 10% indicated otherwise, and 5% were uncertain in this regard (*c.f.* 4.3.3.1 of qualitative findings).

If one interprets the quantitative data descriptively, it is clear that the vast majority of participants saw the advantage of the deaf child using a mode of communication common to both home and school. That mode would offer the child greater support and consolidation for school based activities at home. The above findings concur with those of Meadow-Orlans *et al.* (2003: 27) in that most families used the same mode of communication with their deaf children at home as that used by their deaf children at school. The few participants who indicated that the mode of communication with their deaf children did not correspond with the medium of instruction used at their children's school, probably saw a need to promote the bilingual communication skills of their deaf children. Such skills would equip them to interact with hearing and deaf people, and increase their chances of employment in the future (*c.f.* Graph 4.2.1.17). Alternatively, perhaps these parents could not communicate effectively through sign language, as they may have had limited opportunities to acquire competence in this regard. In either case, the lack of a common mode of communication at home and at school is likely to impact negatively on parent-child interaction.

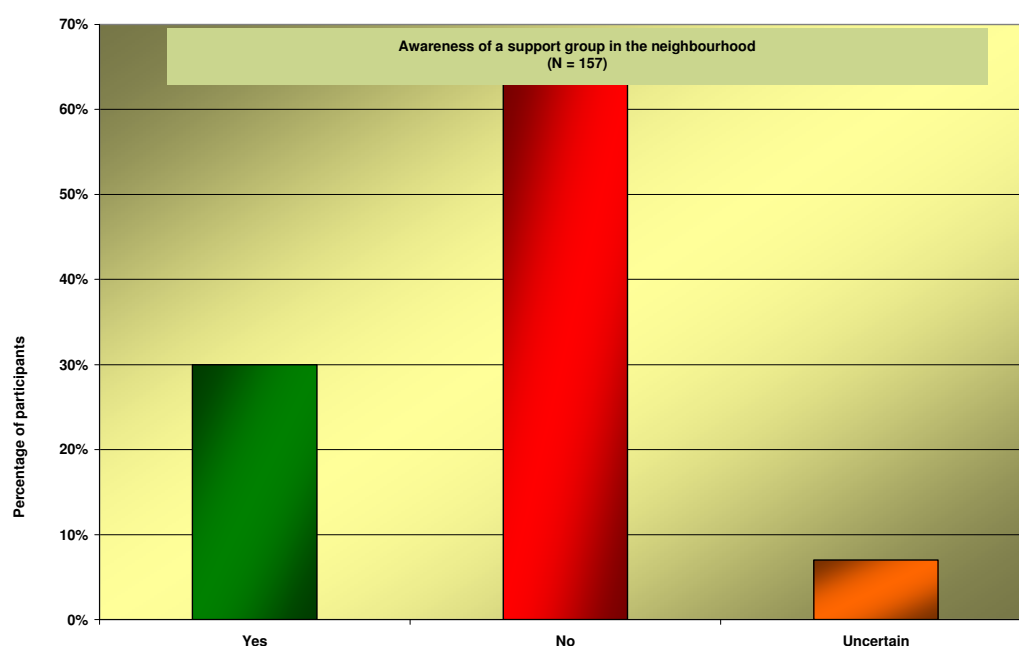
**Graph 4.2.1.19: Necessity for people to be better informed about deafness in order to understand the challenges facing the families of deaf children**



The quantitative data, in response to question nineteen of the questionnaire, show that 96% of participants agreed that people need to be better informed about deafness in order to understand the challenges facing families of deaf children, while 1% did not agree, and 3% were uncertain in this regard (c.f. 4.3.3.2 of qualitative findings).

If one interprets the quantitative data descriptively, it would seem that the vast majority of participants believe that it is necessary for people to be better informed about deafness in order to understand the challenges facing the families of deaf children. The implication is that generally people do not fully understand the problems of hearing families raising deaf children, as they are not fully informed about the nature of deafness and its consequences. It is possible that these participants, having encountered negative experiences from the community, therefore see the need for people to be better informed about deafness, so that they would be more accepting of the deaf child and the family. Corker (in Ross *et al.*, 2004: 154) holds the view that “the devaluative attitudes of society towards deaf people” can affect their social development, and therefore it is important to have a knowledgeable community who can engage comfortably with deaf individuals. Since the hearing world is largely dependent on the aural/oral mode of communication, deaf individuals are placed at a serious disadvantage.

**Graph 4.2.1.20: Awareness of a support group in the neighbourhood**

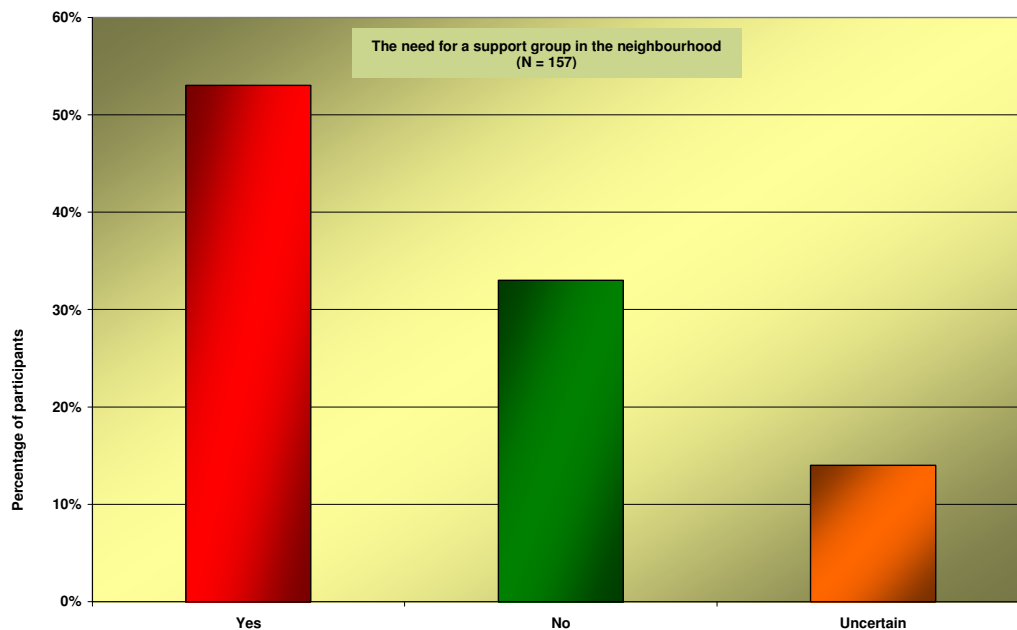


The quantitative data, in response to question twenty of the questionnaire, show that 30% of the participants were aware of a support group in the neighbourhood where they could receive counselling about coping with their children's deafness; 63% were not aware, and 7% were uncertain in this regard (*c.f.* 4.3.3.3 of qualitative findings).

If one interprets the quantitative data descriptively, it is clear that the majority of participants were not aware of a support group in the neighbourhood where they could receive counselling about coping with the child's deafness, possibly because such a facility does not exist in the community. It points to a lack in the community of a database of parents in a similar position, who could provide emotional support. Hintermair's (2006: 495) conclusion, drawn from various studies of stress among hearing parents of deaf children, is that the availability of personal and social resources such as support networks, facilitate coping. Ross and Deverell (2004: 172-173) emphasise the need for health care professionals, psychologists, social workers to counsel parents, provide them with information on deafness, help them make informed decisions about communication and educational options, and arrange parent support groups. Those participants who were aware of the existence of a support group in the neighbourhood probably accessed this support and benefitted by it. The awareness of the availability of a support group could contribute to peace of mind for participants, knowing that they had somewhere to turn to if the need arose.



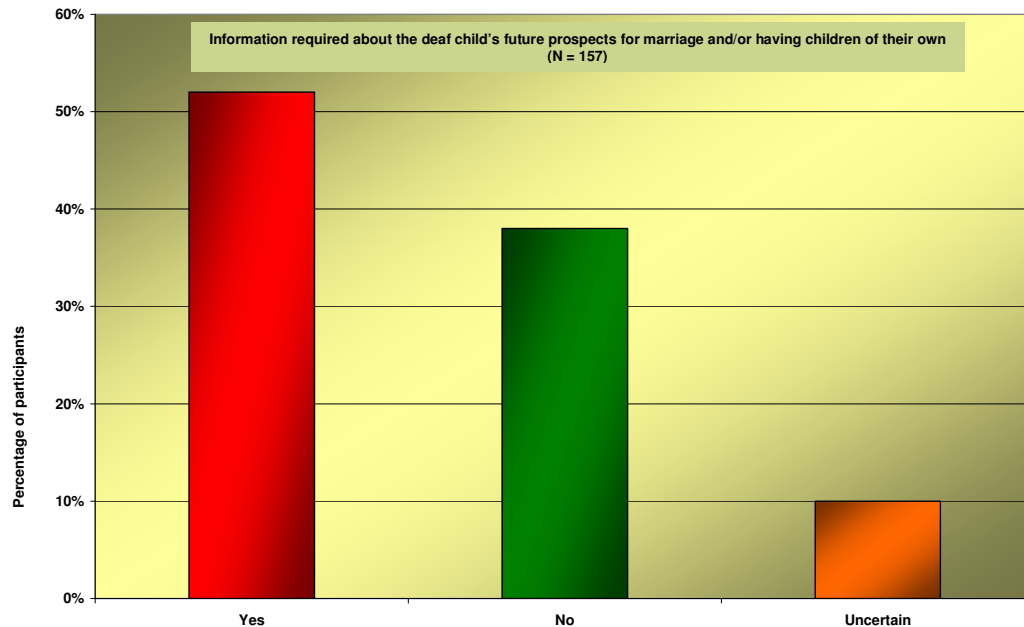
**Graph 4.2.1.21: The need for a support group in the neighbourhood**



The quantitative data, in response to question twenty-one of the questionnaire, show that 53% of participants agreed on the need for a support group in the neighbourhood, while 33% did not agree, and 14% were uncertain (*c.f.* 4.3.3.3 of qualitative data).

A descriptive interpretation of the quantitative data reveals that the majority of participants felt the need for support groups in the neighbourhood, an indication that they possibly required emotional or moral support in raising their deaf children and managing their parental role more effectively. McBride and Shonkoff *et al.* (in Britner *et al.*, 2003: 337) concur that social support can serve as a buffer against stress, difficult parenting situations as well as depression, and can promote adaptation to the presence of a child with a disability in the home. Hintermair (2006: 495) states that an extensive body of literature in recent years has focussed on stress and coping processes in parents of deaf children, and that while various factors can increase stress levels, lack of a support network has been specifically identified as such a factor. In the case of participants who indicated that they did not need a support group in the neighbourhood, it is possible that they were able to manage adequately with their parenting role, and perhaps had extensive support from family. Alternatively, they may be of the view that a support group in the neighbourhood would not make a difference to them with regard to raising their deaf children. In the case of some participants who were uncertain of the need for a support group in the neighbourhood, it is possible that they did not have access to the benefits of a support group to enable them to form an opinion in this regard.

**Graph 4.2.1.22: Information required about the deaf child's future prospects for marriage and/or having children of their own**

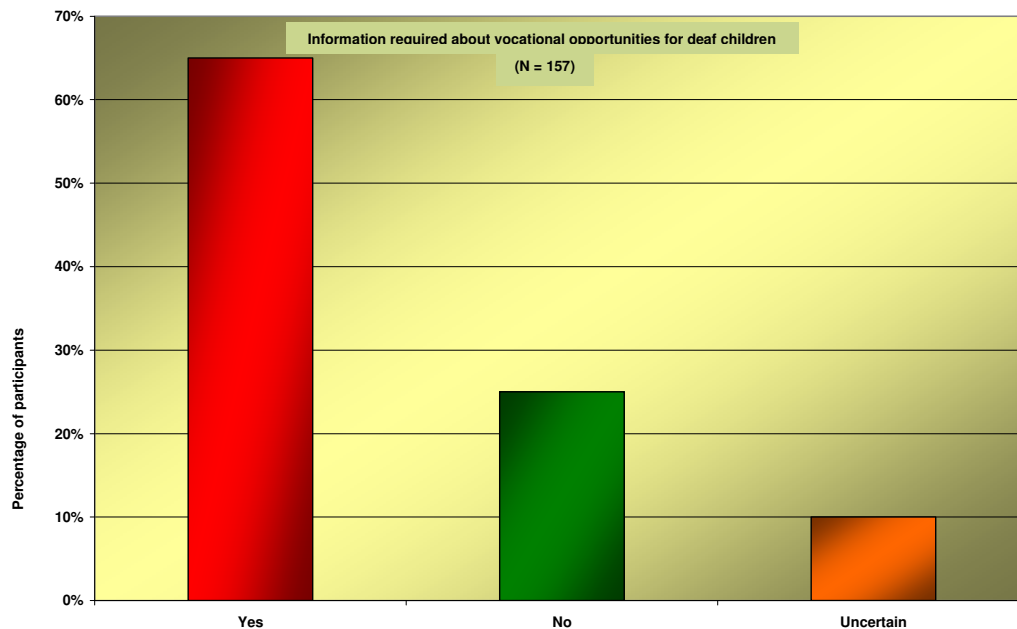


The quantitative data, in response to question twenty-two of the questionnaire, show that 52% of participants required information about deaf children's prospects for marriage and having children of their own, while 38% did not require such information, and 10% were uncertain.

A descriptive interpretation of the quantitative data reveals a concern of those participants who indicated their need for information about the deaf child's future prospects for marriage and having children of their own. They probably consider this milestone as a marker of success or fulfilment in life. This is usually a concern for parents of children who are deaf (Meadow-Orlans *et al.*, 2003: 124) and, as pointed out by Vernon and Andrews (1990: 130), could possibly contribute to parental stress (*c.f.* Graph 4.2.1.13).

In the case of participants who indicated that they did not require such information, they probably had enough information and were optimistic about their children's future prospects. The few participants who were uncertain in this regard were perhaps unsure whether such information would be useful to them in the early stages of child rearing.

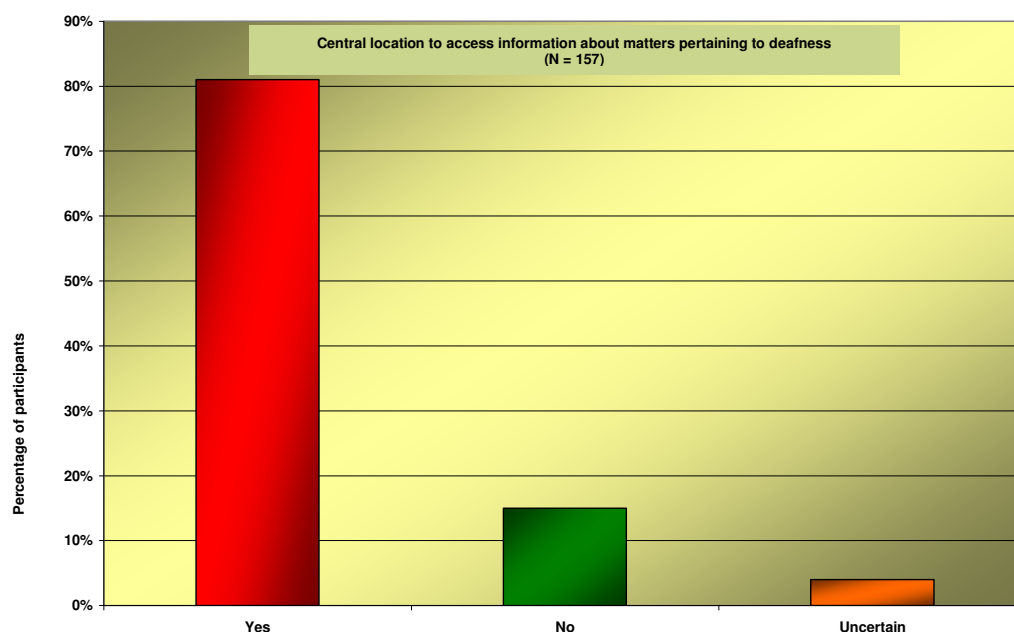
**Graph 4.2.1.23: Information required about vocational opportunities for deaf children**



The quantitative data, in response to question twenty-three of the questionnaire, show that 65% of participants required information about the vocational opportunities for their deaf children; 25% did not require such information, and 10% were uncertain.

A descriptive interpretation of the quantitative data reveals the need of the majority of participants for information about vocational opportunities for their deaf children, probably because of their concern about the limited employment opportunities available for deaf people. According to Ross *et al.* (2004: 155) DeafSA estimated that 70% of deaf people in South Africa were unemployed in 1997. This implies that there is a lack of employment opportunities for deaf people in South Africa, and possibly a lack of understanding by society about deaf people. According to the Commission for Conciliation, Mediation and Arbitration (CCMA, 2006), the South African Employment Equity Act No. 55 of 1998 compelled employers to employ people with disabilities due to unfair discrimination against people with disabilities, because such people experience high unemployment rates in society. It is likely that anxiety regarding vocational opportunities for the deaf could lead to stress among participants. Participants who did not require information in this regard probably already had access to such information. Alternatively, it is possible that since their deaf children were still very young, they may have had other more pressing issues to worry about. This concurs with the findings of Porter and Edirippulige (2007: 525) in that many parents of older deaf children need information about the post-school period, hearing support at university, career guidance and employment options.

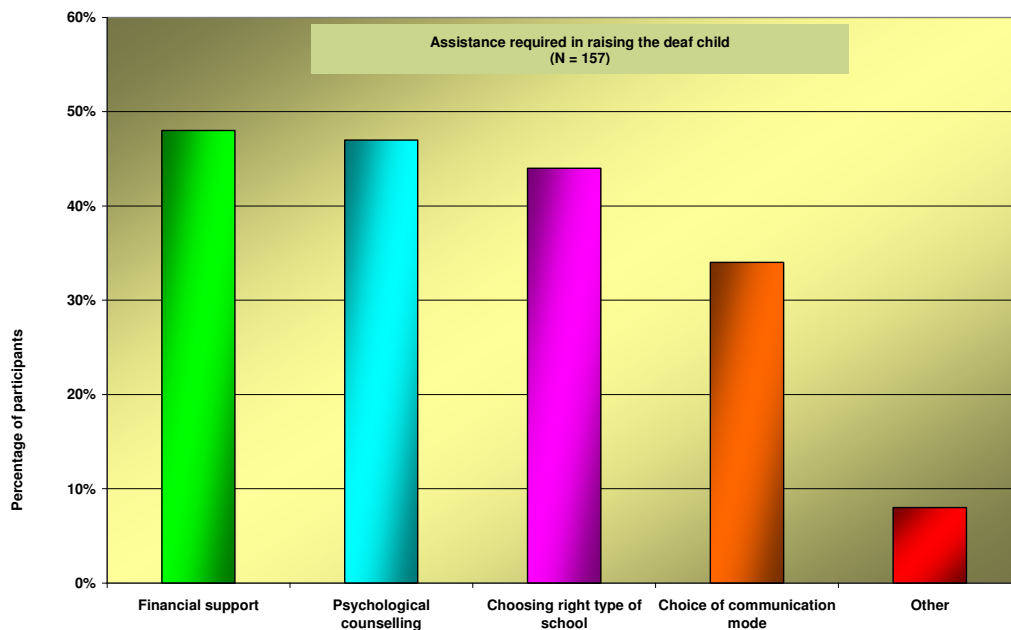
**Graph 4.2.1.24: Central location to access information about matters pertaining to deafness**



The quantitative data, in response to question twenty-four of the questionnaire, show that 81% of participants indicated their preference for a central location to access information about matters pertaining to deafness, while 15% indicated that they did not, and 4% were uncertain.

If one interprets the quantitative data descriptively, the vast majority of participants expressed the desire for a central location where they could access information about matters pertaining to deafness, as it probably would empower them and facilitate their parenting role. This concurs with what Bemrose and Young (in Porter & Edirippulige, 2007: 518) put forward, *i.e.* that information empowers parents and provides them with confidence to raise a deaf child. Porter and Edirippulige (2007: 518) maintain that research confirms the importance of information to families of recently diagnosed deaf children, and that the internet has become an important source of accessing reliable health information quickly, conveniently and privately. DesGeorges, Kurtzer-White and Luterman (in Porter & Edirippulige, 2007: 518) agree that parents of deaf children require information that is accurate and reliable to enable them to make informed choices regarding assistive hearing devices, as well as communication and education options, at a time when they are emotionally vulnerable. Although information may be provided by professionals, families are turning to the internet to access additional information. In the case of participants who indicated that there was no need in this regard, they probably had sufficient access to information they required to facilitate their parenting role.

**Graph 4.2.1.25: Assistance required in raising the deaf child**



The quantitative data, in response to question twenty-five of the questionnaire, reveal that 48% of participants require assistance with regard to financial support in raising their deaf children; 47% require assistance regarding psychological counselling; 44% need assistance in choosing the right type of school for their deaf children and 38% require help in choosing the mode of communication to adopt with their deaf children. As 8% indicated that they need other types of assistance, it is clear that the questionnaire did not cover the entire range of help required in regard to raising a deaf child (*c.f.* 4.3.3.1; 4.3.3.2 and 4.3.3.3 of qualitative data).

A descriptive interpretation of the quantitative data clear shows that it is costly to raise a deaf child. Since participants ranked financial assistance as the main priority, it is likely that their financial burden could be stressful (*c.f.* Graph 4.2.1.12). As several participants indicated their need for psychological counselling, the implication is that raising a deaf child is accompanied by issues that threaten their emotional well-being. If one notes that several participants indicated the need for assistance in choosing the right type of school, the implication is that an informed decision is difficult to make in this context. The implication for those who indicated the need for help in choosing the mode of communication with their deaf children, is that an uninformed decision could impact negatively on their children's education, and thus cause stress. As Zaidman-Zait and Jamieson (in Porter & Edirippulige, 2007: 518) state, the process of information gathering by parents can affect both parental coping and the decision-making process.

#### **4.2.2 Conclusion**

The quantitative data were analysed and interpreted qualitatively by exploring possible reasons for the responses, and also by supporting the interpretation with literature. The findings show that for many parents, raising a deaf child is a complex process containing many ecosystemic variables which come into play and influence their experience. The findings from the quantitative data serve as a background and complement the findings emanating from the qualitative data which follow, and deepen the understanding of their parenting experiences.

### **4.3 EXPERIENCES OF HEARING PARENTS RAISING DEAF CHILDREN: WHAT DO THE QUALITATIVE DATA REVEAL THROUGH THE INDIVIDUAL STORIES?**

#### **4.3.1 Introduction**

The data collected from the interviews of twenty hearing parents of deaf children has been coded according to Tesch's (in Creswell, 2003: 192-194) guidelines for open coding as explained in chapter three. Where relevant, a comparison of the qualitative and quantitative findings will be made, by drawing the findings of the questionnaire into the themes.

The main themes are derived from various categories emerging from the analysis of the data, and are underpinned by Bronfenbrenner's (1992: 1079) ecological systems theory of human development, which was subsequently revised as the bioecological model of human development (Bronfenbrenner & Morris, 1998: 994; Bronfenbrenner, 1992: 189). According to Bronfenbrenner's (1992: 225) ecological systems theory, no person exists, or exerts influence in isolation, and that every human quality is inextricably imbedded and finds meaning and expression in particular environmental contexts. These contexts are explained as a series of 'circles-within-circles', and refer to the complex interaction of various systems that influence a person's life. These circles-within-circles are most likely to

play a more dynamic role in the lives of parents of children with disabilities (Luster & Okagaki, 2005: 196).

Most of the participants relate the story of their experiences as if they had “no choice” but to embark on these journeys towards acceptance, learning a new language, endurance, celebration, developing trust in their inner voice as a parent, as well as in God, and making meaning of their experiences. Parents tell the story of these journeys in which they experience many challenges, which play themselves out as an interaction between the parents’ own coping mechanisms, the impact of the deaf child on the parent-child relationships as well as on family relationships, the (amount of) support they receive from the family, school and community including the support from the professional community, and the community’s response to their children’s deafness. Finally, parents suggest a partnership approach between all stakeholders as they share their knowledge and experiences gained by focussing on attaining the best for their deaf children, while also sustaining their own emotional well-being.

The themes and categories identified through the analysis of the data are tabulated below. This is followed by a detailed discussion of the themes and categories. All direct quotations from the participants are reflected in inverted commas and typed in italics. To protect the identity of participants, their deaf children, as well as the schools they attend/attended, pseudonyms have been used.

#### 4.3.2 Representation of the qualitative data as themes

**Table 4.3 Hearing parents' experiences of raising deaf children**

<b>THEMES</b>	<b>CATEGORIES</b>
Finding direction	<ul style="list-style-type: none"><li>• Psychological response to the diagnosis of the child's deafness and the journey towards acceptance</li><li>• Learning sign language and the language of 'normality'</li><li>• Endurance, sacrifice and 'celebration'</li><li>• Trusting own 'inner voice' and making meaning</li></ul>
Challenges in the family, school and community	<ul style="list-style-type: none"><li>• A deaf child in the family: parent-child relationships, marital relationships, and lack of support from extended family</li><li>• The deaf child's education</li><li>• Stigmatisation in the community</li></ul>
The partnership approach towards support	<ul style="list-style-type: none"><li>• Parents, extended family and the deaf child</li><li>• Parents and the school</li><li>• Parents and the community</li></ul>



### **4.3.3 Discussion of findings: the journey**

#### **4.3.3.1 Finding direction**

Hearing parents' experiences associated with the diagnosis of, reaction to, and acceptance of their children's deafness as well as its consequences thereof form the basis of the first theme. The categories that constitute this theme are discussed below.

- **Psychological response to the diagnosis of the child's deafness and the journey towards acceptance**

Most parents' emotional reaction to the initial diagnosis of their children's deafness was one of intense shock. Calderon and Greenberg (in Brown, Abu Bakar, Rickards & Griffin, 2006: 208) state that many parents also experience feelings of stress, anxiety, sorrow or grief as they try to adjust to their new circumstances. While most participants reported reactions of emotional shock, grief, devastation and despair, some took it in their stride and apparently accepted the diagnosis more easily. In keeping with Bronfenbrenner's (1992: 197; 1998: 996) ecological systems theory, variations in parents' reactions to the diagnosis of their children's deafness may be viewed as "a joint function" of the characteristics of the person and the environmental contexts, over a period of time.

Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.3), 69% of the participants experienced shock; 40% anger; 48% anxiety; 43% depression, and 34% experienced feelings of guilt. The following excerpts, taken verbatim from the data, bear testimony to the emotional responses of hearing parents on the diagnosis of their children's deafness:

*"When I heard, I was absolutely devastated...we had no experience of anybody who was deaf...so it was a terrible shock...and I don't think there was a day for two and a half years that I didn't cry half the day...and it was devastating."*

This was the inner experience of Edna, mother of Emily. The extent of Edna's devastation was so deep that she grieved over the loss of her dream for a "normal" child for a prolonged period of thirty months, a crucial period in the development of a young child. When a baby is expected, parents expect a "normal" baby who will grow up to fulfil all the aspirations of the parents. When they realise that these aspirations might not be achieved, the shock is immeasurable. Gascoigne (1995: 16) states that many psychologists agree that a parent of a child with a disability needs to grieve, "just as if a loved one has died". However, the grieving process is severely hampered by the day to day management of the child, and parents, according to Gascoigne (1995: 16), require time to grieve for the loss of the dream child, to love and accept the child that they have, "and to turn that love into a positive attitude". Ross *et al.* (2004: 156) concur with this view and state that much of the literature emphasises the necessity for parents to go through a grieving process "to mourn the loss of a normal child". In addition, Kübler-Ross (in Ross *et al.*, 2004: 156) states that the stages of grieving, which include denial, anger, bargaining, depression and acceptance, are necessary to enable people to adapt to the reality and acceptance of loss.

The inner feelings of Amy, mother of Andrew, were revealed in the following extract:

*"I then found out that he was deaf and I think, if I could have, I would probably have given him back. In fact, I really did not like him very much. I had no option but to love him because he was my child."*

The intense shock upon the diagnosis of Andrew's deafness led to Amy's initial feeling of rejection for her firstborn child. Amy was devastated and she openly revealed her innermost feelings of initial dislike for her deaf child, an indication that she must have experienced emotional shock at the time of diagnosis.

Hemma, mother of Harish, recalled her experience upon the diagnosis of her first-born child's deafness:

*“Obviously, it was a really, really terrible time to hear somebody telling you your ‘child is deaf’. I burst out crying. I didn’t know what to do and immediately thought ‘God, why?’ – I mean my mother had died, my brother was arrested, the trial was in between, the family just split up because of what had happened to my mother...and now hearing that your child is deaf! I mean that it is just the tip of the iceberg – you don’t want to hear that. My mother-in-law did not accept it; my husband took it very badly, and we looked within ourselves for what could have happened...you feel you are to blame because you have had this child, and ‘What wrong did you do?’... ‘And definitely, no more kids!’...”*

The complexity of tragic events in the micro-system (family) of this particular participant contributed to the intensity of her emotional response of shock, devastation, remorse and utter despair. Hemma’s feeling of complete helplessness led her to believe that she was to blame, and to question God, as if she were being unfairly punished. According to Paasche, Gorrill & Strom (2004: 87), as well as Ross *et al.* (2004: 156), parents may blame themselves for the child’s deafness when the cause is not apparent. Scheetz (2001: 60) states that guilt usually follows anger when parents try to rationalise the consequence of having a deaf child.

Grace, mother of Gillian, shared her initial emotional reaction to the diagnosis of her child’s deafness as follows:

*“In the beginning I was heartbroken – I was very upset about it.”*

It would seem as if Grace felt terribly let down when she learnt of Gillian’s deafness, almost as if she had been cheated, and that she had been dealt a heavy blow which broke her heart and deeply hurt her feelings. Young (2002: 7) states that for some parents their initial response to the diagnosis of the child’s deafness is likened to the feeling that “the whole world has turned upside down and nothing will ever be the same again”.

Another participant, Kate, reacted in the following way when her son Kevin was diagnosed as deaf:

*“They were testing him and that’s when they saw he can’t hear...and I can’t believe it; how can they tell me that my child is deaf? He can dance with the music and enjoy it...And so I just sat in my car and cried. I didn’t even go home straight...Oh man! I thought if my child is deaf, I gotta struggle with him, nobody else.”*

Ross and Deverell (2004: 36) explain that shock, numbness and disbelief are common emotional reactions or states of grief, especially if the person had not expected the diagnosis. It is clear that Kate’s perception of parenting is that it is the mother’s responsibility. It would seem that from the point of diagnosis of Kevin’s deafness, Kate took it upon herself to shoulder the burden of raising her deaf son on her own, since she felt that it was her duty and not anybody else’s responsibility. If she had perceived the parenting role as a joint responsibility of both parents, she probably would have coped better emotionally. According to Turnbull and Turnbull (in Levitz 1991: 81), a supportive husband who does not necessarily play an active role in child care, can make a difference in the mother’s reaction to the birth of a child with a disability.

Ross *et al.* (2004: 156) agree that the diagnosis of deafness “is usually a shattering experience and tends to precipitate a crisis for many parents”. In all of the above cases, it seems clear that the emotional well-being of the participants was adversely affected upon the diagnosis of their children’s deafness.

In contrast, Devi, mother of Deshnie responded quite differently to the diagnosis of her daughter’s deafness:

*“Most of the other parents think that I’m lacking in emotion, but when you find out for the first time that your child is deaf, I don’t think...there is any time to sit down and mope and cry. So, when I found out when she was six months old, the first thing I asked him (the audiologist) ‘what’s the next step?’ My husband was very depressed emotionally... he cried; the rest of my family cried, my friends cried...I can’t tell you that I ever had a day when I sat down and thought ‘why me?’ and I sat down and started crying...never ever. For me, it’s just being a parent.”*

This particular participant, like Hemma, had also recently lost a parent with whom she had shared a very close bond, yet her emotional reaction was very different from that of Hemma and in fact, from that of most other participants. Devi's immediate acceptance of Deshnie's deafness spurred her on to find out from the audiologist what step she should take next. It would seem that Devi saw no point in grieving as it would delay the process of early intervention for her daughter's progress.

The difference in the reactions may be explained, according to Bronfenbrenner's (1992: 190) ecological systems theory as follows: "The characteristics of the person at any given time at his or her life are a joint function of the characteristics of the person and of the environment over the course of that person's life up to that time." Furthermore, the process-person-context model allows for variations in developmental processes, and outcomes are seen as a combination of the characteristics of the person as well as the environmental contexts (Bronfenbrenner & Morris, 1998: 996; Bronfenbrenner, 1992: 197).

In the case of two other participants, Barbara and Theresa, deafness was expected as both contracted Rubella within the first trimester of pregnancy, and although they were advised to abort, both made a choice not to settle for the termination of their pregnancies, and to face the consequences of their decisions.

It took some convincing on the part of Theresa to get her husband to agree with the continuation of her pregnancy as he had serious misgivings about the possible consequences, but finally he did.

*"My husband went on the internet, read up all about rubella, all the incredible effects it has on a little baby, and the parents afterwards, and their relationship and the relationship of the family and the children and all of that. He said it's not a responsible thing to do, to have a baby like this...and that he is not prepared to take the risk...I prayed to God to help me convince my husband because I could not convince him...God convinced my husband in a special way".*

Theresa shared her experience of their emotional response to the medical diagnosis of deafness of their son Theo:

*“We expected him to be deaf because I had Rubella when I was five weeks pregnant... We had him tested when he was six months old and it was confirmed that he was completely deaf. Initially it was a shock; it’s always a shock, I suppose; but it’s better than not expecting anything. We could adapt to the idea and, ja, we tried to cope with it from then on.”*

It would seem that it was more difficult for Theresa’s husband to accept the possibility that their child could be born deaf. This is in keeping with what Cunningham & Davis, (in Levitz, 1991: 80) maintain, namely, that a child born with a disability has a greater impact on the self-esteem of fathers because of socio-cultural values such as independence, achievement, manhood, and competitiveness. An alternative explanation is that mothers are better equipped to handle the situation, since they are given a greater degree of support from specialists and service providers dealing with children with disabilities.

Barbara, who contracted German measles in the early stages of pregnancy, went through a similar experience, even though she and her husband mutually agreed from the very beginning not to have the pregnancy terminated. Their son Ben’s deafness was confirmed very early in infancy, just two weeks after his birth, and the diagnosis was expected. According to Ross *et al.* (2004: 156) parents who are knowledgeable about the probable cause of deafness seem to be more capable of coping with the emotions associated with diagnosis. Barbara’s son was equipped with hearing aids at the early age of three months, and, thereafter he started on an early intervention programme with a speech therapist. The early intervention probably contributed to his progress and development as he is now a successful businessman.

In contrast, Queenie, mother of a set of twins, Quinton and Quintus revealed her innermost feelings on learning of their deafness at a very late stage of their infancy:

*“I only found out they were deaf when they were three and a half years old. So, I felt terrible about that because we had our own business – we were so busy with our own lives...but when I found out they were deaf it was a shock. I didn’t expect it, and I didn’t want it. I cried a lot.”*

Queenie possibly experienced feelings of guilt and regret for not finding out sooner that both her twin sons were deaf, because at that time, she and her husband seemed to focus more on their business. Guilt, according to Gascoigne (1995: 13) is “the most damaging emotion of all”, and once the habit of guilt is formed it is very difficult to break. Ross and Deverell (2004: 38) state that guilt is a normal part of the grieving process. Shocked at the diagnosis of her twins’ deafness, Queenie could not accept it initially and grieved over her “loss”, an indication that her emotional stability was temporarily shattered. According to Brown *et al.* (2006: 208), many hearing parents of recently diagnosed deaf children experience anxiety, stress, grief and sorrow as they try to adjust to their new circumstances in their lives.

Olivia, mother of Odette, relates her initial reaction of shock and guilt:

*“Our first experience when she was diagnosed was the shock, or disbelief, and guilt. You can feel guilty because you think “What did I do wrong during the pregnancy to cause my child’s deafness?”*

Guilt, according to Vermeulen (1999: 88), is an emotion that usually masks feelings of anger and resentment; it is an all consuming decoy that conceals the real issues and can drive one to despair. According to Scheetz (2001: 60), it is common for mothers to experience feelings of guilt about what they did or did not do during the pregnancy. Olivia’s feeling of guilt is likely to have impacted negatively on her self-esteem.

Stefan, father of Sonja, recounts his and his wife’s reactions to the diagnosis of their daughter’s deafness:

*“It was hard at the beginning – something totally new. You don’t know what to do – it’s a new world. She was our first-born and the first grandchild on both sides, so everybody was sort of in a state of shock...It’s a totally new life...My wife had a guilt trip in the beginning. It was hard on her. She struggled to accept it. It took a couple of years for her to eventually accept that it wasn’t her fault, and so forth.”*

Ross *et al.* (2004: 161) state that one of the major concerns of hearing parents when a deaf child is born relates to how they will break the news to the child’s grandparents, and how it will affect their relationships. Meadow (in Ross *et al.*, 2004: 161) holds the view that extended family may react in two distinct ways: on the one hand grandparents may be grief-stricken and disappointed, especially if it is their first grandchild, in which case the parents’ feelings of guilt and despair are aggravated; on the other hand, grandparents may provide additional help and support for the parents. The shock, helplessness, and a feeling of deep disappointment at the shattering of their dreams of having a “perfect” child (especially since this was their first child, and first grandchild in the family), was devastating, especially in the case of Stefan’s wife, as it took years for her to come to terms with the fact that she was not to blame for having a deaf child. Her feelings of guilt would probably have affected her self-esteem, which according to Schirmer (2001: 149) and Vermeulen (1999: 61), is the main component of emotional well-being.

Indrani, mother of Indresan, recalled her feelings of shock, guilt, and depression upon discovering that her child was deaf:

*“When I first found out that he was deaf, I was very depressed. I took it very badly...I was shocked, realising that my child was deaf. I blamed myself...I blamed God – ‘Why are you punishing me’, ‘Why does it happen to me?’, ‘Why have you chosen me?’...I blamed myself, like what did I do wrong?’...I decided not to have any more children because I’m scared of this; maybe my second child might be born deaf or with some other complications... (Participant becomes emotional).*



Depression, which according to Vermeulen (1999: 188), is a sensation fuelled by anger and resentment is likely to have driven Indrani to blame herself and God for Indresan's deafness, as she might have been unable to deal with these feelings adequately. The fact that she became emotional while recalling her experiences many years later is an indication that she had not fully come to terms with the situation. As pointed out by Ross *et al.* (2004: 156), for many parents sorrow is something that is chronic, and they are in desperate need of professional assistance over time. Gascoigne (1995: 14) states that guilt is often followed by bitterness and resentment, and the inevitable "Why me" is not an indication that the parent wishes it on someone else. Instead, it is an angry response to the grief that the parent is going through.

Ross and Deverell (2004: 38) state that reactive depression is a normal grief reaction and response to a traumatic experience; moreover, parents of disabled children often feel guilty about the cause of the disability and spend much time agonising over their contribution to the child's condition. The trauma that Indrani experienced contributed to her decision not to have any more children for fear of giving birth to another child with a disability.

The quantitative data analysis (*c.f.* Graph 4.2.1.4) shows that 13% of respondents decided that they would not have any more children after the birth of their deaf children. It would seem that parenting a deaf child is a trying experience, fraught with many challenges, and that the difficulty of raising a deaf child could lead to some parents deciding against having more children.

Patricia, mother of fifteen year old Penny, recalled her experience on learning of her child's deafness:

*"We found out that she was deaf at the age of eight months, when she went to the clinic for her normal tests. I've got a son who was ten at the time. He took it worse – but not too badly, because my husband's twin brother was very ill at birth – so he was deaf and blind and he was in an institute so he is used to that sort of thing on that side of the family...but yes, it was upsetting."*

In addition to coming to grips with her own emotions on the diagnosis of Penny's deafness, Patricia was also concerned about her ten year old son's reaction to the news that his baby sister was deaf, even though he was accustomed to having a paternal uncle who was deaf and blind. It would seem that the birth of a deaf child has a major impact on the whole family. This observation is in keeping with the views of Ross *et al.* (2004: 155), Lederberg and Presbindoswki (in Spencer *et al.*, 2000: 73), Marschark (1997: 16) and Gascoigne (1995: 21) in that the entire family is affected by the birth of a deaf child. According to Atkins (in Ross *et al.*, 2004: 160) the complexity of siblings' interaction is best understood from a family system perspective as whatever happens to one of the siblings "reverberates throughout the family".

The differing psychological responses of the participants can also be attributed to the joint function of the characteristics of the person interacting with differing environmental contexts, as explained in Bronfenbrenner's (1998: 996; 1992: 190) ecological systems theory. Ross *et al.* (2004: 156) also subscribe to the view that various factors such as the personal characteristics of parents, the state of their marriage, their culture and socio-economic class, parents' relationship with members of the extended family, the emphasis they place on verbal communication, as well as the ordinal position of the deaf child in the family, influence parents' response to the birth of a child with a disability.

Some parents apparently experienced much stress related to delays in the medical diagnosis of their child's deafness. It would seem that parents' experiences in this regard depended on facilities available within the community. Some had to make repeated visits to medical practitioners for a battery of tests which was frustrating, time-consuming and costly. Ross *et al.* (2004: 156) state that parents' feelings of anxiety are intensified when they experience difficulties and delays in obtaining a definite diagnosis of deafness.

Frieda, mother of Fiona, recalled the frustration she experienced with the prolonged medical diagnosis of her daughter's deafness:

*“I took her back to the ENT (specialist) who had put in the grommet and I said to him, ‘There’s still no response from her.’ So then a friend of his...a speech therapist, did some tests... and he said that he couldn’t notice that there was anything wrong...and he said he would make an appointment with Phonak in Pretoria. It would take another six months...We did about eight tests and there was still no response, and then they actually said that they couldn’t find anything wrong...it works on your nerves...it was so stressful; and then we moved here (Durban) and we went for another test, and they referred us to Johannesburg; she (the audiologist) did another test exactly the same as with the Phonak...She referred us to...School for the Deaf. I had Fiona’s brain stem tests done in Pretoria – the cost...six years ago it was R443 per test.”*

The annoying and agonising delays in the diagnosis of Fiona’s deafness, coupled with having to travel from one province to another, as well as the financial burden incurred, contributed to her stress and frustration.

Similarly Hemma, mother of eight year old boy Harish, who was only diagnosed as deaf at age three, recalled the stress and frustration she experienced with regard to the delay in the confirmation of her suspicions by medical personnel:

*“When he was about two years or so, I took him to our local paediatrician and he did a routine check-up on him...and I did bring up my concerns...that he’s late with his speech. The doctor said that I should not worry ‘boys are generally late’...and I must give him some time...I mean a paediatrician is telling me not to worry, so who am I to question him? We even took him to an ENT (specialist) and everything seemed fine. We weren’t really checking, as well, whether he was deaf because obviously that thought never had come into my mind – I was just concerned about why he wasn’t speaking as he should have been at that time...but everybody tells you ‘boys are late’...so I accepted it”.*

Hemma obviously relied heavily on the professional opinion of the medical personnel she had consulted for clarification as to why her two year old first-born son was not speaking. However, she did not receive much help in this regard. Spencer *et al.* (2000: 139), in

reviewing the results of a national survey conducted with hearing parents of deaf children in USA, found that comments by parents revealed that one of the reasons for the delay in diagnosis stemmed from professionals' dismissal of parents' concerns based on the assumption that parents were just overly worried. Ross *et al.* (2004: 156) state that the period before diagnosis seems to be more difficult for parents to live through than the period after diagnosis, as the anxiety experienced often leads to self-doubt about their parenting skills. The long road to diagnosis was extremely frustrating and stressful for Hemma, but she continued in her efforts to find an answer to the question that was of great concern to her:

*"Then eventually I went to my local clinic, and I told them that I feel concerned as a mother that something is wrong, and I'm not really sure. So, I was sent to the speech and hearing therapist...I was then sent to the Phoenix Audiology Centre and tests were done there, but he did not respond to that. So we decided that the best thing was to do an ABR of the brain stem...and from that test the audiologist told us that he is deaf...I asked her 'Could I have a second opinion?'...So she suggested to me to see...The brain stem test that was done confirmed her initial diagnosis...It took me a long time to accept, and the next step was to get him to a school, and by that time he was already three years old. It was an extremely frustrating and stressful time..."*

Had Hemma's son's deafness been diagnosed earlier, intervention measures could have begun earlier, and this would probably have eased the burden of her not being able to communicate effectively with Harish for the first three years of his life. The importance of early diagnosis cannot be sufficiently stressed, as it can lead to early intervention measures to develop the child's communication skills (Young & Tattersall, 2007: 209; Meyer, 2000: 83; Marschark, 1997: 9).

Likewise, Indrani, mother of Indresan, whose birth was complicated through the lack of oxygen, recalled the long and traumatic road to diagnosis of his deafness:

*“At about three months, because of his ear being abnormal, we decided to take him for a hearing test. They did not pick up anything. They said, ‘Come back when he’s six months’. We took him then; again they still did not pick up anything. So, when he was two years we took him for another test. Then the audiologist picked up that he was deaf and needed to wear a hearing aid.”* (Participant becomes emotional.)

Indrani’s pain on eventually finding out that her only child was deaf was so intense that recalling the memories several years later rekindled the initial trauma she experienced at the time of diagnosis. According to Gascoigne (1995: 11), the fact that the child has been diagnosed as having a certain condition many years earlier does not mean that the emotions parents initially experienced fade away with time, and it does not take much for the emotional reaction to diagnosis to resurface months or even years later. As Luterman (1996: 48-49) states, “For anyone undergoing catastrophic change, it is the loss of the expected future that is grieved so deeply. The pain of that loss never goes away”.

Nico, father of Nadia, also went through a similar experience regarding the diagnosis of her deafness. It would seem that after the long road to diagnosis, learning that Nadia was deaf in both ears was a shattering experience, which was painful to recall:

*“When we discovered that she was sort of very withdrawn...we took her to the Military hospital and they referred us to the Red Cross hospital, and the doctors were just saying, ‘Well, she’s a bit young, this is normal’. So I took her back to the Military hospital to the audiologist and then she referred us to the medical ENT (specialist). So he tested Nadia and discovered that she is deaf in both ears...there was only about 40% of hearing. It was very bad for us. Nadia was two years old...”* (Participant shrugs, nearly became emotional, but put on a brave front.)

In all four of the above cases the parents Nico, Indrani, Hemma and Frieda had to deal not only with anxiety about their suspicions that something was wrong in terms of their children’s development, but also with professionals who delayed the diagnosis of deafness and who seemed detached from the parents’ concerns.

Brown *et al.* (2006: 209) state that the diagnosis of deafness itself raises major issues for the family. Not only do parents have to cope with a change of their expectations of the child and the future, as well as understanding the nature and implications of deafness, but they also have to “face the prospect of having to deal with a range of professionals who have knowledge, expertise and understanding, but who must remain detached from the emotional experiences of the parents”.

On the other hand, Riana, mother of Richard, had a slightly different experience when her son was diagnosed as deaf at 18 months of age. She recalled her experience as follows:

*“Well, I just have one child – it’s not so bad for me. The other people – it’s more difficult for them because they have hearing children also...and because I’m nursing, it was a little bit of a shock, but I had two children in the children’s ward, so it made it easier for me to see something was wrong with my child. So we took him to the doctor and did everything we could do. It was not so difficult for me because I could see something was wrong, but it is always a shock for everyone that something like this could really happen.”*

The reason that Riana was able to handle the diagnosis of her son’s deafness more easily was probably because of the context in which she found herself. Being a nurse and having easier access to medical personnel might have contributed to her being better prepared for the diagnosis.

From the foregoing it is clear that although most parents experience shock and anxiety upon the diagnosis of their children’s deafness, many parents reported different emotional responses and different experiences on the journey towards acceptance. According to Ross and Deverell (2004: 36), Crittenden *et al.* (in Schirmer, 2001: 27), Scheetz (2001: 60), Marschark (1997: 78), Krause (1993: 207), most parents, irrespective of their differing responses, are devastated at the birth of their deaf child, as their dream of the ‘perfect’ child is shattered. Many researchers concur that parents’ initial emotional response is usually one of shock, and this is often followed by grief, denial, guilt, blame, fear, depression, anger, frustration, and acceptance (Brown *et al.*, 2006: 208; Ross & Deverell,

2004: 36; Scheetz, 2001: 60; Schirmer, 2001: 27; Marschark, 1997: 78-79; Dysart, 1993: 31-33; Luterman, 1991: 146-147; Vernon & Andrews, 1990: 125-128).

The emotions experienced by many hearing parents of deaf children on learning the diagnosis of deafness can be compared to the theory of the stages of grieving, proposed by Kübler-Ross (in Ross *et al.*, 2004: 156). These stages of grieving include denial, isolation, anger, bargaining, depression and acceptance. The principle underlying the need to go through these stages is that those who are grieving will eventually accept their loss and stop grieving. However, Ross *et al.* (2004: 156) point out that the main criticism against this theory is that these emotions do not necessarily occur in the same sequence but rather in a cyclic manner and some people never reach the stage of acceptance as their sorrow is chronic. Moreover, people can re-visit emotional states that they had successfully managed to negotiate in the past (Ross & Deverell, 2004: 36; Gascoigne, 1995: 16).

In this study, it was evident that some parents re-visited their initial emotional response to the diagnosis of the child's deafness, but once they accepted it, they then embarked on the next leg of the journey, that is, dealing with communication problems and the journey towards learning sign language, as well as the language of 'normality', which is the focus of the next category.

- **Learning sign language and the language of 'normality'**

This category focusses on two related aspects, namely, the challenges associated with learning sign language as a means of communication, as well as using the language of "normality", that is, non-labelling language.

With regard to the **challenges associated with learning sign language** research reveals that 90% of deaf children have hearing parents, many who struggle to communicate effectively with them (Ross *et al.*, 2004: 155). According to Kotze and Folscher (in Levitz, 1991: 78), unless parents find a way of communicating effectively with their deaf child, the quality of their parenting is questionable, as a shortfall in this regard can adversely affect

the child's education. Ross *et al.* (2004: 155), Marschark and Spencer (2003: 69), Meadow-Orlans *et al.* (2003: 36), Schirmer (2001: 30), Scheetz (2001: 61) and Marschark (1997: 81) concur that effective communication is an essential ingredient for the deaf child's overall development and progress, family functioning, emotional stability, as well as for establishing stable relationships.

Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.8), 40% of the respondents indicated that communication with the deaf child was one of the challenges they faced as hearing parents of deaf children. A study conducted by Schlesinger and Meadow (in Ross *et al.*, 2004: 158), in which only 10% of the sample could sign, revealed that over half the parents indicated that a major frustration in child-rearing was the difficulty they experienced in communicating with the deaf child. Most of the parents who were interviewed emphasised the importance of sign language as a mode of communication, and displayed a positive attitude towards learning it which helped them to communicate more effectively with their deaf children.

The findings from the qualitative data are in keeping with the findings from the quantitative data analysis (*c.f.* Graph 4.2.1.17) which reveal that 66% of parents indicated that they communicated effectively with their deaf child through sign language. This, according to Marschark (in Meadow-Orlans *et al.*, 2003: 27) is in contrast to the situation that prevailed thirty years ago when over 90% of hearing parents communicated through speech alone with their deaf children. Meadow-Orlans *et al.* (2003: 36) report that, for deaf children's parents, the choice of communication approach was one of the most difficult decisions they had to make.

Devi, mother of Deshnie, shared her views about the importance of learning sign language to communicate with her deaf child:

*"The biggest challenge, I think, is communication, because it's (sign language) a whole other language and it's like you're learning Greek or Spanish or something...if she points to something and if she asks...and you don't know how to sign it to her, then she gets*



*frustrated. As a parent you get satisfaction by being able to answer her...They (teachers) used to allow us (mothers) to sit in class, so we picked up a lot of sign language, and then I was going for sign language classes at the KwaZulu-Natal Academy for the Deaf...we needed classes so that we could be more advanced. So that's how I learnt, and the family basically all had to learn from me."*

It is clear that Devi realised the importance of communicating effectively with her deaf daughter. She therefore tackled the challenge of learning sign language squarely by sacrificing the time to sit in the classroom while Deshnie was being taught through the same medium, in the hope that she herself would pick it up. In order to cope better she then took it upon herself to attend sign language classes and pass on the skill to the rest of her family, so that her daughter would have a greater access to family interaction.

Similarly, the importance of learning sign language to help parents understand deaf children better is clearly enunciated in the words of Constance, mother of Cebo. Prior to learning sign language, she found that communicating with him was stressful and frustrating:

*"Sometimes you can be cross and say, 'maybe this child doesn't listen'...but the problem is that he is bored because he can't hear what you're saying...I'm learning sign language in the class, and it's the easiest, because last time when I didn't know the language I said my child is boring and silly...he does not want to listen to me, he is stubborn. When I'm learning sign language, and he hears (understands) what I'm saying, it's then that my child is well...I experienced a terrible life...it was a very, very hard struggle to know him...I couldn't understand what he wanted...I couldn't understand what he was saying. All these years I was struggling...so now I'm learning sign language...So I can advise someone that if you have a deaf child, learn sign language so that it can be easy to communicate with your child because communication is a problem."*

Similar sentiments are expressed about the advantages of learning sign language by Grace, whose daughter Gillian was also initially very frustrated at the inability to communicate.

However, it was a struggle for Grace to learn sign language, an experience which resonates with the findings of Meadow-Orlans *et al.* (2003: 180) that many hearing parents of deaf children experienced difficulty finding suitable sign language classes, and becoming fluent signers. Grace also tells of her “battle” to learn sign language:

*“Before we had her at this school...we couldn’t cope with understanding her, and she used to get very frustrated. That used to be very hard on us – like you didn’t know what she wanted...But since she’s been at this school and we’ve been attending sign language classes, I can see she’s not that stressed out and frustrated any more...The only thing I find I’m battling with is learning sign language. Erm – I’ve got the basic sign language.”*

Hemma, mother of Harish, recalled her extreme frustration at not being able to communicate with him in the first three years of his life, and how learning sign language, when her son entered school, eased the frustration:

*“It was an extremely frustrating time at home because I didn’t know how to communicate with him and he didn’t know how to communicate with me...After the Easter holiday he started his first week here and...we had to start signing...and I took that on full force...lots of parents don’t know how to communicate with their kids...here at this school and having sign language as their primary source of communication, and lots of parents don’t have that. They either find an excuse, or whatever it is, and I mean, what could be more important than communicating with your child?”*

Ross *et al.* (2004: 155) state that many parents have difficulty in adjusting to their child’s deafness and in communicating effectively with their deaf children. Hemma was frustrated as she was not able to communicate with Harish during the formative years of his life.

Amy, mother of Andrew, tells of her initial embarrassment in public places with regard to using sign language to communicate, and her subsequent change of attitude over time:

*“And then we had to learn how to use sign language. It was still very much new. It wasn’t like it is today on T.V....it was very much something nobody knew anything about, and everybody would stare at you – and I was so embarrassed. Today I’m not embarrassed.”*

This change in attitude can be explained through Bronfenbrenner’s (1992: 201) ecological systems theory, which includes the chronosystem, which focusses particularly on developmental changes which are triggered in children by life experiences, and changes that occur over time. This model can also be applied to developmental changes that occur over time through life experiences of parents, because parenting is a process, and change in attitudes can occur through different types of parenting experiences. The general acceptance of sign language by the public in more recent years made it easier for Amy to adjust to the use of sign language with her deaf son without being ashamed any longer.

Amy further elaborated on the importance of accepting sign language as a means of communication in order to convey thoughts, feelings and values more effectively so as to include the child in family interactions, as well as prepare him/her to become a functioning member of society:

*“If you don’t accept the fact that your children function in a different language to you, how are you ever going to overcome any of the other obstacles that are in their way? And there are huge obstacles...interpreting something on TV for your child...something which you have to do...it’s a pain, it’s annoying...You can’t exclude your child from stuff all the time...If you don’t learn sign language how are you going to tell your child you love him, or you are proud of him? How do you tell your child you are angry with him because...Your child is already isolated from the community; how can you isolate your child from your own family, and then not expect the child to feel anger or rejection? You now have to produce a person...capable of being a functional part of society...You instil values in them...if you can’t communicate these things it’s not up to the school to do it.”*

It is clear that Amy prioritised Andrew’s need to be included in the family and in society, and in order to minimise the possibility of her son being isolated at home and in society she

emphasised the importance of parents learning sign language to communicate effectively with the deaf child, and putting the child before self. Meadow-Orlans *et al.* (2003: 183) report that the most important advice that hearing parents of deaf children offered was to “treat the child as a child first” and the most important thing for parents is “to know what is in the best interest for the child, not for themselves”.

Frieda, whose daughter Fiona attends a school for the Deaf situated 22 kilometres away from home, shared her experiences associated with learning sign language, without the support of her husband:

*“I hated to come for sign language classes, which was very difficult at the beginning. You don’t have a choice. You’ve got to...I mean it’s like any other language...Sign language was the best way...and because we needed her to communicate – she was already two years old – that was the most important thing. Once we started to communicate she was a different child – she wasn’t so dependent on me...like she was before that. My husband’s working shifts...there’s no way for him to come to signing classes, so most of the time I’m working alone...Ja, it was never...it wasn’t easy you know...it was stressful... (Frieda becomes emotional, apologises and continues) – But I think if you don’t accept it, and if you don’t try to cope with it you would never do it. If you blame everybody else you would never get anywhere. Ja...I think once you’re over that...life is easier...of course my life would have been easier if she were a hearing child. ...If only I knew more about the cochlear implant then, than I know now, maybe I would have gone the cochlear way.”*

Frieda obviously realised the pivotal role of effective communication in their lives, and in spite of the difficulties associated with travelling a distance to learn sign language, she was prepared to make the sacrifice for the sake of her deaf child. Her resilience in the face of difficulty is probably what helped her to cope with the responsibility of raising a deaf child.

Frieda became emotional several times during the course of the interview, an indication of the chronic grief she experiences, raising Fiona almost single-handedly. Nonetheless she chose to continue to share her experiences, possibly because she needed to give vent to her

feelings and speak to someone who was prepared to listen impartially. Ross *et al.* (2004: 160) state that as a result of the deaf child being more dependent on the mother, her activities can be gradually restricted, and this can have an adverse effect on the development of healthy relationships in the family. Frieda's life could possibly have been less stressful had she received more support from her husband in rearing their deaf child and their two other hearing children. Bronfenbrenner (1998: 1015) points out that the sustaining of complex interaction and emotional attachment between caregiver and child depends largely on the active involvement and availability of another adult. Such a person would be able to encourage, help, give recognition to, as well as show admiration and affection for the caregiver.

Meadow-Orlans *et al.* (2003: 36) report that hearing parents of deaf children found the choice of communication approach to be one of the most stressful decisions they had to make. The fact that Frieda did not know enough about the cochlear implant at the time of making a crucial decision regarding which mode of communication to adopt for her deaf child, implies that she did not receive sufficient information on all the possible communication options available from the professionals she was dealing with. Young (2002: 3-4) agrees that the vast majority of parents with no previous knowledge of deafness, are required to make very difficult decisions, including communication choices. Therefore, information is regarded as a vital support mechanism in the major decisions they have to make, and research shows that parents sometimes receive partial or biased information from professionals, particularly with regard to communication choices.

With regard to the **language of “normality”**, not all hearing parents who were interviewed considered the use of sign language to be the best way to communicate with their deaf children. Some parents deliberately chose to send their children to a school where only the oral communication mode is used, and where sign language is prohibited. The sentiments expressed by these parents focussed on equipping their deaf children with ‘normal’ language that would facilitate their adjustment in a hearing world. Some of the participants shared their experiences and different views regarding communication with their deaf children as follows:

Kate, mother of Kevin, recalled her experiences:

*“We had to go to the...Day-care Centre, to learn how to cope with deaf children. They taught us sign language there, and we never wanted to learn – we never wanted to take notice of this sign language; and so they gave Kevin hearing aids and they taught me how to just pressure him to say the word not once but maybe a thousand times over. For that one word...and the day he said ‘mummy’ – you know, I jumped!...but he can talk now. I don’t have to learn sign language any more.”*

It is clear that from the outset Kate was averse to the use of sign language with her deaf son, perhaps because she felt that he might be marginalised in a world where speech is the normal mode of communication, or possibly because she was embarrassed to communicate manually. She was prepared to endure the long drawn out struggle to teach him how to speak, hence her overwhelming joy when he eventually uttered his first word.

Lydia, mother of Liesel, wanted her deaf daughter initially to learn to communicate orally, and later through sign language as well. She obviously saw a need for Liesel to be bilingual so that she would be able to interact with hearing and deaf people. Lydia shared her stressful experiences of the journey over five years of perseverance to try to get Liesel to speak:

*“It was very difficult, because we had to come to parent-guidance, and they teach you how to work with your child. It was very new for me. At home...we do the sounds;...we just threw our hands up and sat back... because there was no progress at that stage...we had to raise money for a cochlear implant because the hearing aids weren’t good enough for Liesel;...but the words didn’t come out...it was very hard – it was very stressful... and now, the words are coming, and all the work we put in there in the beginning is starting to come up now. I look at her and I want to cry (participant becomes emotional) because there was a lot of hard work – it took a long time. At five years the first word came out. Ja. Then I said ‘she would turn six, so we must slowly teach her sign language’. So we sent her to Worcester... It was a better school for her; now I’m very pleased with her – because she*

*learns how to communicate with other people, and she can learn how to sign, whether she talks or not. The words are now under about 400. So, ja!’*

Lydia obviously did what she thought was in the best interest of her deaf child, even though it entailed having to send Liesel for an expensive cochlear implant to help her to communicate verbally. She made the decision to switch to sign language to afford her child the opportunity to communicate with deaf and hearing people. Young (2002: 3) holds the view that making a choice “is not a one-off event but a process”, so, if we are to gain a better understanding of factors affecting communication choice, we should also consider the factors affecting “re-choice, and revision of choice”.

Meadow-Orlans *et al.* (2003: 29) found that parents who used both speech and sign language with their deaf children felt that the use of speech would give the child greater exposure to English. According to Meadow-Orlans *et al.* (2003: 26), it would seem that effective communication between the parent and child has a greater impact on the overall development of the child than does the use of a particular mode of communication. Many researchers agree that there is a positive link between effective parent-child communication and the child’s progress at home, in school, and in the community.

Barbara, whose son Ben started a successful computer business after he completed school, attests to the importance of optimally developing communication skills of deaf children, not only sign language, but also signed English, to help them to more effectively develop literacy skills, and enable them to interact with hearing people. She shared her experiences as follows:

*“Deafness is not just an inability to hear. All the input a child receives from the time he is born, a deaf child does not just pick up; so you must talk; communicate! Teach him how to interpret sounds! Talk times factor ‘n’.”*

A survey conducted by Meadow-Orlans *et al.* (2003: 29) showed that parents’ rationale for “total communication” was based on their belief that it is important to give the deaf child

access to communication with everyone. It would seem that effective communication between the parent and child has a greater impact on the overall development of the child than does the use of a particular mode of communication, and many researchers agree that there is a positive link between effective parent-child communication and the child's progress at home, in school, and in the community (Meadow-Orlans *et al.*, 2003: 26). According to Young (2002: 3) several factors affect the choice of communication mode parents make for their deaf children, which include the information that parents have regarding the range of communication options, their expectations of themselves and their deaf children, pre-existing family characteristics, and preferences for what seems appropriate for the family in terms of their value systems.

With regard to the use of **non-labelling terms** to refer to deaf people, several participants expressed the view that in referring to the deaf, people should use non-labelling language, because although they are deaf, they are “normal”. Some expressed strong sentiments in this regard:

Devi, mother of Deshnie, expressed her annoyance at the way people in the community refer to deaf children as “dumb”:

*“Don’t refer to them as dumb...You can say mute, but not dumb. That’s the only thing that annoys me as a parent of a deaf child; it’s the way other people respond.”*

In a similar vein, Hemma, mother of eight year old Harish, shared her sentiments about treating deaf children normally, and expressed her resentment at people referring to her son as “deaf and dumb”:

*“Deafness is not a disability as such – your child is absolutely normal...There is absolutely nothing wrong with a deaf child – it’s just that they can’t hear...they are deaf and not dumb; and I find that a big issue...especially amongst the Indian community where I live...where they refer to Harish as ‘deaf and dumb’ – and that totally annoys me – and*



*especially amongst the older generation. I've tried to educate them as far as that is concerned but obviously the older generation will stick to their guns."*

The sentiments expressed by both Devi and Hemma are understandable in the context of the general attitude of society towards deaf people. Ross *et al.* (2004: 150) state that societal attitudes, beliefs and values have a profound influence on the quality of life of deaf people who, over the years were negatively stereotyped and discriminated against, and made to feel inferior and inadequate. The negative stereotyping of deaf people stems from a deficit model of deafness. Rosen (in Ross *et al.*, 2004: 150) states that for many years the study of people with disabilities was based on the medical pathological model which focussed on their "physical malfunctioning and compensating for it".

Amy, who is employed at the school where her son Andrew had attended, expressed empathy and understanding, based on her own experience, for those mothers who cry when their deaf children are admitted to a special school for the deaf:

*"I actually do know why you are crying. It's the final step in acceptance of the fact that your child has come to register for a special education programme, and 'normal' education has actually been shattered."*

Amy made a strong case for hearing parents of deaf children to develop a positive mindset about their deaf children, and to remove any barrier that stands in the way of regarding them as 'normal':

*"The one thing we've tried to ban all parents from saying is that their child is not 'normal'...Your child may be deaf, but he is normal...We are a normal school. We have normal periods, we teach normal subjects, and we have normal exams. The only difference is that we teach in two languages. That's normal for us. If we can get the parents to see that their children are 'normal', but different, we can break a huge barrier."*

It is interesting to note the remarkable change in Amy's attitude as she, on first discovering that her son was deaf, said that if she could, she would have "*given him back*", that she "*did not like this child for a very, very long time*". After many years she has a different attitude, evidence of which can be seen in the following remark: "*I like him now, as well as love him.*"

The change in attitude experienced by the participant is understandable in the light of Bronfenbrenner's bioecological model, in which *time* is "a defining property" (Bronfenbrenner, 2002: 130; Bronfenbrenner & Morris, 1998: 1018). Ross *et al.* (2004: 155) agree that families of deaf children can also be analysed in terms of the ecological systems theory, since human development is concerned with the "goodness of fit" between people and their environments. Hodapp and Ly (2005: 177) state that in order to understand the parenting of children with disabilities from Bronfenbrenner's ecological perspective, it needs to be appreciated that various changes have taken place in Western society since the 1970's with regard to the way disabilities are conceptualised, the type of services offered to children with disabilities as well as their families, the roles played by adults with disabilities in society, and the increased knowledge available as a result of advances in various sciences related to disabilities.

Moreover, the properties of the bioecological model, namely, process, person, context and time, contribute to the process of development. Throughout the life course human development takes place through progressively more complex interaction between the active, evolving human being and other persons, objects, and symbols in the immediate external environment. The enduring forms of interaction, also known as proximal processes which are reciprocal, must occur on a fairly regular basis over time. Although Bronfenbrenner's model refers mainly to the development of children, it can also be applied to adults, and in the case of this study, to hearing parents raising deaf children, as their parental role evolves over time.

- **Endurance, sacrifice and ‘celebration’**

For many participants, the experience of parenting deaf children involved endurance, sacrifice, and celebration. Much of the frustration experienced by hearing parents and their deaf children related to the breakdown in parent-child communication. In recalling their early experiences many participants emphasised the importance of perseverance in spite of difficulties, especially with regard to developing effective communication skills. From the quotations that follow it is evident that these sub-categories sometimes overlap.

With regard to **endurance** participants shared the following sentiments:

Edna, mother of Emily, shared her experience of the extra effort and time involved in trying to establish communication skills with her deaf child:

*“The communication is so much more difficult that you need to spend so much more time and put in a lot more effort; and very often there is ambiguity in what you are saying, simply because the child may not get the correct message, or you may not be explaining it in the way that the child should be perceiving it.”*

Edna clearly saw the urgent need to establish effective communication skills with her deaf child in order to avoid ambiguity and to get the message across correctly. Meadow-Orlans *et al.* (2003: 12) emphasise the importance of the deaf child acquiring language early, irrespective of the mode of communication, for effective functioning of the child within the family as this is crucial to the child’s overall development.

Amy, mother of Andrew, expressed strong sentiments about the long and difficult journey of endurance in raising her deaf son:

*“We have come a very, very long road, which has been very difficult; and when I sat down and realised how much we’ve been through – how hard the road was, I don’t want to do it ever again, ever again, because it was hard!”*

Amy endured a very trying time when her son was younger, to the extent that she and her husband decided not to have any more children, even though they had only one child. She shared further experiences of endurance in the process of raising Andrew, whose behaviour and health were very difficult to manage:

*“He threw tantrums anywhere, everywhere, and for everything;...How people did not report me to the police is beyond me! Andrew threw tantrums once in Checkers – where he hit me – and we hit each other; and the only reason I won was because I was bigger...I don’t ever want to live through that again;...honestly, jokes aside, it’s a nightmare! He was really very difficult, so we actually decided that we wouldn’t have any more children. Andrew had fever. It was pretty terrible because they had to hold him down and take blood out of his jugular vein...Again he landed up in hospital with convulsions, and he was really ill...So Andrew did everything he could to put me off children, not only being deaf.”*

According to Marschark (in Spencer *et al.*, 2000: 134), hearing parents often describe their young deaf children as “aggressive, disobedient and easily frustrated”. Calderon and Greenberg (in Spencer *et al.*, 2000: 134) state that over the past few years research has revealed that the cause of inappropriate behaviour is not the deafness *per se*, but rather the complexity of variables and interactions pertaining to the child as well as family and environment. Further, a deaf child born in a hearing family temporarily causes disruptions to the parent-child relationship, family functioning, and expectations of parents in some families.

Kate, mother of Kevin, also spoke of her journey of endurance as she struggled to cope with her deaf son’s aggressiveness:

*“Kevin will almost punch you if he can’t get something right; he fights with you – the two of us are always fighting. I don’t know what to do! I can’t hit him back because I know that he can’t hear me right; he can’t tell me what he wants, so now he’s hitting me...One time, he hit me and gave me a blue eye...but that was nothing for me because I know how he must feel...he still has that – aggressive thing – if he wants something he must fight.”*

It is obvious that Kate shouldered the responsibility of parenting without much help from her husband. In spite of her husband's lack of support in this process, she showed her determination to face the challenge and strive for the best for her son:

*"His father, only now, this is the first year his father ever took interest in him because he's talking a lot. He never knew how to talk to...him, because I was the only one, from the morning 'til night, 24 hours. It's a challenge you know; it's really a challenge, but I'm going right to the top with my boy. I'll cope."*

Bronfenbrenner's bioecological model of human development endorses the importance of a supportive and encouraging person (Bronfenbrenner & Morris, 1998: 1015). If the father had been more supportive of Kate in the upbringing of their son, it could have enhanced Kevin's development, and eased the pressure on Kate who, for eight years, endured the struggle of raising their deaf child all alone.

With regard to **sacrifice**, Lydia, mother of eight year old Liesel, recalled the financial sacrifice that she and her husband made when it came to fitting her hearing aids, and subsequently to raise funds to pay for the cochlear implant. As there was no help forthcoming from the extended family, Lydia felt isolated and upset.

*"Each one would say... (Participant shakes her head sadly) and we were all alone and nobody wanted to help us, and you just want to cry about it."*

The isolation from the extended family that this participant experienced at a time when their appeal for financial assistance was turned down must have been a blow to her and her husband, as they had to carry the financial burden of raising their deaf child on their own.

Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.25), the findings indicate that 48% of the participants required financial assistance for raising their deaf children. Several participants who were interviewed indicated that they endured financial sacrifices to cater for the educational and other needs of their deaf children. The quantitative data (*c.f.* Graph

4.2.1.10) also indicates that 13% of parents (mostly mothers) had to leave work in order to take care of their deaf children, while 55% (*c.f.* Graph 4.2.1.8) indicated that one of the challenges they faced as hearing parents of deaf children was the financial burden they had to bear.

Nico, father of Nadia, recalled the financial sacrifice the family experienced as a result of having a deaf child. They lived 30 kilometres away from the school and incurred additional expenses through having to transport their daughter to and from school, morning and afternoon, *i.e.* 120 kilometres per day for four years. In addition they had to attend parent-guidance classes to teach their daughter how to communicate verbally:

*“In my wife’s case she had to give up her job, sort of, and go on half-days, which was the sacrifice she had to pay due to loss of certain earnings and broken service. If you think of the pension she had to lose out after eighteen years of service! She’s got broken service which was a great loss!...but I think we can just be grateful that the effort and sacrifice that we put in all through the years will benefit her today, because my daughter is fully bilingual.”*

It is clear that this participant has no regrets about the sacrifice they had to make for the sake of their deaf child, as it was beneficial in the long run. It also shows that they placed great emphasis on doing what they thought was in the best interest of their deaf child. Meadow-Orlans *et al.* (2003: 157) state that with regard to advising other hearing parents who are raising deaf children, the general sentiment expressed is that parents should do what is best for their child.

Patricia, mother of Penny, shared her experiences of the financial sacrifice she made for the sake of her deaf daughter. She had to leave work to care for Penny, and the resultant shortfall in their income eventually led to the loss of their house. It must have been a stressful time in their lives:

*“It is very difficult! It is very challenging! I couldn’t get employment because no crèche would accept her at such a young age because of her impairment...It was a big sacrifice...financially it took a very big strain on us because we didn’t have my salary. So, of course that was also a lot of pressure with trying to cope with Penny, and at the same time worrying about the rent being paid about the phone bill being paid. So it was quite stressful...and in the end we lost the house...It’s got a lot to do with money; especially if you were all right to start off with, and you’ve got to give it all up!...So it was not very easy.”*

Patricia prioritised the need to stay at home with her young deaf child over remaining in full-time employment, especially since she could not find crèche facilities that could cater for deaf children. Her commitment to doing what she thought was best for Penny and putting her deaf child before self is clear, considering that she was prepared to “give it all up” for the sake of her child.

Some participants made major sacrifices in that they had to relocate from one province to another or one town to another for the sake of their deaf children’s education. Of the 20 parents who were interviewed, 10 relocated for the sake of their deaf children’s education. The quantitative data analysis (c.f. Graph 4.2.1.11) indicates that 28% of parents relocated for this purpose.

Constance, mother of Cebo, spoke of the sacrifice of parting from her family and hometown in the Eastern Cape to relocate to Gauteng so that her deaf son could get access to better education:

*“...I was doing it for the sake of my child. I don’t like Johannesburg, but because my child is here, we are here so that I can help him...My family – my mother, father and also my sisters are in the Eastern Cape still.”*

Devi, mother of Deshnie, explained that she and her husband decided to make the sacrifice to relocate from KwaZulu-Natal (KZN) to Gauteng for the sake of their deaf child because

of better facilities and the chance of a better education at a school for deaf children in Gauteng:

*“It’s now two and a half years...Here, they’re a little bit more...let’s say ‘developed’. Here she has computer literacy...Well, at...School (in KZN) they did the best they could with the facilities they had...; well here, they have extra facilities. So, Deshnie’s got more things going for her here, as such!”*

Queenie, mother of twin boys Quinten and Quintus spoke of the sacrifices of relocating from Pretoria to Western Cape, for the sake of her sons:

*“I found out they were deaf when they were three and a half years old ...We decided on this school (Western Cape)...We had to give up everything in Gauteng – our business... our house – we had our own house. We were, I think well-off, but for my twins, for my kids, I would do anything because they are my life.” ...We gave up everything. We came here; we had to live in a caravan park. We had no money. Luckily we had the caravan. When they were four and a half years old I got divorced because my husband was seeing someone else, and since then it was all on me. I had to look at everything and feed them, and it was such a challenge!”*

Riana, mother of Richard spoke of the sacrifices she had to make for the sake of her deaf son. The family had to relocate from the Free State to the Western Cape, as there were no facilities for deaf children where she lived with her family. She and her husband got a transfer to the Western Cape, but she could not take up her employment since she had to transport her son to and from school daily, driving for 5 hours in heavy traffic. Moreover, she had to learn how to communicate with him through sign language, as well as manage his hyperactivity, which gave her very little time to rest. In spite of her difficulties she coped, probably because of her positive attitude:

*“To move away from your family is very hard – my whole life was there in the Free State. I grew up there – for 42 years near my family – but we did it for our child. That’s the most*



*important thing, and I'm glad we did it...I had to learn sign language...When you come from places like Free State, you don't know about deafness and those kinds of things; you don't know about sign language. What's difficult is that if you don't know sign language, you don't know how to cope, what to do...you can't understand your child. Your child can't speak, or understand what you want to say to him...He was hyperactive – I had to run after him all the time. He was a very busy body...I would sleep 1½ hours out of 24 hours. I think I've been mentally prepared. I've been coping through it..."*

Grace, mother of Gillian, spoke of the sacrifices associated with caring for a deaf child who has an additional complication of lack of balance. It was a very demanding task which resulted in the curtailment of the family's social life:

*"Gillian's not just deaf – she's not supposed to have any balancing because she hasn't got the inner ear at all. They said she would never sit, never walk, and never hold her own bottle or anything like that...we don't go out, you know – if it's once a month it's a lot, honestly. In the beginning we had to get a 2x2 meter playpen; we just put Gillian in the house and keep her there, because she used to cry, and stand up, and fall over, and bump her head...You can't just leave her alone...you've got to run around and be after her all the time. You can't just leave her unattended. That's very demanding, but I cope with it very well."*

Meadow-Orlans, Smith-Gray and Dyssegaard (in Meadow-Orlans *et al.*, 2003: 58) report that mothers with deaf children who have other complications, experience different patterns of stress compared to mothers whose children are only deaf; therefore their ability to cope as well as their need for support differs from other families. Hintermair (in Meadow-Orlans *et al.*, 2003: 58) found that parents whose deaf children have an additional condition experienced increased levels of stress as a result of having to deal with a more complex situation.

The journey also includes celebratory experiences. With regard to **celebration**, Lydia recalled her joy when Liesel uttered her first word at the age of five years. This was a great

accomplishment for both of them after a prolonged period of perseverance and hard work. The following excerpt is also an indication of Lydia's determination and years of patience in her efforts to get her deaf daughter to speak:

*"For six months there was nothing. Then for a year we put everything in it. Every time we'd talk, and we'd listen to music and we'd listen to the sounds and everything – and then the words were coming out. Huh! At five years the first word came out!"*

Kate, mother of Kevin, recalled her experience of celebration and excitement after a long struggle to try to get him to speak:

*"They gave Kevin hearing aids, and they taught me how to just pressure him... 'Say the word not once, but maybe a thousand times over, for that one word, so that he can hear that one word' ...and the day he said 'Mommy', you know I jumped. I was jumping up and down on the bed, and he was seeing that I was getting excited...but, it took him nearly – Kevin was in the second year – for the words to come out, two, three in a sentence. I was so excited."*

Amy, mother of Andrew, also recalled her experience of celebration after the difficult times she endured while trying to find alternate education in a mainstream school for him for grade seven. They were refused admission and eventually he was accepted at a school which at that time still offered remedial education. Andrew was the first deaf learner there, a challenge he met squarely as Amy recalled:

*"At the end of the year Andrew was their top grade seven pupil. He got a merit award for being academically first. He got a merit award for what he had achieved as a deaf child. We're going to have to find a high school for him. Where do we go to from here? We're going to have to redo the whole thing when he's finished grade 12. Because there's so little open or available to the deaf, and because they can cope in so few environments, our options become limited."*

Queenie, mother of the twin boys, shared her experience of celebration despite the major challenges that she was confronted with, including a divorce when her sons were four and a half years old. Although the trauma of Queenie's experiences at that time was intense, her resilience and positive outlook probably helped her cope with the situation and emerge triumphant in the end:

*They are stunning boys, they're so clever. They are deaf, they are very clever. There's nothing else wrong with them! They are using voice. They can communicate with you; they have no problem...They can lip read, use sign language and use their voices. They've got a sense of humour. They're really very, very special and their father doesn't know what he's missing! I live in a flat here. I work in the kitchen. I'm very happy with everything! I feel very rich!"*

Devi, mother of Deshnie, shared her excitement and feeling of accomplishment as she spoke of the celebration every time her deaf daughter uttered a 'word'. Her positive attitude contributed to her own self-esteem and that of her deaf daughter:

*"Your sense of hearing becomes heightened when you have a deaf child. Every new sound Deshnie makes, or word, okay I know it's not a 'word', but it's so much more exciting. If she has to say something it's like a celebration! It's such a big accomplishment! It's very, very rewarding...Just go for it. For parents who have deaf children, just think positive; it's amazing...be positive and you can be a better parent."*

This category gave insight into the journey of endurance, sacrifice and celebration experienced in different ways by hearing parents raising deaf children. Meadow-Orlans *et al.* (2003: 117) found that many parents of deaf children described their children in positive terms, such as being smart, or being good in mathematics or art, or skilled in sports, while others balanced the positive descriptions with negative child personality characteristics such as being stubborn.

Ross *et al.* (2004: 155) state that families with deaf children could be understood in terms of the ecological systems theory and the way they achieve an adaptive balance in their environments. The complex interactions between people and their environments are often fraught with imbalances resulting from discrepancies between problems and the ability to cope on the one hand, and factors in the environment on the other hand. Germain and Glitterman (in Ross *et al.*, 2004: 155) hold the view that stress in families is likely to arise from needs and problems associated with tasks linked to life transitions, tasks relating to the use and influence of environmental elements, as well as problems associated with interpersonal hindrances such as communication and obstacles to family interrelationships. This brings us to the final category of the first theme, that of parents trusting their own “inner voice” and finding meaning in having a deaf child.

- **Trusting your own parental ‘inner voice’ and making meaning**

Most participants found meaning in having a deaf child by drawing strength from transcendental support. The following excerpts from the transcripts attest to these participants’ faith in their God, which they say made them perceive their role as parents of deaf children in a very special way.

Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.7), 62% of respondents indicated that the birth of their deaf children drew them closer to God, while 57% indicated that God had made them better people.

Amy, mother of Andrew, who revealed that initially she did not like her deaf son for a very long time, spoke of how she made meaning from having a deaf child, and the positive impact this had on her life:

*“God’s given me Andrew to teach me compassion...to take stuff and deal with it...to accept the fact that you can’t change Andrew...you have to go with the flow, so as bad as things were, I still had to be thankful for my mercies...I still have some kind of access to resources and my son is really bright.”*

Similarly Constance, mother of Cebo, shared her way of making meaning from the situation by regarding her deaf child as a gift from God to whom she is very thankful:

*“Because I love Cebo I was very willing to accept it (his deafness). I call it a gift because...I planned him. So for the gift that’s given I thank God very much...I’m a better person.”*

Likewise, Devi mother of Deshnie, spoke of how she felt closer to God, and how having a deaf child has made her become a better person, having more respect for parents of children with disabilities. She was thankful that her daughter was deaf and not blind, as she perceived blindness to be a worse fate than deafness. Her positive attitude probably contributed to her ability to manage raising her deaf child successfully, as well as take control of her own emotional wellness and that of her deaf daughter.

*“I’ve always been close to God, but I think it’s safe to say that I’ve become even closer... You just take it in your stride...don’t look at it as a setback. Just look at it as a challenge ...and every challenge you cross, it’s like a win. I’m perfectly happy with Deshnie, and there’s not a time when I wished she were hearing...Having a deaf child has made me a better person in many ways, maybe in every way. You suddenly have so much respect for the parents of children that have disabilities. I have tremendous respect for parents of children with severe disabilities, ’cause Deshnie can see. I don’t know how a mother of a blind child can cope! So ja, it’s definitely made me a better person – definitely, definitely.”*

Indrani, mother of Indresan, initially thought that God was punishing her by giving her a deaf son (her only child), but also blamed herself for having a deaf child. However, she viewed the situation very differently once she accepted his deafness, and found meaning in having a deaf son. She felt that she was especially chosen by God to care for a deaf child:

*“I was shocked, realising that my child was deaf...I blamed myself. ‘What did I do wrong?’ I blamed God. ‘Why are you punishing me? I started realising I have to be there for my child and communicate, and I have to accept it because I have to live with it for the rest of*

*my life...that couldn't change...Then I realised that I was accepting it...my child being deaf. God thought I was a special person and he gave me this child. He knew I could take care of him; and that's how I feel now – I feel special; but it's still very difficult."*

Kevin's mother Kate, shared her experience of making meaning of what initially was a situation of despair. The helplessness she felt at the beginning changed to a feeling of being "the chosen one", especially selected by God to care for a deaf child. Having a deaf child also helped her to see another positive spin off in that it expanded her social network as she made friends with other parents of deaf children:

*"The first time when I heard he was deaf, I thought; 'God! What do I do now? How must I cope with him?' But after it just sank in – 'I've got a deaf child'. I thought maybe that's what God wants. Maybe there wasn't a right...somebody else to have that child...and I always tell my friends, 'God gave this child to me because I would look after this child; it's a challenge for me...He gave Kevin to me for a special reason: to look after this child. Yes! I'm the chosen one'. Maybe that's God's will for all these children to be like this, for people to come together, meet each other, talk with each other...I've got friends here, and their children are also deaf."*

Liesel's mother Lydia related a similar type of experience in coming to terms with having a deaf child and making meaning of it. After initially blaming God, her relationship with God was strengthened as a result of a change of mindset upon talking to a priest:

*"Ja, there was a time when I blamed God, but then this priest came and told me: 'God gave you that child because it is a special child, and not everybody can have a deaf child or disabled child; because other parents are not going to look after the child the way you do.' Ja, I've got a special child in my life...My relationship with God has been strengthened very much."*

In keeping with Bronfenbrenner's bioecological model, it would seem that the intervention and encouragement of an influential person made a difference to Lydia's attitude and

helped her to find meaning in having a deaf child. This change of mindset probably had a positive impact on her emotional well-being (Bronfenbrenner & Morris, 1998: 1015).

Queenie, mother of twin boys shared her experience of making meaning of her situation:

*“They’re really very, very special...Jesus planned everything for us. That’s what I believe, because if I look back, everything so far was meant to be...They haven’t got another illness or sickness or brain damage or something. They are just deaf. They can see. Everything else is normal; I’m grateful for that...and I say, “Thank you very much Jesus that they’re both deaf” because what would I have done if the one could hear and the other one’s deaf? That would’ve been very difficult. I don’t think I would’ve or could’ve handled that...He (God) knows what He’s doing”*

Nico, father of Nadia, also gives credit to God for what he and his wife achieved with their deaf daughter, whom he says is coping very well at school and with life in general:

*“We put everything into it...You have to speak all the time. You have to discipline that child exactly as you would a hearing child. As a Christian, I think it was a sort of gift that we, as parents, are able to communicate and sort out the problem and not get emotional...and it if wasn’t for God, first of all, we never would have achieved what we’ve achieved today!”*

Odette’s mother Olivia shared her experience of making meaning of her situation by seeing it as her way to grow, taking it as a challenge, adopting a positive outlook and not thinking of it as something negative:

*“Our first experience was shock, disbelief, and guilt. You feel guilty because you think, ‘What did I do wrong during my pregnancy to cause the deafness?’ Being an educator myself, and a Christian, I came to the belief that this is now my way to grow, and I must make the best of it, so I actually see it as a challenge in the end...You’ve got to see it as a challenge, not as something negative”.*

Olivia admits that having a deaf child is stressful but with the help of a supportive husband, and faith in God, they were able to face the challenge and look at the positive aspects for the deaf child:

*“It was very difficult for us at first and it caused stress, but we both (she and her husband) believe that God places things along your way, and you must make the best of your challenge. So we took it one day at a time and we worked through it...Where God takes away some of their hearing, I think, He gives them more guts (laughs); and they are go-getters.”*

On the contrary, Marie, mother of Melanie, made meaning of having a deaf daughter in a different way, although she too was drawn closer to God. She felt that having a deaf child is not something God chooses for a person, but sustained prayer and faith in God helped her cope with the situation. Marie did not think that she could fully accept having a deaf child, but she eventually got used to working out ways of coping, such as taking it “year for year” and “day by day”:

*“It made me nearer to God...In Afrikaans they say; ‘God kies die ouers van ’n gestremde kind’...I think that it isn’t the right thing to say, because I don’t think God chooses you for that child; it happens to you! In our family it makes you pray for that child your whole life and you don’t stop at all...Ja, when you first learn that your child is deaf, it’s a shock. You immediately think about school...and if it’s possible for her to have work one day... but I think you mustn’t think like five or ten years ahead. You must take it year for year, and we do that, and it works fine...I think that you must take it day by day. I don’t think you can fully accept it. Ja, you accept it, but it will always be a problem how to handle it, and how she will cope...but you get used to how to work it out in the end.”*

It is clear that, linked to making meaning, there is the issue of the deaf child’s future. Marie made a point that thinking too far ahead into the future was not helpful, and that taking it a year at a time worked well for them. While some participants expressed concern about the future of their deaf children, others, like Marie, felt that it did not help to worry too much



about the future. Instead, taking one day at a time could help parents cope with raising their deaf children. The analysis of the quantitative data (c.f. Graph 4.2.1.13) corroborates this finding. While 44% of participants agreed that the future of their deaf children was a particular problem to them, 43% disagreed and 14% were uncertain in this regard.

Andrew's mother Amy related her experience of trusting her own inner voice, by being assertive, knowledgeable and questioning authority. This is how she made meaning of having a deaf child:

*"You have to be proactive in whatever you do in life...When you're given a deaf child you don't know anything...One needs to find out stuff...Don't sit back, and accept what people tell you in terms of, 'Oh don't worry, there's nothing wrong with your child'. If your child does not respond...and if you think there's a problem, pursue it...because you can't make up for the first three years of a child's life."*

Amy emphasised the importance of parents trusting their own inner voice and standing up for their rights as well as the rights of their deaf children:

*"If you feel in your heart there's something wrong, go and see another person. I learnt to question things that people told me. Don't jeopardise your child's future by accepting it if you really, really believe that something is wrong. Andrew has taught me to question authority...to stand up for my rights...actually more his rights than my rights."*

However, it took a long time before Amy could develop this attitude since she is the same mother who said that for a long time she did not like her son very much, and that if she could have, she "would have given him back". *"It took a long time and a lot of soul-searching and what-have-you, to come to terms with the fact that it's okay not to like your child...but you still love your child irrespective of what they do to you...I like him now as well as love him."*

Harish's mother Hemma, who was initially devastated when her son was diagnosed as deaf, began to make meaning of her situation in the following way once she started to accept his deafness:

*"The sooner you accept the deafness of your child, the better it will be for you as a parent, and for the child as an individual; the sooner they can move on and get on with life...and there's absolutely nothing wrong with a deaf child – it's just that they can't hear, but they've got sign language – they can even speak sometimes...I can say I'm definitely a stronger person, with all the experiences that I went through. My son and I...we're much, much closer. I wouldn't think Harish would be the same child if he were hearing. There's just something very special about him...I can proudly say that he's very intelligent...and if he wasn't deaf...there are so many (good) things in my life that wouldn't have happened;...I'm thankful for a lot of things..."*

(At this point Hemma became emotional, probably an indication that reflecting on her experiences was a sensitive issue that tugged at her heart strings. However, after regaining her composure, she chose to continue with the interview and share her story of the blessings she experienced in her life as a result of having a deaf child).

Some hearing parents recalled their experience of feeling isolated after the diagnosis of their children's deafness, but their exposure to other hearing parents and their achievements with their deaf children made them realise that they were not alone, since others also went through similar experiences. This realisation gave them the hope of living a normal life and helped them to make meaning of the situation. Andrew's mother Amy shared her sentiments in this regard:

*"When your child is diagnosed as being deaf, you actually feel quite isolated, and that you're the only person in the world that's ever had this problem. Once you start coming to school and you see that there are all these other kids at school...and other parents have survived this, and their kids have gone on to tertiary education...then you tend to realise that there is kind of 'life after death'."*

Similarly, Deshnie's mother Devi also recalled her experience of making meaning by drawing strength and hope from other, more experienced parents of deaf children:

*"At...School for the Deaf in KZN, there was a teacher ..., who had two deaf daughters at Springfield College of Education. I think these girls have done well. When one of her daughters started teaching at that school, she was so proud of her. I would actually like to feel like that one day when Deshnie graduates and whatever."* (Participant laughs).

Devi shared her sentiments about how her positive attitude also helped her to find meaning in having a deaf child:

*"Everybody says they don't understand how I can have this attitude. First and foremost, it's your child...and if you have to take a negative attitude when the child is born, it's hard for it to leave...You don't want to see this child always as a problem or a burden. So I think you just take it in your stride...Don't look at it as a setback. Just look at it as a challenge...Be positive!"*

Emily's mother, Edna, shared her experience of making meaning of her situation through prayer and her faith in God, and by learning to love her deaf child:

*"It's an enriching experience; it is an enormous challenge...and with a deaf child communication is so much more difficult...I can honestly say, it is only through faith and prayer that you cope..."* (Edna became emotional momentarily, and after regaining her composure, chose to continue with the interview). *"There are still times that it is really difficult, and in these moments I have to just step back and pray, because that's all I can do... I was told by a very wise person - and it was the best advice that I got – just to love them, and love them, and love them."*

Researchers, according to Meadow-Orlans *et al.* (2003: 128), report a strong association between religion and disabilities; for instance, Mapp and Hudson report that families in America who attended church more frequently also experienced lower levels of stress and

fewer adjustment problems and these parents also indicated that their religious belief was a helpful source of support in coping with disabilities. Meadow-Orlans *et al.* (2003: 127-128) found that many Black and Hispanic families in the USA reported that their religion helped them in terms of support, and that prayer helped them cope with raising their deaf children.

Many of the participants in this study acknowledged that it was their faith in God that helped them cope with having a deaf child in the family, and making meaning of their situation. Some participants felt that they were especially chosen by God to care for their deaf child, and this is likely to have boosted their feeling of self-worth. It is interesting and encouraging to note that many participants turned what they originally perceived as a negative situation, into something positive, to the extent that they now regard themselves as better people as a result of having deaf children. A survey of coping strategies used by parents of children with disabilities indicated that the three most frequently used strategies were: “(a) concentrating on the next step, (b) increased efforts to make things work, and (c) create positive meaning by coming out of the experience better” (Judge, 1998: 265). This brings us to the end of the first theme, namely, that of hearing parents in the process of being and becoming. The second theme focusses on the challenges parents face in the family, school and community.

#### **4.3.3.2 Challenges in the family, school and community**

This second theme tells the story of how the hearing parents’ journey is filled with many challenges relating to interpersonal relationships within the family, school and community. The challenges encountered play themselves out as an interaction between the parents’ own coping mechanisms, and the challenges the deaf child brings to family relationships, including parent-child relationships, marital relationships, lack of family support, and the attitudes of the community – both in general and in relation to the school.

- **A deaf child in the family: parent-child relationships, marital relationships and lack of support from extended family**

The process of parenting is a complex one, and circumstances within the context of the family and the environment can influence the way parents cope with their parenting responsibilities. The relationships and interactions between members of the family and the environment can exert a powerful influence on many hearing parents' experiences of raising deaf children. In the process of parenting, the family can be regarded as the focal point. The dynamic, interactive relationships among the four principal components of Bronfenbrenner's bioecological model, namely, process, person, environmental contexts and time, can be seen as the backdrop against which hearing parents' experiences of raising deaf children are played out (Bronfenbrenner & Morris, 1998: 994).

Ross *et al.* (2004: 155-157) maintain that with regard to the effect of deafness on the family, there are three interrelated areas of life where families and individuals can experience stress. These include life transition events (such as marriage and parenthood, the crisis associated with the diagnosis of deafness in the young child, and the transition through various developmental stages); issues related to the physical and social environment, such as expenses incurred in the purchasing and repair of hearing aids, audiological examinations, transport to and from schools for the Deaf, and social isolation; and interpersonal relationships between subsystems in the family, *i.e.* the parent-child relationship, the marital relationship and the relationship of siblings and grandparents.

The following excerpts are indicative of the challenges that the deaf child brings to **parent-child relationships**:

Edna, mother of Emily, spoke of the challenge in terms of balancing time spent with members of the family:

*"I think the most difficult thing really is – to give each child the correct amount of attention – to keep a balance in the family; because you naturally tend to give the deaf child a lot*

*more attention, simply because you are needing to interpret for the child and include the child. You really do need to keep an awareness of how the other child is feeling in that situation.”*

Frieda, who was employed at the school where her daughter Fiona attended, referred to a similar experience, in terms of making time for her hearing child as well:

*“In the beginning, I think my hearing child was very jealous. She used to cry in the mornings and she would complain of “feeling sick”. When she came with me a couple of times to this school, and realised that I wasn’t with Fiona the whole day, I think that made it easier. The fact that she knew that I was here with her sister made her feel left out.”*

Likewise, Penny, mother of Patricia, spoke about the effect of a deaf child on her relationship with her hearing son:

*“It’s a bit tough because you tend to spend more time with a hearing impaired child, because they need your attention more...My hearing son – in the beginning, we didn’t notice that he was feeling ‘left out’; but later on in the years he then would say he did feel left out a bit.”*

In considering the effect of the deaf child on family relationships, Atkins (in Ross *et al.*, 2004: 160) states that “What happens to one of the brothers and sisters reverberates throughout the family”. According to Ross *et al.* (2004: 160) and Schirmer (2001: 41), it is natural for parents to spend more time with their deaf children than with their hearing children because of the nature of the care and attention required by the deaf child. Ross *et al.* (2000: 160) state that parents, in their grief over the child’s deafness, may not be able to respond to the needs of their hearing children. However, as pointed out by some of the participants, it is important to balance the time spent with each member of the family, so that they do not feel neglected.

Hemma, mother of Harish, whose deafness was diagnosed after a long delay, spoke of her frustrating experience regarding her early relationship with her son, as a result of the inability to communicate with each other:

*“It was an extremely frustrating time at home because I didn’t know how to communicate with him and he didn’t know how to communicate with me. There was a time when he wasn’t happy to be with me...I used to feel very, very unworthy as a parent. There was nothing I could do, and I didn’t know what to do.”*

Hemma’s feeling of unworthiness as a parent, coupled with a feeling of helplessness, had a negative effect on her self-esteem, and it is likely that her emotional well-being was affected. Mertens *et al.* (2000: 134) point out that the inability to sustain a mutually satisfying parent-child relationship can lead to parents losing confidence in their parenting abilities, and a reduction in the quality and quantity of positive parent-child interactions.

Constance spoke of the years of struggle she went through while raising her son Cebo because of his perceived stubbornness and noisy behaviour:

*“I couldn’t understand what he wanted...Then he started to be stubborn; he started to cry...All those years I was struggling, because he made a lot of noise – all this noise that let’s say, you cannot afford to cope with.”*

Constance perceived Cebo’s behaviour as stubbornness, as she did not realise that he was deaf. Her struggle in coping with a ‘stubborn’ child, whose ‘noise’ she could not tolerate over the first few years of his life, is likely to have taken its toll on her patience. Mertens *et al.* (2000: 134) state that parents who experience long delays and uncertainty with regard to the diagnosis of deafness are often confused and may misinterpret the child’s perceived unresponsive or inconsistent behaviour as deliberate disobedience or rejection.

Amy, mother of Andrew, revealed her initial feelings of detachment and rejection of her son Andrew, as her dreams were shattered, and how those feelings affected her interpersonal relationships within the family:

*“I really did not like this child for a very, very long time...I felt sick when I realised...you have to accept that your child is not ‘normal’, does not conform to society’s norms. It wasn’t a great feeling at all...It is a whole process that you go through – you go through grief, anger...you grieve because all those dreams you had are shattered”.*

The process of anger and grief that Amy went through is indicative of a deep sense of loss, in this case the shattering of her dreams of having a ‘normal’ child who would grow up achieving the aspirations she set for him. Solnit and Stark (in Hodapp & Ly, 2005: 180) describe this as “maternal mourning” which refers to “a grief process” which mothers go through upon the birth of their children with disabilities; “mothers mourn, as in death, the loss of the perfect child”.

With regard to the effect of a deaf child on **marital relationships**, some of the participants shared their experiences as follows:

Amy, who is employed at the school which her son Andrew attended, shared her experience of what happens in the case of marital relationships in many of the families of the deaf learners at that school:

*“If you take what’s normal in our school, you’ll find that many of our families break up; and a lot of people either can’t take the blame or they can’t take the strain, or one of them’s too busy doing stuff, and the other one goes.”*

Drawing from the quantitative data analysis (c.f. Graph 4.2.1.4) the findings show that 9% of spouses separated while 3% got divorced. It is encouraging to note that 48% of participants indicated that they grew closer to their spouses while 37% revealed that having a deaf child in the family did not affect their marital relationship. 11% of participants



blamed their spouses for the child's deafness, while 13% decided against having any more children, and 2% sought counselling to save their marriage. 10% of the participants indicated that having a deaf child in the family affected their marital relationships in other ways.

Nadia's father Nico, who is employed at the school his daughter attended, made an observation about the broken marital relationships of parents of deaf learners at the school:

*"I've noticed there are a lot of single mothers here. Why? Is it just because 'you gave me a deaf boy or girl, I'm not interested anymore; I'll just divorce you now and carry on with another woman, and whatever?' So there's a social problem in that regard here."*

Nico's emphatic point is that, in order for a family to accept the situation and get on with doing what's best for the child, no parent should be blamed for the child's deafness. Parents should be supportive of each other in their endeavours to provide a caring, nurturing and encouraging environment for the child to develop.

Riana, mother of Richard, revealed her painful experience of having gone through a recent upheaval in her marital relationship, when her husband cheated on her:

*"We became very close to each other...We were a wonderful family, and I don't know what happened. I can't understand it. Yes, another girl – I don't want to go there right now...Richard's father's been very close, and now that we're divorced, I'm the 'wrong one' and yet I didn't do anything...I loved my husband. I love him now also. I can't understand..."*

(Riana became emotional at this point in the interview, but soon regained her composure and chose to continue with the interview). It seems that the pain of a broken marriage after many years still affected her adversely, especially since she still loves her husband.

Queenie, mother of deaf twin boys, also went through a painful experience in her marriage when her husband became unfaithful and started seeing another woman:

*“When the twins were four and a half years old I got divorced because my husband was seeing someone else, and I decided to divorce him... Ja, as I look back now I think he has no backbone... because you don’t just throw away your kids. I mean, they really, really need him now... but I can promise you one thing – I won’t get married again.”*

It must have been a bitter pill to swallow for Queenie especially since the divorce took place so soon after the twin boys were diagnosed as deaf at the age of three and a half years. The point she made about the twins really needing their father now is an indication that she probably was finding it difficult to cope with raising them on her own. Her bitterness and hurt seems to have had so strong a grip on her emotions that almost ten years after the divorce Queenie still harbours deep resentment towards her ex-husband. It would seem that this feeling of intense dislike and distrust has been generalised to all men, as Queenie vowed never to get married again.

Amy shared her experience of lack of support from her husband while raising their son Andrew:

*“I have an issue with my husband...My husband did not accept much responsibility, and still does not accept much responsibility in terms of the education process...That’s the kind of person he is”.*

Deshnie’s mother, Devi, disclosed some of the challenges she encountered in her marital relationship because of her husband’s limited sign language skills:

*“My husband...we are close, but he is less involved, and sometimes he doesn’t bother to ask a certain question, as such; and communication between him and our daughter is limited...We tend to argue a little bit when I tell him he needs to be more communicative”.*

Devi probably experienced a degree of tension in her marriage as a result of her arguments with her husband regarding the limited communication between him and Deshnie, owing to his limited signing skills. This is in keeping with the findings of Meadow-Orlans *et al.* (2003: 147) that fathers of deaf children are less likely than mothers to learn sign language and to attend parent meetings, and that mothers, more often than not, assume greater child-care responsibilities than fathers especially with regard to caring for deaf children.

According to one of the propositions derived from Bronfenbrenner's (1998: 1015) bioecological model of human development (*c.f.* Chapter 2.2), even though it may not be possible for both parents to share the responsibility of care-giving equally because of work or other commitments, it is beneficial for the main caregiver to receive the acknowledgement and support of the other parent.

With regard to **lack of support from the extended family** some participants shared their experiences as follows:

Hemma, mother of Harish, spoke of her frustrating experience of parenting at the time of the diagnosis of deafness, as well as the lack of support from the family:

*"It was an extremely frustrating time at home because I didn't know how to communicate with him...There was nothing I could do, and I didn't know what to do...I obviously had no support like in terms of the family understanding or accepting his deafness...I did not have anybody to turn to. I mean my husband and I were basically in the same shoes – this was totally new to us...Nobody tells you how you're supposed to deal with it."*

Hemma's dilemma of not knowing what to do in this situation, coupled with not having any family support probably left her feeling vulnerable. Her state of despair is likely to have affected her emotional well-being, especially since the diagnosis of Harish's deafness was confirmed soon after she had lost her mother and brother in tragic circumstances.

Constance, Cebo's mother, spoke of the effect her son had on her relationship with the extended family:

*"When I went to visit my sister..., then she would say to me, 'No this child is making a lot of noise...okay you must go away now, because it is very terrible'...".*

Constance was probably very upset by her sister's attitude, as she might have expected her to be supportive and understanding. This experience is likely to have made her feel isolated from her extended family, and it probably adversely affected her emotional wellness. It could also have been a factor that contributed to her decision to relocate from her hometown in the Eastern Cape to Gauteng.

Amy, fourteen year old Andrew's mother, spoke of her mother's non-acceptance of her deaf son:

*"My mother did not accept the fact that my son is deaf. She couldn't come to terms with it."*

The fact that her own mother did not accept Andrew's deafness must have been hurtful, as it is generally accepted that a mother is someone a person can turn to when support is needed. According to Hartman and Laird (in Ross *et al.*, 2004: 161), families exist not only in space but through time as well and each generation influences the next generation. Therefore when a child's deafness is diagnosed, the grandparents are also affected. Meadow (in Ross *et al.*, 2004: 161) states that one of the ways that grandparents respond is through grief and disappointment as their hopes of realising their own frustrated dreams for themselves and their children through their grandchildren are destroyed.

Devi, mother of Deshnie, spoke about the tension that prevailed in extended family relationships, especially between herself and her mother-in-law:

*With my mother-in-law especially, there is a bit of tension because she thinks I don't do enough. You can't keep going at it, because you unsettle the child as well. When Deshnie*

*was about six and a half months old, we had bought her her first pair of hearing aids for about R12 500. When Deshnie was a year old the Hearing Institute in Durban opened, and then my mother-in-law said “Get there! Get there!” She made the appointment and the next thing, we were buying her new hearing aids which cost me R30 000. She hasn’t accepted it (deafness) yet. She feels maybe, that Deshnie can talk. She says, ‘Put her in a hearing school’. So we have a tiff every now and again because I say, ‘You can’t; this is not going to happen’.”*

It would seem that the tension between Devi and her mother-in-law, with whom she lived at that time, could have contributed to the decision to move from KZN to Gauteng, as she may have seen it as interference rather than support from her mother-in-law.

Grace, mother of Gillian, spoke of the lack of support from the extended family and the curtailment of social life as a result of having a deaf child:

*My eighteen year old (daughter) – she normally takes care of her (Gillian) when we do need to go out. She’s capable of handling her...As for help from family, friends and that – (shakes her head to indicate that no help was forthcoming in this regard); we don’t go out, you know – if it’s once a month it’s a lot, honestly...you just can’t leave her unattended. That’s very demanding.”*

Taking care of a young deaf child is probably time-consuming for the immediate family, especially if no help is forthcoming from the extended family. It could also be stressful, because of the lack of balance between parental responsibilities and leisure-time activities.

Vermeulen (1999: 11) states that energy losses can drain one’s life force and can impact upon the events in one’s life. In addition, a lack of physical power can translate into a future health crisis. Moreover, if a person has no emotional energy to spare, it could result in unsatisfying or even “calamitous” relationships.

According to the quantitative data (*c.f.* Graph 4.2.1.5), 86% of participants indicated that the attitude of the extended family was positive while 8% experienced negative attitudes from the extended family, and 6% were uncertain in this regard.

To conclude this category reference can be made to a study conducted by Schlesinger and Meadow (in Ross *et al.*, 2004: 158) which showed that more than half the parents reported that communication difficulties constituted a major frustration in raising the deaf child. Furthermore, findings from a survey conducted by Meadow-Orlans *et al.* (2003: 126) revealed that parents of deaf children reported varying degrees of support from the extended family, while Black and White parents reported a greater degree of support than Hispanic parents. Meadow-Orlans *et al.* (2003: 148) found that several mothers of deaf children reported the greater difficulty of their husbands in adjusting to the identification of deafness in their child than they did.

Moreover, parents recognised that their spouses' reactions may differ, and that the onus falls on one of them to carry the charge alone while the other requires additional time to adjust. On the one hand, children with disabilities can increase marital stress, according to Brand and Coetzer (in Meadow-Orlans *et al.*, 2003: 148), while on the other hand, they can strengthen family ties as reported by Koester and Meadow-Orlans (in Meadow-Orlans *et al.*, 2003: 148). Meadow (in Ross *et al.*, 2004: 159) found many parents reporting that, when there is conflict in the family, the deaf child becomes the issue around which battles are centred. However, the divorce rate was no greater among families with a deaf child than among families with no deaf child. This brings us to the next category, namely, challenges associated with the deaf child's education, and stigmatisation in the community.

- **The deaf child's education**

With regard to the challenges associated with **the deaf child's education**, the following are some of the experiences shared by participants:

Amy, mother of Andrew, related her painful experience of rejection when her deaf son was not accepted at a mainstream school in grade seven, after a psychological evaluation had been done:

*“The lady that did the test told me that Andrew had to stay in a manual (sign language) environment, and I wouldn’t accept that...I moved him to remedial education – small classes where he would cope. They had a challenge in that he was the first deaf child that they had had.”*

Amy related her concerns about Andrew’s future education, and drew attention to the fact that educational options are limited for deaf children, *“because they can cope in so few environments...”* She made reference to having to *“redo the whole thing”* when she had to find a high school for Andrew, and again, when he completed grade twelve:

*“For those that are dependant on sign language, there are very few interpreters. So that cuts down what options a child can do. He’s very clever. He’s very bright, and he loves Science. I don’t know where he’s going to end up.”*

Amy’s concerns are shared by 53% of hearing parents who, as reflected in the quantitative data analysis (c.f. Graph 4.2.1.8), indicated that one of the challenges they faced was limited educational opportunities for deaf children. Related to this finding, the quantitative data analysis (c.f. Graph 4.2.1.23) reflects the indication by 65% of participants that they required information about vocational possibilities for their deaf children.

Despite her concerns for Andrew’s educational prospects, Amy displayed a positive attitude:

*“We’re going to hit a lot of brick walls when we get there, and I don’t know how we’re going to overcome them but we’ll get there! We seem to have done very well so far. The interview to get Andrew into his current school was a nightmare. They just couldn’t cope with the fact that they couldn’t timetable Afrikaans...Andrew had to do something different*

*for Afrikaans...It's hard, it's tough, it a slog, and who want to do it? None of us want to do it...but you have to, at the end of the day, do what you did for your hearing child – and that is – the best you can...and sometimes that means that you've got to send your child to a school that's further than the school down the road."*

Marie, mother of Melanie, spoke of the challenges she faced with regard to the attitude of teachers in a mainstream school towards her deaf daughter:

*"One of the greatest challenges was to send her to 'normal' school. We wanted her to be normal and not excluded...The hearing aids were not as sophisticated as today...So she got used to lip reading...so ja, we always had a 'buddy' in class, someone that would help her; and at the beginning of each year my husband and I would go to the school and ask the principal to have a meeting with all her teachers for that year, and we only stressed that the teacher does not turn around, and write on the board, while talking to the children, because then, Melanie misses a lot...Although it is the normal standard and teachers should not to do that, but they do. At school it happens that people don't want to accommodate. They don't want to repeat stuff. They don't want to adjust to someone's needs. I think that's the main problem."*

Marie expressed her concern about Melanie's hearing classmates ridiculing her during oral reading lessons, as her pronunciation was not perfect. This negative response from some hearing learners towards a deaf learner has some serious implications for the successful implementation of inclusive education in the country. There is a need for learners in the mainstream school to learn to accept and encourage learners with disabilities so that they do not feel excluded.

It is possible that the fear of ridicule from hearing classmates could be one of the reasons for the finding emanating from the quantitative data analysis (*c.f.* Graph 4.2.1.15): 30% of the participants indicated that it would be to the advantage of their deaf children to be at a mainstream school, while 51% indicated otherwise, and 19% were not sure in this regard.



Hemma, mother of Harish, spoke of the challenges she encountered trying to get her son into a certain school for the Deaf in KZN. The person in charge at the Assessment Centre, where Harish's deafness was diagnosed, had immediately submitted his name for admission to that school. However, because of tragic circumstances in the family, Harish was taken to the school only at the beginning of the following year. Unfortunately, Hemma was told that he had lost his place. *"We can't take him in – we're fully booked"*, was the response she received, and Hemma was told that Harish's name would have to be added to a waiting list, which could be anything from six months to a year.

*"I was extremely upset and I made quite a few phone calls to the school. I eventually spoke to the principal and had this long conversation with him and explained to him; and I asked him if that was the case, why wasn't I informed? I mean, I would have jumped at the chance to put him into school because I did not know what to do with him at home. I mean, we were just taking every day as it came."*

Hemma, who at that time thought that Harish's deafness was something temporary, inquired about the possibility of a transfer to another school at a later stage. She recalled the abrupt manner in which she was spoken to by the person in charge of admission at the school. *"Why would you want to do that?"* was the response that she received. The tone in which she was spoken to while seeking answers to her queries was upsetting. The principal suggested the names of two other schools which she had not even heard of. Hemma and her husband decided to try out the school that was closest to where her husband worked, for transport reasons. This meant travelling 120km a day, leaving home at six o' clock every morning and returning home late in the evening, something both Hemma and Harish have been doing on a daily basis since the day he was accepted at the school five years ago.

Devi, mother of Deshnie, expressed her concerns about placing her child in a mainstream school:

*"I think she's better off here...She works at her own pace and there's not too much pressure on her...In a hearing school obviously...she's gonna be pressured...Here*

*everyone's communicating in sign, and I think she fits in better. In a hearing school...those hearing kids are not gonna take time to really learn sign language or, you know...Basically I prefer sign language to be her first language".*

Devi obviously felt strongly that her daughter would be marginalised at a mainstream school, both in terms of educational and social development, which could be stressful for the parents and child. This could be the reason why, according to the quantitative data analysis (c.f. Graph 4.2.1.14) 81% of hearing parents placed their deaf children in special schools for the deaf. Ross *et al.* (2004: 157) concur in that the school-going period could be the next potential source of stress after the crisis of diagnosis of deafness. That is when parents are expected to make major decisions regarding placement in a school for the Deaf or mainstream setting, day and boarding schools, and the language of learning and teaching.

- **Stigmatisation in the community**

With regard to challenges associated with **stigmatisation in the community**, the following are some of the experiences shared by participants:

Devi, mother of Deshnie, expressed her annoyance at the response of some members of the community who stare at her child signing, or show pity towards her, or refer to her as '*deaf and dumb*':

*"For me, it's just being a parent. I don't really think all the time, 'okay, I'm a parent of a deaf child'. It just comes up now and then when people say 'Oh, shame, I'm so sorry'... The minute they see her signing those eyes they just... (Devi opens her eyes wide to indicate the way people stare) That's the only thing that annoys me as a parent of a deaf child. It's the way other people respond. If they're not staring...they just come up to you and say 'I'm sorry, she's deaf?', and the other thing is, when they say 'deaf and dumb'... Some people are keen to learn. They would apologise...because you tell them 'you can say mute, but not dumb'. Ja, that's the only thing – other people's response."*

Hemma, mother of Harish, shared similar sentiments with regard to the attitude of the community:

*“There’s absolutely nothing wrong with a deaf child it’s just that they can’t hear...They are deaf not dumb...and I find that is a big issue, because up till today, when they (people in the community) refer to a deaf child, they refer to him as ‘deaf and dumb’, and that totally annoys me – and especially amongst the older generation. I’ve tried to educate them...but obviously, the older generation will stick by their guns...Is it dumb as in being silly or dumb as in not being able to speak?...I really don’t like that term...deaf and dumb”.*

Many of the parents interviewed expressed the need for the community to be better informed about deafness, so that deaf children would not be stereotyped as stupid or mentally challenged. Drawing from the quantitative data analysis (c.f. Graph 4.2.1.19), 96% of the participants indicated that there is a need for the community to be better informed about deafness.

Frieda, mother of Fiona, also related a similar experience regarding peoples’ use of the term *“deaf and dumb”*, and their attitude of pity towards deaf children within the community in which she lives:

*“People who don’t have a lot of experience with deaf children seem to think that children who are deaf are also dumb...or ‘Ag, shame!’ That’s the last thing you need! You don’t want anyone to feel sorry for the child.”*

Frieda related an incident that occurred at a supermarket, when Fiona hid a chocolate bar in her pants after her mother had told her that she did not have enough money to pay for it. The security guard stopped them before they left, and in the presence of everyone – much to the mother’s embarrassment – told her that her daughter had stolen a chocolate bar. The mother apologised and said that because the child is deaf, she probably did not understand fully when told that she did not have enough money to pay for it:

*“And immediately they were feeling sorry for her once they heard that she’s deaf, and that was the last thing they should have done because I felt like – ‘Don’t feel sorry for my child, don’t feel sorry for me...Just because she’s deaf now, ‘Oh no, she can take the chocolate; Shame man!’... It doesn’t really make a difference. The fact that she hid it, she knew what she was doing. You can’t if you see a deaf child, say: ‘but they are dumb’.”*

The community’s response of pity really angered Frieda because of her firm belief that values remain the same irrespective of one’s hearing status. She was making a strong case for instilling correct values in all children, and applying the same norms that prevail in society for hearing people, because being deaf does not exempt a person from the general rules and values in society.

The stigmatisation and lack of support from the community was experienced by several parents of deaf children. Drawing from the quantitative data analysis (c.f. Graph 4.2.1.6), 30% of participants indicated that their deaf children were not fully accepted by the children in the neighbourhood.

Lydia, mother of eight year old Liesel, narrated her experience of the community’s rejection of her daughter:

*“The community – there was really little support from them. Ja, on the playground they (hearing children) told her, ‘You’re deaf, and we don’t want to play with you’...She is only a normal child, and she’s special to me, and they must accept her the way she is.”*

The attitude of hearing children in the neighbourhood towards her deaf daughter was hurtful as her child experienced social isolation on the playground.

Likewise Marie, mother of Melanie, recalled her unpleasant experience of rejection by a neighbour when her daughter was diagnosed as deaf at the age of two years:

*“It happened that one of our neighbours said that her child couldn’t play with my deaf child any more, as if she’s got a disease! I think the people outside are not informed about what it is to be hearing-impaired. They think it is like the child is dumb, or something like that.”*

Kate, mother of Kevin, spoke of her experience of the community’s response to her son’s deafness as the greatest challenge that she encountered:

*“In the community the children are always making fun of him...You have to explain. Some parents don’t explain to their children why the child is wearing that (hearing aids)...This staring at my child is making me... (Kate shrugs and shakes her head and does not complete the sentence.) Some of these big grown ups are staring at my child, like something’s wrong with him. When I’m talking to him and he’s talking back, then their eyes just grow bigger and bigger, because they expect sign language now but here, he’s talking and he’s deaf! Then I go and explain that he is deaf, but he’s wearing hearing aids and he can talk now, and they say ‘Phew, we never...’ They can’t believe it. Yes, you have to explain. It’s a challenge you know, it’s really a challenge.”*

Olivia, thirteen year old Odette’s mother, also experienced lack of understanding from the community regarding her deaf child’s mode of communication:

*“I just get the ignorance of the people out there. If you tell them you’ve got a deaf child, they can’t understand why your child is talking. They think that the child must use sign language because she is deaf...and they can’t understand how it is that the child attends a normal mainstream school.”*

It would seem that some people in the community have the perception that deaf children can only communicate through sign language, and that they cannot speak at all.

Patricia, mother of fifteen year old girl Penny, spoke of the pain and hurt she feels when her daughter is not treated like a ‘normal’ girl by the boys in the community:

*“You’ll see the guys look at her now because she’s a very pretty girl (laughs). You will see they will walk past and they will look, but as soon as they see the thing (hearing aid) stuck against her head – (gestures) there’s a total change. Ja, but that’s just part of it. Sometimes it hurts, because they treat her like she’s not really ‘normal’, when all that’s wrong is just the hearing impairment. It does hurt sometimes, but you tend to get hardened, and you tend to get used to it.”*

Hemma, mother of eight year old Harish, encountered pressure from the community to change her religion and convert to Christianity so that her deaf son “*would be able to hear*”:

*“I felt like I was in the centre, and I was being pulled from every side – people were wanting to convert me; ‘Change to Christianity and the child will hear’...and I also had people from the Muslim faith, and I did every prayer that was possible to be done – and I was willing to do anything for my child to be hearing. Nobody wants a deaf child...I really didn’t know what to do. I was very open-hearted and open-minded. My husband and I were ready and willing to accept, if that’s the way our life was to head because of having a deaf child.”*

The community in which Hemma and her husband lived was obviously neither supportive nor ready to accept the fact that the Deaf are part of society, hence the parents’ desperation, and willingness to try out anything so that their child could hear. The macrosystem in which parents find themselves is challenging, and this affects their ability to accept and cope with their children’s deafness.

Constance, eight year old Cebo’s mother, who relocated from the Eastern Cape to Gauteng so that her son’s education would not be stifled, revealed the attitude of the community towards deaf children, who were marginalised and not sent to school because it was believed that they were weak and would not cope in school. Constance disclosed that the attitude of the community in her hometown was the greatest challenge that she had to cope with:

*“Some parents would even ignore their child because he is deaf...they would say, ‘No, he is deaf’ and just leave it at that and they do not even do the searches for the school. Some of them said, ‘Oh, this one is deaf’...You know with some people deaf children don’t look like they’re a person...and then they are mean, ‘Oh, you’re swak’ (weak)... ‘Don’t call it because it’s isithuli lento’ (that thing is deaf). I was very, very hurt because I felt that maybe my child was not welcome in that area...When we are at church people said, ‘Why don’t you take your child outside because he’s making a lot of noise’. I said, ‘No, this child can’t hear’. When they call at him he ignores them...and now I’m upset...some of them think ‘What type of parent am I?’ It makes them think my son is disrespectful – the most difficult thing was with the community. Even now some of them don’t accept him; but that’s okay because I know he’s learning very much....”*

Upon conferring with a Xhosa-speaking colleague regarding the translation of the participant’s mother-tongue utterances, it became clear that the community in Constance’s hometown did not regard deaf people as human beings, but rather as inanimate objects devoid of emotions and thoughts. Hence there was a complete disregard for the deaf child’s education. Constance’s experiences can be viewed against the backdrop of Bronfenbrenner’s (1992: 229) revised ecological model of the macrosystem. The principal types of macrosystems in which a culture or subculture exists, can be identified by social address labels such as “social class, ethnicity, or region (e.g. rural vs. urban)”. In this case ethnicity and the belief systems that existed within Constance’s Xhosa culture in the Eastern Cape contributed to the challenges she faced with regard to her community’s attitude. This attitude drove her to the point of relocation to another province where her son could be afforded the opportunity of receiving an education.

To conclude discussion of the theme relating to parental challenges associated with interpersonal relationships, family, school and community, reference can be made to the theoretical framework that Bronfenbrenner (1998; 1997; 1992) puts forward regarding human development. According to Bronfenbrenner’s bioecological model, the family can be regarded as the microsystem, which is the core of the bioecological paradigm. In terms of the bioecological model, a microsystem is “a pattern of activities, social roles, and

interpersonal relations experienced by the developing person in a given face-to-face setting, with particular physical, social, and symbolic features that invite, permit, or inhibit engagement in a sustained, progressively more complex interaction with, and activity in, the immediate environment” (Bronfenbrenner & Morris, 1998: 1013).

Within the microsystem of the family, personal characteristics also influence the parenting process. These include what Bronfenbrenner (1998: 1009-1010) refers to as force characteristics, that is, positive or negative behavioural dispositions, resource characteristics (biological liabilities and assets), and demand characteristics (the capacity to invite or discourage reactions from the social environment that can foster or disrupt the parenting process). The microsystem is embedded in the macrosystem which includes, *inter alia*, the school and the community. The experiences of parents raising deaf children are inextricably linked to influences and interactions within the family as well as between the family, school and community. Hence, the prevailing attitudes of the people in the broader systems influence the individuals in the family, school and community.

In the next section discussion will focus on the final theme, namely, the partnership approach towards support.

#### **4.3.3.3 The partnership approach towards support**

The third theme focusses on the partnership approach as a way of supporting hearing parents raising deaf children. The discussion of the findings emanating from the analysis of the data is best understood against the backdrop of two propositions derived from the bioecological model of human development (Bronfenbrenner, 2000: 130; Bronfenbrenner & Morris, 1998: 996). Proposition 1 pertains to human development that occurs through the dynamic interactions that take place on a regular basis throughout life between the developing person and the immediate external environment. These interactions, referred to as proximal processes, may be considered the driving forces of development. Proposition 2 identifies four sources of these proximal processes which vary according to the way they function jointly. These include a developing person’s characteristics, the environment in



which the processes occur, the type of developmental outcomes envisaged, and the social changes that take place over the person's lifetime (*c.f.* Chapter 2.2).

Bronfenbrenner and Morris (1998: 1015) take the second proposition a step further: in order to establish and maintain “patterns of progressively more complex interaction and emotional attachment between caregiver and child”, it is important to have another actively involved adult available to encourage, assist, give status to and show admiration and affection for the one who cares for and interacts with the child. According to Hetherington and Clingempeel (in Bronfenbrenner & Morris, 1998: 1015), it is the quality of the relationships and activities that take place within the family that counts most, and from this perspective, situations can occur in which “quality overrides quantity”.

Although Bronfenbrenner's theory is associated with child development, it can be extended to include adults and more specifically parents, who are continually growing and developing in their role as they journey through the hills and dales of parenthood. The relevance of the propositions may extend beyond parental relationships to include close ties with other caregivers, relatives, peers, educators, and members of the community (as will be seen in subsequent sub-sections of the theme, ‘the partnership approach to support’).

The following partnerships emerged: parents, extended family, and the deaf child; parents and the school; parents and the community.

- **Parents, extended family, and the deaf child**

This category focusses on mutual spousal/partner support, extended family support as well as parents' support of the deaf child.

With regard to **mutual spousal/partner support**, participants shared the following experiences:

Constance, mother of Cebo, shared her experience of spousal support, which eased her pain and helped her cope:

*“Around the time I heard that my child was profoundly deaf, he (my husband) tried to convince me that it would be okay, and so there was not much pain – because there was somebody next to me... and I see he loves Cebo very much.”*

The support that Constance received from her husband made it possible for them to relocate from the Eastern Cape to Gauteng for the sake of their child’s education. The relocation meant sacrificing their jobs, and leaving behind their extended families, but they felt it was worthwhile because of the benefits for their deaf son’s education:

*“We know Cebo’s growing well. He’s learning very much...so that’s why it’s okay, because I know he is learning...I don’t like Johannesburg – but because my child is here, we are here so that I can help him.”*

Devi, mother of seven year old Deshnie, narrated her experience of spousal support, and intimated that greater involvement is needed from her husband in terms of communicating with their deaf daughter:

*“With my husband, we are closer...but...I’m more involved and he is less involved; he needs to be more communicative.”*

Marie, mother of Melanie, shared her experience of the support of her husband and their hearing children in bringing up their deaf daughter:

*“We’ve got a very close relationship - my husband and me and the children. We’re open for communication.”*

Marie, who is employed at the school for the deaf where her daughter attended, shared her observation of how some husbands’ negative attitudes towards their deaf children can be

problematic in terms of “holding hands” and sharing responsibility for raising their children:

*“It often happens that the husbands are not working with the child every day like the mum is, and often, the husband’s experience, I think, is that ‘this child is an intruder in the family’. It took my husband a long time to get used to how to work with Melanie. So it helps when the dad is involved with everything...but I don’t think that everyone is involved with the child in the same way.”*

Stefan, father of Sonja, spoke of the support he provided for his wife, who “*had a guilt trip in the beginning*”. It took him years to convince her that it was not her fault:

*“It was hard on her. She struggled to accept it. It took her a couple of years to eventually accept it – that it was not her fault and so forth.”*

Nico, father of Nadia, spoke of how he and his wife took joint responsibility for their daughter’s upbringing and how he supported her in this regard:

*“You have to speak (to the deaf child) all the time and try not to burden the one partner alone with the bringing up of the child. Sometimes it happens that the father just wants to do certain things, and everything is pushed onto the mother. It doesn’t work that way because in any child’s life, there are certain things that the father can also teach the child. You have to teach the child in a normal upbringing.”*

With regard to **extended family support** some participants shared their experiences as follows:

Constance, mother of eight year old Cebo, spoke of the support and encouragement she received from her extended family in the Eastern Cape, although she encountered a degree of intolerance from one of her sisters towards her deaf son because of the “*terrible noise*” that he made:

*“...but my other sisters and my mother, they encouraged me...and my mother looked after my deaf baby while I was at work.”* The support Constance received from the family enabled her to continue working.

Lydia, mother of Liesel, spoke of the love and warmth of her extended family towards her daughter, after the cochlear implant:

*“They love her! Only at the time when we needed money for the cochlear (implant), there was a split; and now that the cochlear is implanted, and she talks, they love her and they want her to come and visit and everything! Ja, it brought us closer.”*

Devi, mother of Deshnie, shared her varied experiences of support from her extended family:

*“My mum has been very supportive...but with my in-laws, my mother-in-law especially, there is a bit of tension because she thinks I don’t do enough.”*

Edna, mother of Emily, spoke of the enriching experience she had raising her child and of the loving support from her extended family, which obviously boosted her morale and helped her cope better with the responsibility of raising her child:

*“It certainly is enriching and I certainly wouldn’t change the experience I’ve had...I come from an incredible family that has always provided me with an abundance of love and acceptance. So obviously Emily has just become bigger and better, and the support has been marvellous! I mean, from the time we heard about her deafness, grannies, grandpas, aunties, uncles, brothers, girlfriends of brothers – everybody learnt to sign”.*

Grace, mother of three year old Gillian, shared her experience of a supportive family that helped her cope with raising her child even though she bears most of the responsibility in this regard:

*“The people in the family were supporting us with all our issues and hardships...It actually brings us closer as a family when we found out she was deaf...and everybody’s very eager to learn sign language to communicate with her...since she’s been at the school, and we’ve been attending sign language classes...I can see she’s not that stressed out any more and frustrated...As far as my husband – I mean, we’re close; and the kids are close with their little sister. Basically I’m the one who’s doing most of the communication because I’m attending the sign language classes, the other lot’s still catching up, but they know the basics of how to communicate with her.”*

Stefan spoke of the support that he and his wife experienced from his mother-in-law when their daughter, Sonja, had to go for tests at the pre-primary school for deaf children in the Cape Province, while they were living in Pretoria:

*“We heard about the...Centre (for deaf children) in Cape Town. We sent her down for tests; my folks-in-law were staying in Cape Town, so Sonja stayed with them for six months; and my mother-in-law was continuously, everyday with her at the...Centre.”*

Olivia, mother of thirteen year Odette, one of a set of quads, spoke of the support and encouragement she received from the extended family, and how this helped her cope more effectively with the raising of her daughter:

*“The family was okay with it. We got all the support from my parents, and they said to me, ‘Just keep up hope; it’s not all that bad’. So ja, we got a lot of support.”*

According to Meadow (in Ross *et al.*, 2004: 161) additional support may be provided by grandparents, in which case “a network of expressive and instrumental help” is provided.

A supportive extended family plays an important role in helping hearing parents cope with a deaf child. Many of the parents interviewed experienced a positive attitude from the extended family. This finding is in keeping with the quantitative data analysis (*c.f.* Graph 4.2.1.5) which shows that 86% of participants indicated that the extended family displayed a positive attitude.

With regard to the **parents' support of their deaf child**, the following experiences were shared:

Hemma, who works at the school for the Deaf where her son Harish is a learner, drew attention to the importance of parental support of deaf children. She shared her observation that many of the deaf learners' parents are unable to support their deaf children fully with regard to school activities, as they do not know how to communicate with them through sign language, which is the chief mode of communication at that school:

*"We're working with the deaf kids – we can see those kids that have their parents with them to support them and communicate with them; we can see that coming out in their work...and we can see those kids that don't have that support – their parents can't communicate with them, and they don't help them with their work – with the simple things in life, and we can see what a disadvantage it is."*

Edna shared her positive attitude towards raising her daughter Emily:

*Obviously you want the best for your child...It didn't take me long to realise that what was important for her was communication, and once I got over this whole idea of thinking that she must speak, it was just wonderful...to learn sign language and to communicate...Everything that she did was absolutely on par with the other children – except speaking, but she could communicate well...Once you can accept...and get on with trying to help the child, then half the battle is won."*

Constance, mother of eight year old Cebo, also had to learn sign language so that she could be supportive of her son:

*"I like to be an encouraging parent, because a deaf child is the same as a normal child, but the problem is that he can't hear...so now I'm learning sign language so that I can understand what he wants...When I didn't know sign language I thought my son is silly and*

*that he doesn't want to listen to me, he is stubborn...Now I can say to him, 'you're not allowed to do this and this and this'...I try to be supportive."*

Devi, mother of Deshnie, also made deliberate attempts to learn sign language so as to communicate more effectively with her daughter. She attended sign language classes at the KwaZulu-Natal Academy for the Deaf so that she could be *"more advanced than her"*, because she realised that *"the biggest challenge...is communication."* Devi and her husband relocated from KwaZulu-Natal to Gauteng in search of better educational facilities for their daughter. Devi spoke of the very close bond she shares with Deshnie, not only as a daughter, but also as a best friend, an indication of the mutual support that prevailed between them:

*"I'm perfectly happy with Deshnie...I don't know what I'd do without her really, because apart from just being my daughter, she's like my best friend...If I had to lose her I will feel like I'm actually alone, even though I have my husband. We are very, very close."*

Grace, mother of three year old Gillian, spoke of the importance of patience when raising a deaf child, and the need to instil discipline:

*"You've got to have a lot of patience and that's extremely important; and discipline; you've got to be a lot harder on them than you would on a hearing child. If you don't practice that you're going to have a big problem...when she gets bigger, you know. Ja, patience, ja."*

Stefan, father of Sonja, shared his experience of supporting their deaf daughter. It entailed becoming knowledgeable about deafness, relocating to another province, learning sign language and teaching Sonja to be independent:

*"Once we realised she was deaf, we quickly got onto Deaf institutes in Pretoria...In the meantime then we heard about...School in the Cape...so we came through for a week...The principal said, 'There's no problem; we can help her'...So I eventually got a transfer to*

*Cape Town, to Worcester, got a place here; we been here almost fourteen years now...We had to get her hearing aids...Then we had to get into sign language...It was difficult at the beginning because there was no one giving courses, and we sort of thought up our own sign language...We always try to bring Sonja up to realise that she mustn't think, because she's deaf, things will be provided for her, that she must just expect to receive...and we're trying to get her to realise that whether you're deaf or blind or physically disabled, it makes no difference...You've still got to go out there and make a living...And she's picked it up pretty well."*

Amy, mother of Andrew, whom she says is coping extremely well at school, displayed a positive attitude towards raising a deaf child, despite all the challenges she faced.

*"You have to, at the end of the day, do what you did for your hearing child, and that is, 'do the best that you can'."*

Amy stressed the importance of communicating with the deaf child, and including the child in all facets of family life and the outside world. This meant interpreting television programmes for the child, expressing emotions manually, and teaching values:

*"If you don't learn sign language to communicate with your child how are you going to tell your child you love him? How do you tell your child you're proud of him? How do you tell your child 'I'm angry with you because...'? Are you going to have this person growing up in your house sort of separately, but together? It's very important to be able to communicate with your child, ja, because your child is already isolated from the community. How can you isolate your child in your own family, and not expect the child to feel anger or rejection or those kinds of things within their own home? You have to instil values in them."*

Amy expressed the view that despite the many barriers, Andrew was very confident and successful and very fortunate because of the support she provided:



*“He had support, he had help, he had everything he could possibly want, and that made the difference; and that’s why he was able to go out there and keep his head above water, and hold his own, because of the fact that he had this whole framework in place, ja.”*

Eight year old Harish’s mother, Hemma, narrated her experience of how their relationship changed for the better once they learnt how to communicate through sign language, because before that she *“used to feel very, very unworthy as a parent”*, since they could not understand each other. She attributes his success to the support she provided:

*“I’ve come a long way from where we first started...I’ve accepted him...I’m learning sign language, I know what to do with him, I know how to communicate with him, and he just progresses as the years go by...The sooner you accept the deafness of your child, the better it will be for you as a parent and for the child as an individual, the sooner they can move on and get on with life...My son and I are much, much closer. I wouldn’t think he’d be the same child if he were hearing (mother becomes emotional). There’s just something very special about him, and now that I have a hearing child, it doesn’t make me love him any less...I can proudly say he’s very intelligent although he’s deaf, and I’m always there for him.”*

Nico, father of Nadia, shared his experience of how sacrifice and hard work on the part of himself and his wife paid off in the end as they took joint responsibility for raising their daughter. It meant that his wife had to give up her full-time job and take a cut in her pension fund, a sacrifice that was well worth the effort since the support of both parents was most beneficial to Nadia. Today these parents are very proud of their daughter’s achievements, and justly so:

*“We had to attend parent-guidance, which was a major change in our lives; but I think we can just be grateful that the effort and sacrifice that we put in through the years will benefit her today, because my daughter’s fully bilingual. She can communicate with anybody. You won’t say she’s s deaf, if you take it in terms of her speech; it’s normal... We, as parents,*

*decided from the start we're either going to give it a full go, or we're not going to give it a go. She is one of the top students in her class; in all her subjects she is just outstanding."*

Olivia, mother of Odette, narrated her experience of how, over the course of time, her husband's attitude and relationship with their daughter changed for the better and how they both supported her. Initially, he was in denial and didn't want anyone to know that she was deaf, but over the years, through the persistent efforts of his wife, he came to accept that *"it's okay to have a deaf child"*. He attended parent-guidance sessions at the child's school, so that he could be more supportive of their deaf daughter, and, because of her high frequency hearing loss, Odette was able to hear her father better than she could hear her mother:

*"He actually got more out of her than I did because she has high frequency hearing loss....So they've got a special bond today, and I think he's very proud of his girl."*

Lydia, mother of eight year old Liesel, shared her experiences of how her initial feelings of pain and disappointment changed over time to feelings of love and caring on the part of both herself and her husband, once they had accepted their daughter's deafness. This resulted in a partnership approach to supporting their deaf child:

*"In the beginning I was very heartbroken. I was very upset about it; but in time you learn to accept there is a deaf child, and she's our child. We love her. We will give her anything she wants. There are times in the night when she wants to talk – at two o'clock in the morning. There are still lots of problems – she doesn't want to wear the cochlear (implant), so we must learn how to sign; we're very bad at signing! So, we must put everything together so that she understands. With my husband - he's closer now than ever before; he loves it with her."*

Findings emanating from a survey conducted by Meadow-Orleans *et al.* (2003: 155) reveal that the overall sentiment expressed by parents is that deaf children are firstly children and deserve normal childhood experiences. Additional comments from many parents raising

deaf children related to: the need to acknowledge feelings and move on; to become knowledgeable about resources and options available; to seek support from other parents; to advocate for appropriate education; to love the child; be patient; to keep open the lines of communication with the child; and to foster the development of positive self-esteem in the child. These sentiments bear a close resemblance to those expressed by the participants in this study in relation to this category. This brings us to the next category, namely, parent-school partnership as a support mechanism.

- **Parents and the school**

Bronfenbrenner's ecological systems theory of human development takes into consideration the developmentally-relevant characteristics of persons and environments. According to Bronfenbrenner's (1992) ecological systems theory, the context in which the child develops is viewed as a set of nested structures, comprising various interacting systems, which influence development. Families, schools and communities are interrelated systems that contribute to the way that parents manage their parenting role. These nested structures are pointers to the overlapping spheres of influence of family, school and community on children's learning and development (Swart & Pettipher, 2005: 10; Swart & Phasha, 2005: 215; Donald *et al.*, 2002: 51).

The degree of parental involvement in the child's education could influence the child's development, while a supportive school environment could help parents cope more easily with raising their deaf children. Many researchers concur that home-school partnerships exert a powerful influence on children's learning (Swart & Phasha, 2005: 219). Several of the participants in this study made reference to the importance of school support in the deaf child's education, to maximise the child's potential for development and learning.

Many participants shared their experience of how a supportive school environment helped them cope with challenges associated with raising deaf children.

Amy, mother of fourteen year old Andrew, recalled the support she received from his pre-school and the positive attitude of the staff there:

*“Pre-school was wonderful...it was a good place for children who were deaf to be in; they took hearing children with language problems and hearing problems...They kind of ‘kicked your butt’ if you were feeling down, and kept you going on the road, but in a really good way.”*

After Andrew turned six, Amy decided to put him into a school for the deaf, where he performed very well. She attributes his success to the support and encouragement from home as well as school. The partnership between the parent and the school was enhanced since she worked at the school.

When her son was in grade seven she secured a place for him in a school which implemented a ‘small-class inclusion programme’, where he outperformed other learners:

*“The principal was so accepting of the fact that my son was different, not abnormal, but different...he just said ‘if you can’t understand, you’ll make the teachers repeat’. Then he patted him on the back and said, ‘don’t worry, my boy – we’ll take good care of you’. He is very, very happy there.”*

Amy attributes his progress and development to the supportive home and school environment which he was fortunate to experience. She stressed the importance of the partnership between parents and school, and the need for parents to instil values in, and to discipline their deaf children:

*“You have to instil values in them...it’s not up to the school to do it. The school and the parent have to function as a partnership. What some parents are doing is that they are bringing their child here and saying, ‘Here’s my child; my child is deaf; you’re doing everything.’ You can’t, because there are cultural values and all sorts of things which we*

*can't possibly begin to do. If we discipline the child, and there's no discipline at home... that becomes an issue."*

Hemma, mother of eight year old Harish, made a strong case for parents of deaf children to become more involved in the education of their children:

*"It is extremely, extremely important for parents to be involved in the child's education... my being a parent, and working at the school, I see a lot of kids who don't have that support at home. Firstly, lots of parents don't know how to communicate with their kids, and being here at this school, and having sign language as the primary source of communication – lots of parents don't have that. They either find an excuse, or whatever it is, and I mean, what could be more important than communicating with your child?"*

Hemma suggested that it would be a good idea if parents could take some time off from work to spend one day a week at the child's school for the purpose of observation:

*"Parents can see what happens; how the child communicates in the class; what the child is capable of; what is needed of the child; and the difficulties the teachers sometimes go through with the kids. It will make such a difference, such a big difference, because...my being here, it helped both ways with my son and me. I am so much more able to communicate with him. I know what's needed of him...I feel it's very, very important and parents definitely need to be more involved than they already are."*

Judy, mother of seven year old Julia, shared her views about parental involvement in the education of deaf children, in order to support them in their learning and maximise their chances of finding gainful employment in society after school:

*"I think it's very important. I think you need to be involved. It's hard enough for hearing people to get a job. I think you need to be extra involved in helping with homework, and stuff like speech therapy;...not all parents want to do it, but I think it's important; the more you can do (for your child) the better."*

Lydia, mother of eight year old Liesel, expressed the need for the school to become more involved in teaching sign language to hearing parents of deaf children, so that parents can become more involved in their education and thus forge stronger partnerships with the school:

*“My child is signing and I want to help her in her education. How can I help her if I don’t know how to sign? So, I think they (the school) must give us, as parents, a good education...They told us we must learn from the children... but we must know a little more than what they know...They gave us some handbooks, but that’s not the same as when you teach me how to speak in sign language. Ja, well, it’s very difficult.”*

Marie, mother of Melanie, expressed the need for parental involvement in the education of the deaf child, and the importance of establishing a strong parent-school relationship:

*“Ja, parents should be fully involved in the education of their children;...I know in primary school, it’s easier than in high school, because when they’re younger, the teacher gets to know the parents better, but in high school it may be a problem because the subjects are with different teachers, and the parents are not so involved with the teachers as in the primary school, but I think they must. Ja.”*

All of the participants whose deaf children attended a pre-school for the deaf, where they were taught through the oral mode of communication, stressed the importance of parents attending parent-guidance sessions at the school. This would help them to be equipped with skills to work with their deaf children at home. In this way parents could consolidate the work done by the teachers at school, and the partnership could strengthen the learners’ chances of success.

Nico, father of high-performing Nadia, made a strong case for parents to make a concerted effort to attend the parent-guidance meetings:

*“It’s very important. From the start you will attend once a week at a time that suits you and also when they can fit you in, and it’s normally just 45 minutes. So if you only start work at 09:00 you can slot yourself in before work in the morning, or if you work around here,...then maybe you can come during your lunchtime...Your child is not going to be permanently at the school, so obviously you can sacrifice...maybe a week or two from your annual leave for your child, for at least about three years, and after that, it’s finished...; and you’re gonna reap the benefits, because your child’s gonna benefit.”*

Olivia, mother of Odette, attested to the value of attending parent-guidance sessions at the school. The partnership that was established between the parents and the school was mutually beneficial to the deaf child, parents and school, because it strengthened their relationships. Her husband, who initially could not accept their child’s deafness, changed his attitude once he started attending parent-guidance meetings. She said:

*“We started here...with parent-guidance. That helped us a lot. My husband didn’t accept it that easily...but when he came to parent-guidance he actually got a lot more out of her than me”.*

Olivia, whose daughter attended a mainstream school, emphasised the need for parents to work closely with the deaf child’s educators in order to help the child cope with the demands of school work. She explained that the challenges of Outcomes Based Education, with its emphasis on group work, and the changes in the curriculum, have implications for a deaf child’s ability to cope in a mainstream school:

*“I had to give more attention to Odette, especially in grade one, when they start to read, and she had to keep up with her phonics and Maths,...and I always went to the teachers and told them ‘If she’s got a problem, how can I help at home?...and then we got homework for speech therapy; now she had to do a lot more work,...so it was difficult for her as well...In the past, the teacher was the role model for language development...well, they work a lot in groups nowadays, but they’ve only got their peers’ language to help them...I can see in my child’s schoolwork, her language delay hampers her in a lot of*

*areas, not just in the language. Even her learning-content subjects are hampered by the language delay...For a deaf child they don't change the language level of the questions for the exams. So, our children with a language delay have got a big problem in school because sometimes they don't really understand the questions."*

Olivia was stressing the need for parents of deaf children to liaise closely with the school and adopt a partnership approach to the child's education. Being a teacher and a liaison officer, she offers guidance and support to parents regarding the placement of their deaf children in mainstream schools:

*"One of the main criteria before deaf children get placed into the mainstream is: 'How involved are the parents and how co-operative are they?' It's very important because they need to do a lot of extra work with the kids because they've got a language delay ...especially in the first two to four years...because deaf children don't pick up incidental learning. It is quite challenging. I'm a teacher myself, so I want to give my children the best education...we encourage the parents to keep in contact with us...I think that it would be ideal if we can get more support throughout the country, for children with special needs, and for the parents."*

Patricia, mother of Penny, shared her views on why parents should become involved in the education of their deaf children:

*"If you're not involved you're going to lose your child half way along the line, because they need you there. They need you there to guide them, to explain things...Yes; they drain you (participant laughs). It's time-consuming, but you've gotta make the time."*

Queenie, mother of twin boys shared her views regarding the parent-school relationship:

*"Parents must definitely become involved because then you get to know more, to communicate better with them and their education is very important, because when they come home with homework then I must help them. It's very important."*



The views of these parents who were interviewed echo the findings from the quantitative data analysis (*c.f.* Graph 4.2.1.16) since 97% of participants who completed the questionnaire agreed that parents and educators should take joint responsibility for the education of the child. Greater parental involvement in school is needed for the development and scholastic progress of all children, but more especially in the case of children with disabilities.

Many parents who were interviewed suggested that other parents should visit the child's school to see what goes on at school, and to be part of the educational team by cooperating and communicating with the child's educators. This finding concurs with that of Meadow-Orleans *et al.* (2003: 151) who conducted a survey of parents raising deaf children, and found that many parents of deaf children made mention of the importance of being actively involved in the deaf child's education. Ross *et al.* (2004: 157) state that low levels of parent-school partnership can be linked to language and cultural barriers, as well as parents' feelings of being uneducated or unqualified to be part of the decision-making processes at school. Swart and Phasha (2005: 234) state that when the family-school relationship is regarded as a partnership, in which the responsibility for children's education is shared between the home and school, it results in increased levels and types of parental involvement and support for the school. The extension of this partnership to include the community results in even greater benefits. This brings us to the next category, namely, community support for parents raising deaf children.

- **Parents and the community**

In this category, two types of support are discussed, namely, formal support within the community, and social or informal support from friends, neighbours and parent groups. The discussion that follows relates especially to the exosystem as well as the macrosystem as in Bronfenbrenner's (1992: 227-228) ecological systems theory.

The community falls within the domain of the exosystem, which consists of the interrelationships that occur between different contexts, where at least one context does not

contain the child, but nevertheless exerts influence over him (*e.g.* a father's work situation does not include his child, yet the child is directly affected if the father loses his job). The family is part of the community, and there is a close interrelationship between family and community.

The macrosystem, according to Bronfenbrenner's (1992: 228) revised definition, encompasses the overarching pattern of the other systems (micro-, meso-, and exo-) that pertain to a given subculture, culture or other broader social context, "with particular reference to the developmentally-instructive belief systems, resources, hazards, life styles, opportunity structures, life course options, and patterns of social interchange that are embedded in each of these systems". Bronfenbrenner's ecological systems theory describes the various interrelated systems as a set of nested structures, each embedded within the other, "like a set of Russian dolls" and therefore interrelated (Swart & Pettipher, 2005: 10; Bronfenbrenner & Morris, 1998: 1013). Whatever happens in one system influences, and is influenced by, whatever happens in another system.

Parents' choice of school and mode of communication for their deaf children could be influenced by relationships that exist in the community between friends, neighbours, peers, and teachers (mesosystem). The parenting of deaf children could also be influenced by relationships within the community that do not affect the deaf child directly, but indirectly, *e.g.* parents' relationships with employers, and members of the general community, education and health services and the media (exosystem). The relationships, resources and services within the local community could be influenced by the attitudes, beliefs, values and philosophy of the macro system, namely, the broader community (Bronfenbrenner, 1992: 228).

In terms of **formal professional support**, participants in this study reflected on their experiences when they sought professional advice from professionals such as the paediatrician, Ear-Nose-and-Throat (ENT) specialist, audiologist, psychologist, social worker, counsellor, and school personnel. In some cases more than one visit was necessary to confirm the initial diagnosis of deafness. These professionals also advised parents about

the direction to take following the diagnosis of deafness. Some of the participants shared their experiences as follows:

Amy, mother of ‘very intelligent’ fourteen year old Andrew, expressed her gratitude for the professional support she received when her son’s deafness was diagnosed:

*“I was lucky. I was given advice; I was helped. Most people are not that fortunate. My paediatrician pointed me in the right direction – pointed me to a pre-school.”*

However, Amy challenged the audiologist who told her that Andrew had high frequency hearing loss. According to Amy, he had *“extremely good high frequency hearing...and it took many years to get a good audiogram”*.

Meadow-Orlans *et al.* (2003: 158) concur that, although parents depend on professionals for guidance, support, and encouragement, many professionals that parents interact with do not have much experience working with young children and families, even though they may be experts in their field.

Patricia, mother of 15 year old Penny, stressed the importance of having access to the services of a psychologist to help deaf teenagers cope with problems:

*“I think it’s important to have a psychologist – because when they (deaf children) get older to the teen-age stage, a lot of them end up with complexes and all sorts of problems. If they could have someone that they could talk to, it would help.”*

Queenie, mother of a set of twin boys attested to the value of having access to the services of a social worker and counsellor at the school in order to cope with problems arising from parenting deaf children:

*“Definitely! If it wasn’t for the people here at the school (participant shakes her head), I don’t think I would have coped. They have made me a stronger person. If I’ve got a*

*problem I always go to them and they show me how to handle the situation...and I've had lots of problems"*

Frieda, mother of Fiona, had her daughter's brain stem test done in 1999 to confirm whether Fiona was deaf when she was about two years old. At that time the cost of the test was R443. When her son was born three years later, the hospital arranged for a person from the Ear-Nose-Throat centre to perform a similar test on her new-born child, at a cost of only R47, and it happened to be the same person who conducted both her children's brain stem tests. The important point she was making is that there should be screening for all new-borns as part of the routine check-up, instead of waiting for two years to find out that a child is deaf. This would give parents a better chance and more time to decide on what intervention measures to follow, in terms of the choice of hearing devices, and mode of communication to pursue. She said:

*"I know they say that we don't have money in South Africa, to do a hearing test when a child is born...but I think it's a good thing if they started that here...the sooner you find out the better."*

In this regard Young and Tattersall (2007: 209) maintain that the rapid expansion of Universal Newborn Screening (UNHS) programmes across the world has given rise to early intervention measures that can lead to developmental gain and realisation of the potential advantage of early diagnosis for the deaf child and the family. Yoshinaga-Itano (in Young & Tattersall, 2007: 209) concurs that there is compelling evidence of the substantial advantages for linguistics and socio-emotional development when linked to early identification of deafness.

The need for psychological support becomes clear and is also supported by the quantitative data analysis (*c.f.* Graph 4.2.1.25). 47% of participants expressed a need for psychological counselling. Here we see a clear indication for counselling services to be provided for parents of deaf children, to ease their burden. Where to find such support is not always clear as shown in the quantitative data analysis (*c.f.* Graph 4.2.1.20), which corroborates

this finding, as 63% of participants indicated that they were not aware of a support group for parents.

Judy, mother of Julia, related her experiences of confusion as she was given many different options about what to do and where to go, in order to get help with raising her deaf child. She eventually sought guidance from a school principal who advised her of the importance of bringing up her deaf child “*within the context of the family*”. She followed the advice, placed the child in a local school for the Deaf, where both parents eventually took up employment, and subsequently their close co-operation with the school staff brought about better coping strategies with their daughter.

This once again highlights the need to have access to information, as shown in the quantitative data analysis (*c.f.* Graph 4.2.1.24), where 81% of the participants indicated that they would like to obtain information about various matters pertaining to their children at one place. In addition, 44% of participants (*c.f.* Graph 4.2.1.25) expressed the need for assistance in choosing the right type of school for their deaf children.

In terms of more **informal or social support**, most parents attested to the value of parent-support groups within the community, as a means of “holding hands” to help parents cope better with raising deaf children. The quantitative data analysis (*c.f.* Graph 4.2.1.21) shows that this view is held by 53% of the participants who responded to the questionnaire. Moreover, 42% of participants (*c.f.* Graph 4.2.1.8) indicated that one of the challenges they faced was the lack of support services in the community.

Amy, mother Andrew, shared her views regarding parent-support groups within the community:

*“I think it’s very, very important... to set up some kind of parental support group, so that the parents feel that they’re not alone, and they don’t feel that they’re the only ones that have this problem... When your child is diagnosed as being deaf – you actually feel isolated, and that you’re the only person in the world that’s ever had this problem. Once*

*you realise... other parents have survived this and their kids have gone on to tertiary education and stuff like that, then you tend to realise that there is, kind of, 'life after death'.*"

Constance, mother of Cebo, affirmed the need for parent-support groups, especially in her home town in the Eastern Cape:

*"There is a need for support groups because some parents would even ignore their child because he is deaf. Parents need a lot of support. They need a lot of encouragement."*

Devi, mother of seven year old Deshnie, spoke about the social value of joining a parent-support group in the community:

*"I like meeting other parents as well...On a weekend, you wanna pick up so-and-so's child, and you wanna baby-sit on that day...That's what actually happens – and the husbands become friends...So, you strengthen your social ties, your friendships and so forth...You know the kids enjoy themselves because they've got other hearing-impaired children with them. It's good for parents to communicate with one another. I think it's excellent. I think it's important."*

Edna, mother of Emily, felt that hearing parents of young deaf children would especially benefit from a parent-support group in the community for the following reasons:

*"I think, especially when you have a baby and it's diagnosed as deaf, it's vital to have somebody because you are so desperate, and you need to gain as much information as you can."*

Likewise, Marie, mother of Melanie, expressed similar sentiments regarding the need for parent-support groups:

*“I think, when you hear for the first time that your child is deaf, it’s a terribly awful thing. You don’t know what to expect from it. Especially for the younger mothers, it’s useful to have older mothers to inform them, help and support them; someone you can ask, ‘What must I do?’ and ‘How does it work?’ So, if you’ve got a group, parents can help each other.”*

Similarly Frieda, mother of Fiona, shared her views about a parent-support group in the community to help parents obtain more information and advice on raising deaf children:

*“Once you actually realise that your child is deaf, you actually feel alone. There’s nobody who can actually tell you that speech is the best, or that sign language is the best, or a cochlear implant would be the best...I think I would have gone the cochlear implant way, if I only knew then what I know now. So, I think it’s good to have somebody that can actually lead the way.”*

Hemma, mother of eight year Harish, also expressed the need for a parent-support group, so that hearing parents could share their experiences of raising deaf children:

*“By talking to people who have a deaf child, you are able to share your experience, and they share theirs’ with you, and you feel like this whole burden lifts off your shoulder, because you’ve got somebody to share it with, who will understand exactly what you’re going through, who will give you feedback on what worked with them, and what didn’t.”*

Indrani, mother of nine year Indresan, expressed similar sentiments about the value of a parent-support group in the community for hearing parents of deaf children:

*“It is very important. Other parents can learn from different parents’ experiences, ’cause some of them just bottle it up inside, and you’ve got no-one to talk to...and we need to talk about it. It really helps to talk to others.”*

Kate, mother of Kevin, expressed the need for a ‘*mothers’ group*’ as well as a counsellor, to help mothers cope better with raising their deaf children:

*“It’s very important, I feel, to have maybe a mothers’ group... and meeting, talking about your children, sharing questions and answers – because you can learn a lot out of each other’s experiences. A counsellor will be helpful to mothers in that group, if it’s possible, to advise parents who have problems – like in my experience with Kevin fighting... he can’t hold it (aggression) in.”*

Patricia, mother of Penny, shared her perspective on the need for parents to support one another through ‘holding hands’.

*“I think it’s good if the parents can get together and say, ‘well, listen, try this’, or, ‘you must do this’. If you know that there are people out there who are battling like you – it helps. It gives you encouragement to carry on. Hearing it from other parents – what they did, and how they coped with certain things – I think it’s very good to hear other parents’ perspectives”.*

From the foregoing sentiments expressed by participants it is clear that there is much value in having access to formal and informal support in the community, and to engage in a partnership approach with professionals and other hearing parents of deaf children, to help them in their parenting role. In this regard Elman (in Ross & Deverell, 2004: 271) asserts that group therapy is gaining in popularity as a result of the high cost of professional resources in many countries. In support of group therapy Toseland and Rivas (in Ross & Deverell, 2004: 271) maintain that a small group in which members share common goals and use the group experience to accomplish tasks and realise these goals, can also meet the socio-economic needs of its members. Luterman (in Ross & Deverell, 2004: 271) holds the view that healthy group experiences can serve as a strong healing and educational tool and that the collective wisdom of the group is stronger than the wisdom of any single member. Solomon, Pistrang and Barker (2001: 113) found that 56% of parents of children with



disabilities indicated that they found mutual support groups to be very helpful, and they were very satisfied with the support provided by the groups.

A clear indication that support is required from other role-players in the ecosystem, is evident in the comments by Nico, father of Nadia, who made a strong case that the government should provide funding to transport deaf children who have to travel long distances to attend special schools, as travel costs imposed financial strain on parents. Not all parents could afford to pay for transport, let alone the cost of travelling to and from school to attend parent-guidance sessions. Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.8), 40% of the participants indicated that transport to and from the deaf child's school was one of the challenges they faced, while 55% indicated that the financial burden was a problem.

Nico also made a case for employers to cooperate with parents, by allowing them time off work to attend parent-guidance sessions at the school. He suggested that, since these sessions were forty five minutes in duration, employers could take time off from the employees' annual leave, to obviate the problem of the parent having to resign from work to attend to the needs of the deaf child (as his wife had done) at the expense of loss of salary and a subsequent reduction in pension benefits.

Several parents expressed concern about limited educational opportunities for their deaf children because of the lack of interpreting services support due to the shortage of sign language interpreters in the community. In this regard, DeafSA (2006) concurs that the dire shortage of sign language interpreters in the country contributes to the limited opportunities deaf persons have for higher education and employment. Drawing from the quantitative data analysis (*c.f.* Graph 4.2.1.8), 53% of the participants agreed that one of the challenges they faced was the limited educational opportunities available for deaf children, while 61% felt uncertain about their deaf children's future.

Amy, mother of a "*really bright*" fourteen year old boy Andrew, expressed concerns for her son's future when he completes grade twelve:

*“There’s so little open or available to the deaf, because they can cope in so few environments, they cannot cope in a lecture hall of two hundred students. So your options become limited...for those who are dependent on sign language, there are very few interpreters. So that cuts down on what options a child can do.”*

Similarly, Devi, mother of Deshnie, expressed her concerns and aspirations for her child’s future, in terms of tertiary education:

*“I want Deshnie to go to university and graduate, and get into work, and be independent, ’cause if I’m not here one day – if something has to happen to me – I’d like to know that she didn’t have to wait for handouts. So, I want her to grow up to be a very independent individual...I want the same thing for my child, like any hearing child’s parent wants...I would be so proud one day, when she’s ready, when she graduates and whatever” (Devi laughs).*

Likewise, Indrani, mother of Indresan, expressed similar sentiments regarding her son’s future prospects, and her concerns in this regard:

*“I have concerns about his future – because of job opportunities...I don’t know what his future holds for him. I’d like him to have a tertiary education...but there’s limited things in this country for the deaf; and most importantly for him is to get a good education and get a nice job to secure his future, because I’m not gonna be there all the time for him. Ja, it is a major concern to me.”*

Similarly Lydia, mother of Liesel, said that she frequently thought about her child’s future, and expressed her desire for her daughter to acquire tertiary education after she completes school:

*“Liesel tells me...after school she’s going to work...I think I want her to go further after school – go to college and learn more”.*

For these parents' aspirations to be realised, and for them to manage their parenting role more effectively without undue concern about the future, effective support structures are called for. In this regard Hintermair (2006: 493-494) concurs in that parental access to personal and social resource-orientated support is associated with significantly lower levels of stress, and that availability and use of such resources is central to the empowerment of parents of deaf children. Similarly, Minchom, Shepherd, White, Hill and Lund (2003: 93) also identified the need for broader social and language support for deaf children and their families.

In drawing the above discussion to a close, it is clear that the role of parenting is related to the interaction between the various systems of Bronfenbrenner's ecological systems theory, which describes these inter-connected systems as a set of nested structures, each embedded within the other, "like a set of Russian dolls" and therefore interrelated (Swart & Pettipher, 2005: 10; Bronfenbrenner & Morris, 1998: 1013). Whatever happens in one system influences, and is influenced by whatever happens in another system.

#### **4.4 CONCLUSION**

This chapter has dealt with the analysis and findings from the quantitative and qualitative data as well as a discussion of the findings. The findings emanating from the quantitative data were interpreted and were also used to complement the findings from the qualitative data. The qualitative data, presented as themes and categories, drew on the participants' direct quotations as well as on literature control, to recontextualise the findings. The findings indicate that hearing parents of deaf children often go through traumatic, stressful, challenging and sometimes life-changing experiences. Many parents travel a long, hard journey, fraught with challenges and sacrifices, and yet their resilience, in trying to optimise the development of their deaf child, enables them ultimately to experience a sense of celebration.

In the next chapter a summary of the findings and inferences, the limitations of the study, as well as recommendations and implications for the well-being of hearing parents raising deaf children will be presented.

## CHAPTER 5

### SUMMARY, INFERENCES AND RECOMMENDATIONS

*“I think it’s very, very important... to set up some kind of parental support group, so that the parents... don’t feel that they’re the only ones that have this problem... Once you realise... other parents have survived this, and their kids have gone on to tertiary education and stuff like that, then you tend to realise that there is, kind of, ‘life after death’.”*

(Amy, participant: 2006)

#### 5.1 INTRODUCTION

The aim of this study is to explore, from an ecosystemic perspective, the phenomenon of hearing parents’ experiences of raising deaf children in South Africa, and the way they manage and deal with their unique parenting role. In this chapter, a summary of the previous chapters will be provided and the inferences drawn from the qualitative and quantitative data will be presented. The usefulness of the mixed methods approach in answering the research questions will be addressed. This will be followed by recommendations for facilitating the emotional well-being of hearing parents raising deaf children. A discussion of the limitations of the study and suggested recommendations for further research will be provided thereafter.

#### 5.2 SUMMARY

##### 5.2.1 Statement of the problem

The problem addressed in this study relates to the experiences of hearing parents raising deaf children, and the way they manage and deal with issues associated with the upbringing of deaf children. Since over 90% of deaf children are born to hearing parents, many of whom are not prepared for the consequences of deafness, the journey is complex, and different ecosystemic variables relating to the parent, the deaf child, the family, school and community influence the way such parents manage and deal with the

associated issues. It is argued that the extent to which hearing parents are able to support the holistic development of their deaf children depends on the unique ecosystemic variables affecting each family, including, *inter alia*, the availability of resources and amount of support that parents receive within the home, school and community. The marginalisation of deaf children in society places an even greater strain on hearing parents, threatening their emotional well-being and this, in turn, can affect the optimal learning and development of their deaf children.

### **5.2.2 Theoretical framework for understanding deafness and parenting**

The development of the deaf child and parenting is viewed from an ecosystemic perspective, and Bronfenbrenner's (1998; 1992) ecological systems theory underpinned this study. This multidimensional model provides a framework for understanding the complexity of influences, interactions and interrelationships between an individual and the various systems that are linked to the individual. These complex, on-going, reciprocal interactions result in change, growth and development, in both the parent and deaf child. The deaf child and the parent do not exist in isolation but are at the centre of the ecological system, embedded in other nested systems that influence growth and development. The nested systems are indicative of the overlapping spheres of reciprocal influence of the family, school and community that inform the experiences of hearing parents raising deaf children.

The body of literature pertaining to the nature of deafness, its clinical features, and its prevalence internationally and locally is included to gain a better understanding of the complexity of deafness and the magnitude of the phenomenon. The literature suggests that unless deafness is diagnosed early, and early intervention measures are instituted for the deaf child's language and communication development, hearing loss could have far-reaching consequences for the quality of life of hearing parents and the holistic development of their children. A brief exposition of the development of the deaf child includes cognitive, socio-emotional and personality development and does not imply that the other aspects of development are less important.

A survey of literature pertaining to parenting, including parental responsibilities, parenting and the deaf child, the family and the deaf child, the child's deafness and the emotional well-being of hearing parents, and the issues associated with raising deaf children also contributed to understanding the complexity of parenting. The literature reveals that the challenges associated with raising deaf children could affect the emotional well-being of the hearing parent, which in turn could influence the holistic development of the deaf child.

### **5.2.3 Research design and methodology**

The research paradigm underpinning this study is pragmatism. A mixed methods approach incorporating the concurrent triangulation design is employed. This entails a combination of quantitative and qualitative methods of data generation and analysis, with the qualitative data taking priority while the quantitative data are used to complement and corroborate the qualitative data, and vice versa.

A structured questionnaire, which was used to collect quantitative data, was completed by 157 participants from 3 provinces. It was designed to answer the first research question by providing an understanding of various ecosystemic variables influencing the experiences of hearing parents raising deaf children. The qualitative data was generated through semi-structured interviews with 20 hearing parents whose deaf children had attended, or were attending, schools for the Deaf in KwaZulu-Natal, Gauteng and Western Cape, to find answers to the second research question, by providing an understanding of the experiences of hearing parents raising deaf children.

Both sets of data are analysed and integrated during the discussion of the findings. The quantitative data, which are descriptive in nature, are presented in the form of bar graphs, while the qualitative interviews, which were audio-taped and subsequently transcribed, are coded according to themes. The validity of the research is ensured through subsection of the qualitative data to criteria of trustworthiness, while the questionnaire for the quantitative data has content validity. Additionally, since the mixed methods concurrent triangulation design is used, the two sets of data are integrated and the findings complement each other.

The mixed methods concurrent triangulation design was adequate to answer the key research questions. The chief advantage of using the mixed methods approach lies in the quality of the inferences that are made at the end of the study. The term “inferences” refers to the conclusions that are derived inductively or deductively, and are based on the researcher’s interpretations of the results of quantitative and qualitative data collection and analysis (Tashakkori & Teddlie, 2003: 35). The triangulation of quantitative and qualitative data serves to provide a better understanding of the phenomenon of hearing parents raising deaf children, and the findings from both sets of data are corroborated.

Ethical clearance was obtained to conduct the study according to the guidelines stipulated by the University of KwaZulu-Natal.

#### **5.2.4 Summary of findings and inferences**

##### **5.2.4.1 Quantitative findings**

The **quantitative data** derived from the questionnaires, which are represented in the form of bar graphs, serves mainly to provide background information to the phenomenon under study. The survey questionnaire explored factors in the individual family, school and community that could influence hearing parents’ experiences of raising deaf children.

The quantitative findings show that for many hearing parents raising a deaf child, the process is affected by various ecosystemic variables which come into play in their parenting experiences. Strong concerns relating to the education of the deaf child are echoed by the majority of participants, who prefer a special school for the Deaf rather than a mainstream school, thus indicating that the mainstream school would not be beneficial to their child. Additionally, there exists a strong belief amongst parents that a shared responsibility between themselves and the educators could optimise the education of their deaf children. The results also indicate that parents prefer their mode of communication with their deaf children to be congruent with the medium of instruction used at the school. Similarly the need for information about vocational



opportunities for their deaf children, linked to anxiety about the future of their children, became apparent.

The survey also highlights the importance of, and need for, a support group in the neighbourhood, as well as a preference for a central location where they could access information about matters pertaining to deafness. The data also reveals the very important issue of financial assistance to help absorb the costs associated with raising a deaf child. These findings corroborate the qualitative findings.

#### 5.2.4.2 Qualitative findings

The **qualitative data** from the 20 semi-structured interviews were coded to generate themes and categories. Three main themes emerged in response to how the parents experience their parenting role.

The theme of **finding direction** is a journey that hearing parents make from the time of diagnosis of the child's deafness to the stage of making meaning of their situation. The findings reveal that hearing parents' *psychological responses* to the diagnosis of the child's deafness differ, depending on their unique circumstances. However, many go through a grieving process as for the loss of a loved one before they accept the reality of deafness.

Communication with their deaf child presents a major difficulty for parents in terms of making a choice of the mode of communication to be used, as well as having to learn sign language if necessary. Sacrifices in terms of cost and effort to learn sign language are made in the belief that the quality of life of their child would be improved. However, this is marred by the pain of experiencing their children being referred to as "deaf and dumb" or "that thing" by members of the community. This highlights the need for the public to be better informed about deafness.

The journey of *endurance, sacrifice and celebration* is echoed by many parents in speaking of their experiences of raising their deaf children in a hearing world. The journey often included relocation of their family to access better education, as well as a

change in their employment position, in order to take care of their deaf child. In the midst of these struggles, parents also experience feelings of joy and celebration as their deaf child showed signs of communicative competence and scholastic progress, thus contributing to an improved relationship with the child.

The findings also reveal the intense struggle that parents experience in dealing with the diagnosis of deafness of their children. In *making meaning* of their circumstances, some trust their own intuition and gut feelings, while others turn to the Transcendental for comfort and strength. A notable proportion also feels especially chosen to care for a deaf child and relate this to becoming “a better person”.

The second theme, referring to **challenges**, underscores the critical importance of stable *family relationships* in providing an enabling and supportive environment for all members of the family. Parents speak of how important it is to work at maintaining these relationships so that their spouses and hearing children are not made to feel neglected. The *deaf child's education* poses a further challenge and many parents articulate their concerns regarding the limited educational opportunities available for deaf children. The shortage of sign language interpreters places further limits on the educational options available to deaf children. This problem extends beyond school to tertiary education as well. The problem of marginalisation of deaf children at mainstream schools is a further concern of some parents. *Stigmatisation from the community* poses yet another challenge. Prejudiced attitudes from members of the community towards deaf children turn out to be a painful issue for some parents. The need for awareness-raising among the general public about deafness is expressed by several parents.

The third theme indicates the need for a **partnership approach towards support** between *parents, extended family and the deaf child, the school and the community* to provide for the effective learning and development of their deaf child. Many parents call for the establishment of support groups in the neighbourhood where they would be able to share their experiences with other parents in similar circumstances. The need for a partnership approach towards the deaf child's education arises as parents emphasise the importance of the joint responsibility of parents and educators in this regard. The call

for a central access point, where parents would be able to get information and advice on matters relating to deafness, is iterated.

The above summary of findings is used to draw the inferences below.

#### **5.2.4.3 Inferences**

The study aims at exploring how various ecosystemic variables affect the way hearing parents raise their deaf children, as well as exploring the lived experiences of hearing parents raising deaf children. The participants' experiences identify particular core needs. These are reflected in both the quantitative and qualitative findings. The inferences drawn from the parents' accounts in the semi-structured interviews are corroborated by the data which emerge from the questionnaire.

A key inference that emerges relates to the emotional trauma experienced by parents upon the diagnosis of their children's deafness. This infers that there is insufficient support from professionals handling the disclosure of the diagnosis in terms of relating to the emotional needs of parents. Additionally, delays leading to the late diagnosis of deafness infer concomitant delays in the introduction of intervention programmes for deaf children which may have serious repercussions for their language and communication development and consequently their holistic development.

With regard to communication, the parents' difficulty in acquiring sign language skills, which includes making sacrifices in terms of time, effort and finances, indicates a lack of sufficient accessible facilities to equip themselves with competence in this regard. Further, their difficulty in making an informed choice relating to the communication mode, points to the need for more information to be made available to them.

A further inference relates to the financial sacrifices made, as the costs incurred from medical bills, hearing devices and transport to and from school resulted in financial strain for many parents. This was exacerbated in the case of some mothers who had to resign from full-time employment to care for their deaf child. The inference arising from this finding points to the need for financial relief to be made available to parents. In

spite of the difficulties that parents had to contend with, and the sacrifices they made for the sake of their deaf child, many parents spoke of the celebration of their deaf child's progress, and the consequent joy they experienced. The inference emanating from this finding is that the resilience and resourcefulness of parents result in their ultimate opportunity for celebration. Parents' experiences vary with regard to how they make meaning of having a deaf child. The inference here is that individuals make meaning in different ways depending on their own strengths, initiatives, resourcefulness as well as the circumstances and resources in the environment.

The strained relationships between parents and their deaf children resulting from their perceived aggression, stubbornness and tantrum-throwing, infers a breakdown in communication. This poses a threat to effective parenting as well as the optimal development and learning of the deaf child. Strained interpersonal relationships between hearing parents and spouses, as well as the deaf child's hearing siblings, is an indication that parents tend to spend more time with the deaf child, to the apparent neglect of the rest of the family. Tension in marital relationships, as a result of the perceived lack of sufficient support from the deaf child's father in caring for the deaf child, may result in heavy reliance and strain on the mother as the main caregiver.

A critical inference that emerges from the findings relates to the issue of access to educational facilities that can adequately cater for the specific needs of the deaf child. The relocation of families to different regions or provinces for the benefit of their deaf child's education and development is an indication that there are insufficient educational facilities in some regions or provinces. Further, this shortcoming in the provision of suitable educational facilities perpetuates the marginalisation of the deaf learner not only in schools but also at tertiary institutions. This infers a lack of suitably qualified sign language interpreters at mainstream schools and tertiary institutions which presents a barrier to appropriate inclusive education for deaf learners and students.

Several parents express strong feelings regarding the apathy and ignorance regarding deafness in the community, which often led to episodes of insensitive and cruel remarks being made about their deaf children. Prejudiced attitudes and unacceptable treatment of their deaf child exacerbated the pain and hurt felt by parents. This stigmatisation proved

difficult for the parents to handle. The inference here is that the community by and large remains poorly informed about deafness and that a better-informed public can play a more supportive and caring role in terms of accommodating the Deaf. A further inference is that stereotyping and stigmatisation of the Deaf by the public may contribute to limited employment opportunities for the Deaf.

The finding relating to the call by parents for the establishment of support groups in the community, as well as the creation of a central access point for information on deafness, infers that there may be ignorance on the part of parents regarding important decisions to be made, especially in terms of choice of communication mode, educational options and hearing devices for their deaf children. There is a need for parents to be better informed about all matters relating to the growth and development of their deaf child. This inference further highlights the possibility that uninformed decisions could result in negative consequences for the development of the deaf child.

The above discussion exposes the importance of all levels and interconnection of the ecosystem, according to Bronfenbrenner's (1998: 996; 1992: 191) ecological systems theory, in creating an enabling context for parenting a deaf child. It is clear that the collaborative involvement – in various ways – of the whole family, school and community is essential for providing the best environment for parenting and the deaf children's progress. A reciprocal interplay at all levels of the ecosystem contributes to the creation of an enabling and empowering environment for the actualisation of the deaf child's potential.

The above realisation is also linked to the tenets underpinning the policy of inclusive education, namely, human rights, social justice, inclusion and equal access to education. These principles, which attempt to create an inclusive society, play themselves out in the findings and inferences. Even though the policy of inclusive education is in place in South Africa, the implementation of the policy requires all levels of the ecosystem to respond to it in an integrated manner. Although this is the ideal, the voices of parents raising their deaf children quite clearly indicate that society in general is still far from achieving this ideal. However, small steps in the right direction hold the potential of creating a more just and inclusive society, where diversity is accepted and celebrated

and where the necessary systemic support is provided. The following recommendations are therefore offered.

### **5.3 RECOMMENDATIONS**

The following recommendations are offered to improve the experiences and facilitate the emotional well-being of hearing parents raising deaf children in the hope that they could lead to a better quality of life for the entire family and the actualising of the deaf child's potential at home, in the school and in the community. In terms of time-frames for implementation, some could refer to short term, medium term or long term goals, depending on the availability of resources and basic infrastructure. The recommendations relate to the various levels of the ecosystem, and address issues that emerge from the findings.

#### **5.3.1 Informal support: family support groups**

Family support groups where parents can learn from the experiences (both positive and negative) of other parents raising deaf children need to be established. This sharing of experiences can be a source of encouragement and inspiration, and can help parents come to the realisation that they are not alone. The social network of hearing parents raising deaf children can thereby be increased and this can in turn contribute to raising their morale and giving them a sense of emotional well-being, especially when they share experiences of the 'celebrations' of their deaf children's progress. Guest speakers, who can share expert knowledge pertaining to aspects of deafness, or deaf role models who can give testimonies and share their experiences with parents, could be invited to address hearing parents from time to time. Such support groups should be established at schools for the Deaf, or in a community centre which is easily accessible to families. The principal or a designated member of staff or a parent could take responsibility for initiating the establishment of the support group.

The support offered can be extended to other members of the family as well, since the research reveals that siblings and grandparents are also affected by the presence of a deaf child in the family. Special meetings could be held to cater for the deaf child's

siblings as well as grandparents, focussing on their particular needs and interests, to enable them to cope better and improve their interpersonal relationships not only within the family, but also in the wider community. Members of the support group could provide input regarding the topics they would like to be addressed, and a schedule could be drawn up to suit their needs and interests. Such support groups could be initiated with immediate effect, and planning of a programme could proceed with input from the members. Family-centered support groups can only lead to positive outcomes and improve the quality of life for all members of the family, including the deaf child.

### **5.3.2 Formal support from professionals in the community**

#### **5.3.2.1 Medical professionals**

Formal support of parents from professionals in the community (in particular, the medical fraternity) is essential to help parents cope with the reality of the diagnosis of deafness, as well as the raising of a deaf child. Since the emotional stability of many participants suffered a severe setback upon the discovery of deafness, the need for psychological counselling for parents is strongly recommended. This service could be accessible to parents at suitable venues which may be located at provincial hospitals and regional municipal ante-natal clinics. The funding for establishing these facilities should be the responsibility of national government. Where such services cannot be established (as a result of factors such as the lack of finance or qualified personnel), it is then recommended that existing psychological services at schools for the Deaf be extended to the parents affected by deafness.

Since the emotional well-being of parents can positively influence the development of the child, the converse is also true and can have far-reaching consequences for the growth and development of the deaf child. Clearly, there is a strong need for psychological support for parents caught up in these circumstances. Such support needs to be ongoing and sustained over many years until the parents are able to manage the deaf child in the family and parent effectively.

Paediatricians and audiologists responsible for the diagnoses of deafness should understand and accommodate the emotional needs of parents in terms of how to manage the breaking of the news, and be able to guide parents regarding the next step to follow. This can be brought about through appropriate curriculum interventions in the training of specialist paediatricians, audiologists and other professionals (such as social workers) concerned with treatment of the Deaf. Perhaps a policy of 'best practice' needs to be drawn up by psychologists which can then be implemented by these professionals in order to support parents in the early stages of disclosure. This entails an ethic of care and teamwork on the part of various professionals to support parents. The collaborative efforts of professionals dealing with deafness have the potential to bring about welcome changes to the manner in which parents handle the disclosure of deafness as well as subsequent actions to be taken.

Delays in the diagnosis of deafness can have serious consequences for the timeous language development of deaf children. Therefore, a strong recommendation is made for a policy to be put in place by the government for the mandatory implementation of newborn hearing screening in South Africa, similar to that which is in place in the United States of America and the United Kingdom. Early diagnosis of deafness can lead to the implementation of early intervention programmes for the education and development of young deaf children.

Part of the process of supporting parents should include sharing appropriate knowledge about their child's deafness, affording them opportunities for genetic counselling, informing them about preventable causes of deafness, and advising them about the possible options regarding communication and school placement.

#### **5.3.2.2 School professionals**

A further recommendation for parental support relates to the deaf child's school. The initiation of collaboration with parents rests with educators, and it can, and should be, implemented as soon as possible by school management teams consisting of the principal, deputy principal and heads of department. As a prerequisite to forging a partnership approach to the education of the child, it is recommended that educators



identify the strengths of the family and use these to advantage in promoting the learning and development of the deaf child. Close collaboration with parents entails getting to know the child's family and home background well, while respecting cultural diversity and establishing a relationship of trust. It also involves setting up appointments to meet parents, and structuring a support plan for mutual decision-making and sharing of information and resources, as well as mutual agreement regarding the resolution of conflicts in a constructive manner. In addition, it also entails educators keeping parents informed about the child's progress or lack thereof, and the child's behaviour at school. The school can also initiate much-needed sign language classes for parents so as to improve their communication skills with deaf children.

The training of educators to manage deaf children is strongly recommended especially in the context of inclusive education. Tertiary institutions responsible for the education and training of teachers should build into the curriculum a component that will equip them to cater for children with disabilities, including deaf children. Further, parents need guidance from professionals concerning the choice of school for their deaf child. They need information regarding the three educational options offered within the context of inclusive education, namely, special schools, full service schools and mainstream schools which cater for diverse needs of the child. Informed parents will be equipped emotionally to manage the challenge of raising their deaf children more effectively. This is linked to the next recommendation.

### **5.3.3 Centre for Deaf studies (Central access point for information on deafness)**

Informed parenting could be a goal of educational programmes at centres for the Deaf which could be located at universities or hospitals. An overwhelming majority of parents articulated the need for a central access point for accurate information pertaining to deafness. Such a facility does not currently exist in KwaZulu-Natal, unlike Gauteng, where a centre has been established at the University of Witwatersrand. It would be helpful to parents if they could quickly access authoritative information about deafness from a central location. Access to accurate information has the potential to empower parents and raise their self-esteem and confidence as they raise their deaf children.

Currently, some internet sources of information are available. Websites pertaining to deafness and related issues can serve as points of access to information on deafness. However, the great majority of indigent parents cannot afford this technology and thus remain marginalised. A central access point known to all would alleviate many dilemmas that parents experience in their efforts to raise their deaf children. A centre for the Deaf could provide information and advice on various aspects of deafness and parenting, such as different modes of communication, psychological counselling services, educational services for deaf children, access to institutions for learning sign language, assistive hearing devices, and avenues for financial support among other things. It is envisaged that such a service to the deaf community would be better served if it is located in a central city (in each of the provinces) that has good transport infrastructure, to enable easy access.

A centre for the Deaf could be located at universities and maintained by the Faculty of Education where the Deaf can benefit from appropriate research and services of educational psychologists and guidance counsellors. Further, they can also have access to support services of professionals from other related faculties such as Health Sciences, (in particular, the Departments of Audiology, as well as Speech and Hearing Therapy), and the Faculty of Humanities, (in particular the Department of Psychology). Personnel from the Faculty of Education could be responsible for the smooth running of such a centre.

Alternatively, such a centre could also be located within a well-known medical facility in that city (*e.g.* provincial or private hospital), so that links to, and networking with, relevant medical and other sources of help (*e.g.* audiologists and psychologists) can be more easily managed by an already existing management control office.

Such a centre is envisaged primarily as an information dissemination point, not requiring many people to maintain its core function, and relying on normal office hours together with a good technologically advanced communication network. It is important that members of staff at the centre are easily approachable and competent in speaking the most used languages in the particular region (*e.g.* Zulu, Afrikaans or English in KwaZulu-Natal).

#### **5.3.4 Employment and higher education opportunities for the Deaf**

Several parents spoke of the stigma they experienced in relation to the general public. This stigma seems to find expression in terms of access to employment for deaf persons. Since the findings show that the majority of hearing parents are concerned about the future of the deaf child, and have serious concerns about the extremely limited opportunities for deaf people, it is clear that not enough is currently being done to accommodate deaf people in society adequately. Although the Employment Equity Act No. 55 of 1998 makes provision for people with disabilities to be afforded opportunities for employment, there is a strong need for workable mechanisms to be put in place to enforce the implementation of this policy. Work opportunities do exist in which deaf persons can play an equal role to hearing persons (such as in the Information Technology environment), but they are often overlooked. Prejudices such as these need government intervention if change is to come, and urgent action is needed to bring about such change. Here again, awareness-raising has a role to play, and society needs to be more welcoming towards deaf persons, in order to be truly inclusive.

With regard to the lack of opportunities for deaf persons in gaining access to tertiary education, parents' concerns in this regard need to be addressed. The dire shortage of qualified sign language interpreters is cited as one of the obstacles in this regard. Universities and technikons could offer bursaries to potential students to attract them to register for diplomas and certificates that would equip them to become qualified sign language interpreters. In addition the Department of Education, the Department of Trade and Industry, as well as and the private sector could be tapped for resources that would provide financial assistance in this field to potential students.

Further, opportunities also exist for technological devices to be created that could convert the spoken word to a written form, in order to assist deaf students to gain access to information, and participate in discussions that take place during lectures and tutorial sessions. To this end, Higher Education institutions need to liaise with computer software business sectors, such as Microsoft, to provide such a service, so that deaf persons would be able to cope better with higher education studies.

Another barrier cited by parents regarding access to tertiary education is the cost factor. In terms of the costs associated with higher education, arrangements should be made by the parents or the tertiary institution for the private sector to fund deaf students' studies, with the proviso that deaf students would be apprenticed to the same business, and upon completion of the qualification, become employed by that business (such mechanisms in the private sector are already in place for hearing students). Such a reciprocal arrangement would be mutually beneficial to both deaf persons as well as the business sector. With regard to time frames, this is considered to be a medium-term goal. Financial issues are not only confined to tertiary education for deaf persons, but also extend to other aspects of parenting deaf children. This will be addressed in the next recommendation.

### **5.3.5 Financial assistance**

Most of the parents in the study mentioned that their medical aid provider did not cover the medical costs associated with their children's deafness, and indicated that their inability to meet these costs proved to be a source of great stress in their lives. Even the costs of externally worn hearing devices were beyond the budget of many parents, some of whom embarked on fund-raising drives to raise money to pay for hearing aids. Clearly, appropriate measures need to be implemented so that medical aid providers could alleviate the financial distress of parents.

The Department of Health and Social Welfare could be urged to make hearing aids freely available to deaf children. Failing this, the large majority of economically disadvantaged people affected by deafness will continue to be marginalised. Parents and educators should lobby for this, as well as for an increase in the allocation of social welfare grants for persons with disabilities, including the Deaf.

Moreover, the cost of transport to and from schools for the Deaf is a drain on the pocket for many parents, as these schools, being few in number, are usually situated very far away from their homes. The Department of Transport needs to subsidise the transport of deaf children to a greater degree, and thus ease the financial burden of parents. The role of government is important here. Appropriate policies and their implementation can

have beneficial consequences for parents of deaf children. Government intervention is required to enable funding to be made available to parents of deaf children. The business sector also has a role to play in terms of their community service programmes, and could be called upon to fund the transport of deaf children to and from school.

### **5.3.6 Public awareness programmes**

Since the findings reveal that an overwhelming majority of parents report a need for the public to be better informed about deafness in order to understand the issues facing families of deaf children, the recommendation here is for public awareness programmes to be arranged to educate the population about the concerns, issues, problems and obstacles families of deaf children have to face. This will help minimise the negative, unsupportive attitudes of the public that cause many parents heartaches and make them feel like social outcasts. A better understanding of the situation on the part of the general public can exert a positive influence on the quality of life and emotional well-being of parents raising deaf children, and in so doing contribute towards building an inclusive society.

Public awareness programmes could go a long way to alleviate the unnecessary stressful experiences of parents as they raise their deaf children in the midst of hurtful and damaging encounters with the general public. Newspaper journalists and public broadcast services specialising in social justice awareness-raising programmes can play an effective role here. Likewise, other agents such as government and religious organisations can also elevate the importance of social justice and respect for diversity in the public consciousness.

Educational programmes at school should include strong deterrents to unacceptable public attitudes towards the Deaf. The Life Orientation Learning Area is the appropriate point at which educational interventions can be made. The Department of Education, through the promulgation of appropriate policies, can play a significant role in monitoring this process through the district offices and specific ward managers.

## **5.4 SIGNIFICANCE OF THE STUDY**

The significance of this study lies in its contribution to the body of knowledge in the field of parenting of children with special needs, and in particular, deafness. Through the voices of hearing parents raising deaf children we get a glimpse of their struggles (and also victories) as they come to terms with deafness in the family. Parents, especially mothers, exhibit resilience and a firm, deep resolve in their commitment towards providing the best opportunities for the advancement of their deaf children within the context of a society grappling with accepting diversity. Often, they find themselves constrained and/or marginalised in their efforts to construct meaning and identity for themselves as well as their deaf children within a hearing world that does not appear to be very welcoming towards them (in terms of being truly inclusive). The rich stories of their struggles and triumphs contribute to a deeper understanding of the phenomenon of how the parenting of deaf children is experienced by hearing parents. The study, in affording hearing parents raising deaf children the opportunity for their voices to be heard, also gives us a glimpse of how others in the family, school and community contribute towards the construction of the deaf child.

The findings emanating from the data reveal that hearing parents face many challenges relating to the parenting of deaf children, and the implications of the findings indicate a need for change in policy, infrastructure, facilities and support services that will help parents cope more efficiently with their responsibility. Access to better facilities and resources such as formal and informal support services, as well as funding, will help reduce parental stress. Progress of this kind will contribute to the emotional well-being of parents and in turn, the well-being of their deaf children. The importance of all levels of the ecosystem contributing to building an inclusive society, in which hearing parents of deaf children can function optimally, has already been shown. However, it must be noted that systemic change is not easy to achieve, as it requires transformation of attitudes, mindsets and beliefs towards the sharing of a common ethos amongst people.

## 5.5 LIMITATIONS AND RECOMMENDATIONS FOR FURTHER STUDY

This study focused on exploring the experiences of hearing parents raising deaf children. It did not include the experiences of deaf parents raising deaf children, and the voices of other members of the deaf child's family.

Although the study aims at exploring the phenomenon of hearing parents' experiences of raising deaf children in South Africa, the research sites include only three provinces, selected on the basis of their having the highest number of schools for the Deaf in the country. The under-resourced provinces, some of which have higher numbers of deaf persons, are not included in this study. The study may therefore be constrained in that it does not tap into the voices of parents in the under-resourced provinces.

Recommendations for further study include:

- broadening the scope of research to include economically disadvantaged provinces so that a broader perspective of the phenomenon under study can be achieved
- including deaf parents in the sample to draw comparisons between the experiences of hearing and deaf parents raising deaf children
- exploring the experiences of educators of deaf learners
- extending the study to include a deeper insight into the psychological well-being of parents
- exploring the experiences of deaf children so that their voices may also be heard
- Conducting a tracer study of deaf children.

## 5.6 CONCLUDING REMARKS

*“You know with some people deaf children don’t look like they’re a person...and then they are mean, ‘Oh you’re swak (weak)’... ‘Don’t call it because it’s isithuli lento (that thing is deaf)’. I was very, very hurt because I felt that maybe my child was not welcome in that area...”*

(Constance, participant: 2006)

The above quotation clearly highlights that the attitudes of others nested within the family, extended family, school and the community at large contribute in no small measure to the challenging experiences that bear on parents in their pursuit of providing the best they can for their deaf child. The partnership approach to the learning and development of the deaf child, based on the premise that it takes an entire village to raise a child (Swart & Phasha, 2005: 214), can only contribute positively to the emotional well-being of hearing parents raising deaf children. Such well-being will lead to positive spin-offs for the improvement of the quality of life of their deaf children.



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**STRICTLY CONFIDENTIAL**

# **Questionnaire**

**HEARING PARENTS RAISING DEAF CHILDREN**

**MRS. V. JOHN**

**St. No: 951058567**

Dear Parent

## **QUESTIONNAIRE: HEARING PARENTS RAISING DEAF CHILDREN**

At present I am engaged in a research project towards my PhD degree at the University of KwaZulu-Natal under the guidance of Prof. N. de Lange (*tel*: 031-2601342). The research is concerned with the factors influencing the way hearing parents manage the role of parenting deaf children.

I have taken the liberty of writing to you, as one of the selected participants in order to seek your assistance in acquiring information about factors influencing your experience of raising a deaf child.

I believe that the recommendations that emerge from this study will improve the circumstances for the Deaf in this country. Your input therefore will be highly valued.

### **CONFIDENTIALITY**

All the information will be regarded as CONFIDENTIAL and no personal details of any participant will be mentioned in the findings, nor will any of the results be related to any particular parent, child or school.

Your co-operation will be deeply appreciated.

Yours sincerely

---

Mrs. V. John

(*tel*: 031-4043973 ; *work*: 031-2603614)

Date: \_\_\_\_\_

### INSTRUCTIONS TO PARTICIPANT

1. Please read through each statement carefully **before** giving your opinion.
2. Please make sure that you do not **omit** a question, or skip a page.
3. Please be totally **frank** when giving your opinion.
4. Please **do not** discuss statements with anyone.
5. Please **return** the questionnaire after completion.

Kindly answer **all the questions** by supplying the requested information in writing, or by marking a cross (X) in the appropriate block.



## SECTION ONE: BIOGRAPHICAL INFORMATION

### 1.1 Relationship of participant to deaf child?

Mother ☐

Father ☐

Grandparent ☐

Guardian ☐

Other (please specify) ☐ \_\_\_\_\_

### 1.2 Gender of participant

Male ☐

Female ☐

### 1.3 Home language:

English ☐

Afrikaans ☐

Zulu ☐

Other (please specify) ☐ \_\_\_\_\_

### 1.4 Age (in full years) of deaf child \_\_\_\_\_

### 1.5 Age at which child's deafness was discovered? Years \_\_\_\_\_ Months \_\_\_\_\_

Question	Statement	Yes	No	Uncertain
2.1	The cause of my child's deafness was:			
	<input type="checkbox"/> Genetic (hereditary) factors			
	<input type="checkbox"/> Maternal rubella (German measles)			
	<input type="checkbox"/> Use of alcohol during pregnancy			
	<input type="checkbox"/> Encephalitis			
	<input type="checkbox"/> Meningitis			
	<input type="checkbox"/> Otitis media (middle-ear infection)			
	<input type="checkbox"/> Injury during birth (forceps)			
	<input type="checkbox"/> Shortage of oxygen (asphyxiation) at birth			
	<input type="checkbox"/> Loud noise, for example, explosion			
	<input type="checkbox"/> Other (please specify): _____ _____			
2.2	I am aware that if I have more children there is a possibility that they could also be deaf.			
2.3	I experienced the following emotional responses on learning of my child's deafness:			
	<input type="checkbox"/> shock			
	<input type="checkbox"/> anger			
	<input type="checkbox"/> guilt			
	<input type="checkbox"/> anxiety			
	<input type="checkbox"/> depression			
	<input type="checkbox"/> Other (please specify): _____ _____			
2.4	The experience of having a deaf child had the following effect on our marriage:			
	<input type="checkbox"/> we became closer			
	<input type="checkbox"/> we were separated			
	<input type="checkbox"/> we got divorced			
	<input type="checkbox"/> we blamed each other			
	<input type="checkbox"/> we decided not to have any more children			
	<input type="checkbox"/> it did not affect us			
	<input type="checkbox"/> we sought counseling to save our marriage			
	<input type="checkbox"/> Other (please specify): _____ _____			

Question	Statement	Yes	No	Uncertain
2.5	The attitude of my extended family towards me has been positive.			
2.6	My deaf child is fully accepted by other children in the neighbourhood.			
2.7	My relationship with the Transcendental has been affected in the following way/s since the birth of my deaf child:			
	<input type="checkbox"/> I am closer to God			
	<input type="checkbox"/> I think God is punishing me			
	<input type="checkbox"/> I have changed my religion			
	<input type="checkbox"/> I stopped believing in God			
	<input type="checkbox"/> God has made me a better person			
	<input type="checkbox"/> My relationship with God has been unaffected			
	<input type="checkbox"/> Other (please specify): _____ _____			
2.8	Some of the challenges facing me as a parent of a deaf child are:			
	<input type="checkbox"/> financial burden			
	<input type="checkbox"/> social isolation and stigmatisation			
	<input type="checkbox"/> limited educational opportunities			
	<input type="checkbox"/> transport to and from school			
	<input type="checkbox"/> uncertainty about my child's future			
	<input type="checkbox"/> communication problems with my child			
	<input type="checkbox"/> concern about my marital relationship			
	<input type="checkbox"/> lack of support services such as parental counselling in my neighbourhood.			
	<input type="checkbox"/> Other (please specify): _____ _____			
2.9	I had to find work for the benefit of my deaf child.			
2.10	I had to give up work in order to take care of my deaf child.			
2.11	I had to relocate (move home) for the sake of my deaf child.			
2.12	My medical aid scheme covers the costs associated with my child's deafness.			
2.13	I am concerned about my deaf child's future.			

Question	Statement	Yes	No	Uncertain
<b>2.14</b>	My deaf child attends:			
	<input type="checkbox"/> A day school for the Deaf			
	<input type="checkbox"/> A mainstream school with hearing children			
	<input type="checkbox"/> A boarding school for the Deaf			
	<input type="checkbox"/> A mainstream boarding school with hearing children			
<b>2.15</b>	I believe that it will be to the advantage of my deaf child to be at a mainstream school.			
<b>2.16</b>	Parents and teachers are jointly responsible for the education of the child.			
<b>2.17</b>	I can communicate effectively with my deaf child using the following mode/s of communication:			
	<input type="checkbox"/> Sign language			
	<input type="checkbox"/> Oral communication			
<b>2.18</b>	The mode of communication I use with my deaf child is the same as the medium of instruction used at my child's school.			
<b>2.19</b>	People need to be better informed about deafness in order to understand the challenges facing families of deaf children.			
<b>2.20</b>	I am aware of a support group in my neighbourhood.			
<b>2.21</b>	There is a need for a support group in my neighbourhood.			
<b>2.22</b>	I require information about my deaf child's future prospects for a marriage partner and/or having children of their own.			
<b>2.23</b>	I require information about the vocational possibilities for my deaf child.			
<b>2.24</b>	I would like to obtain information about various matters pertaining to deafness at one central place.			
<b>2.25</b>	I require assistance in raising my deaf child with regard to the following:			
	<input type="checkbox"/> Financial support			
	<input type="checkbox"/> Psychological counselling			
	<input type="checkbox"/> Choosing the right type of school			
	<input type="checkbox"/> Choosing a mode of communication			
	<input type="checkbox"/> Other (please specify): _____ _____			

*Thank you for your time.*

## INTERVIEW SCHEDULE

The following question will be asked:

- *What is your experience of raising a deaf child?*

Based on the responses, further probing questions will be asked, *e.g.* :

- *What were the greatest challenges you encountered and how did you cope?*
- *What are your views regarding the establishment of a parent support group in the neighbourhood?*
- *What effect, if any, has raising a deaf child had on your relationship with others in the family, school and community?*
- *What advice would you give to other hearing parents of young deaf children?*

PARTICIPANT: Amy

Q1) *Thank you for your willingness to participate in this interview. As you know, I am gathering information for a PhD research project about the experiences of hearing parents raising deaf children. What are your experiences of raising a deaf child?*

A: Okay, my name is Amy. I have a son, Andrew, who currently is 14. Erm, we picked up when he was 6 weeks old that he had a hearing problem. At that time it was very, very early. His doctor did a very simple test, by rattling keys at him at the six week check-up. At the 12<sup>th</sup> week check-up, he did the same thing. He was fitted with hearing aids. The 3<sup>rd</sup> time, he was referred to the units for language and hearing impaired children in Parktown, at 4 months and at 4½ months, he was fitted with hearing aids. At that point in time he was probably the youngest child fitted with hearing aids... He was not the easiest child. He was sick in the beginning. He did not sleep. I then found out he was deaf and I think if I could have, I would probably have given him back. Er, in fact, I really did not like him very much. I had no option but to love him because he was my child, but I really did not like this child for a very, very long time. It took a long time and a lot of soul-searching, and 'what have you' to come to terms with the fact that it's okay not to like your child, which is something I try to tell these parents here when their children are throwing tantrums, that you don't have to like your child. But you still love your child irrespective of what they do to you. My dear son is 14 years old and he is bigger than me. He has a sense of humour which is very dry, and he can make you laugh immensely and I like him now as well as love him. So, we have come a very, very long road – which has been *very* difficult. Erm, I still don't know why I've been given a deaf child; ...when I sit here and do things like this, and talk to you – when I sit here and talk to other people about their children, or, I've just recently come back from 2 weeks of selling Christmas cards and have promoted the school, and spoke to other parents who became involved with things like cerebral palsy or muscular dystrophy, because they had children in the same situation and then you realise that – that's why you get involved in a particular thing, I think, because your child has a particular problem. Having been on both sides of the desk has made me have a lot of sympathy for parents. I'm not only the authority who should actually sympathize with the mother who brings her child in here and says, "You know why I'm crying?" – because I actually do know why you are crying. It's the final step in acceptance of the fact that your child has to come and register for a special education programme.. or, 'normal' education has actually been shattered. We recently started a support group for school and erm, the one thing we've tried to ban all parents from saying is that their child is not 'normal'. Your child *is* normal. Your child may be deaf but he is normal. He may be normal in your life, but he may not be 'normal' in my life... I live done the road and normally it takes me 5 minutes to drive home, and you may live 2 hours away; it normally takes you 2 hours to drive home'. We are a normal school; we have normal periods; we teach normal subjects; we have normal exams. The only difference is that we teach it in two languages. That's normal for us. If we get the parents to see that their children are "normal", but different, we can break a huge barrier. I accepted very early that my son needed sign language, because we started at 4 months and he learnt to speak through sign language – immensely! It means going to shopping centres with this baby with hearing aids on. A lot of people would look around, and gawk

at this child with hearing aids on his ears. I could have dived through the floor. I was so embarrassed... And then we had to learn to talk sign language, and sign language was still very much new. It wasn't like it is today on TV: "Phew, sign language is politically correct, and that's normal and 'what have you'. And: *ooh*, that's wonderful! I want to learn sign language". It was very much something nobody knew anything about, and everybody would stare at you – and I was so embarrassed. Today, I'm not embarrassed. Now, I can get up and sign and talk a lot too, ...and you can also communicate when you are over there and I am over here (participant gestures). So it's another skill that one's learnt. So that's it. You kind of 'got through' that, ...but I addressed the parents again about discipline – and when I sat and realised how much we've been through, and how hard the road was, I don't want to do it ever again, ever again, because it was hard! He had tantrums! My son is very clever. I was very fortunate in that. He had hearing problems – he was profoundly hard of hearing, and he had auditory processing problems. If he had only hearing problems he could have been mainstreamed, maybe, but the processing problems meant that he needed visual aid to learn. Erm, it balanced out because he got less dependent on sign language. He threw tantrums – anywhere, everywhere, and for everything. And he used to walk around with knobs on his forehead. He used to look like a 'backward' child. How people did not report me to the police is beyond me! He threw tantrums once in *Checkers*, where he hit me – and we hit each other, and the only reason I won was because I was bigger. He threw a tantrum in the Hypermarket one Thursday night where he thumped himself into a trolley and he has these great big trolley marks on him.. And I don't ever want to live through that again; and when I see people whose children have tantrums... honestly, jokes aside, it's a nightmare. He was really very difficult, so we actually decided that we wouldn't have any more children. Andrew had fever. It was pretty terrible, because they had to hold him down and take blood out of his jugular vein. And this child was also not fun; again, he landed up in hospital with convulsions, and he really was very ill – he had high temperatures... So Andrew did everything he could to put me off children, not only being deaf. I had a second son, by accident. (*interviewee is distracted by a learner on an errand, who had come to see her*)...

As his ability to communicate got better, and his vocabulary grew, so his level of frustration became slightly better. We could communicate and sort of discuss – rationalise things a bit better.. And we generally run sign language classes here for this reason. The thing is, these children live in continuous frustration and they're a nightmare to teach, because you... (*phone rings; interviewee answers call*) And in all of this, with Andrew, I have decided – or my husband really had decided – we wouldn't have any more children, because I was an only child. He (husband) was... he's one of three. Erm, and he was really very difficult – so we had actually decided that we wouldn't have any more children, but as it turned out, I ended up having a second child when Andrew was 4. And the second child turned out to be a walking, talking – he swallowed a dictionary at birth – and he's perfectly fine, and he's 'whatever', he's everything that the other one is and more, and he can talk. When Andrew was very young, after we'd found out that he had a hearing loss, we had to go through this whole thing of genetic counseling, which was very basic at that time. They hadn't... they couldn't tell you much more, except that we had a one-in-six chance of having another deaf child...

Okay, we went through preschool; preschool was wonderful. The preschool was actually a really good place for him to be in. It was a good place for children who are deaf to be in. They did hearing children, children with language problems and hearing problems. ...They kind of 'kicked your butt' if you were feeling down and kept you going on the road.. But in a really good way... When he was 6 we had to decide where he was going to go, and we came here to (this school). There was a lady, who's no longer teaching, and there was another little girl who's still here today... Andrew sat there, almost like an alien had come home to land. He was absolutely mesmerised. You could have left him there, and gone away and fetched him, and an hour later he would still have been mesmerised. It was like he'd finally found where he needed to be... And at that point, I felt sick, when I realised – just like those mothers who 'sit there' and cry for their kids, it's just ... It's when you have to accept that your child is not 'normal', does not conform to society's norm. It wasn't a great feeling at all. He...

Q 2) *Erm – Amy, you mentioned that it was quite a tough life bringing Andrew up and how did you cope with the challenges and what were the greatest challenges?*

A: *Ja.* Erm, you cope, I think, depending on how you cope as a person with life – if you're going to sit in a little corner and not deal with things, irrespective of what kind of things they are, I think that's how you'll deal with things. Erm, I reckon – you have to actually be proactive in whatever you do in life, and that doesn't matter what it is, okay? Obviously – some stuff, you don't know, and when you're given a deaf child you don't know anything; when you're given any child, you don't know anything. One needs to find out stuff. I was lucky I was given advice, I was helped, I was pointed in the right direction with everything that we did, and I was fortunate. Most of the people are not that fortunate. My paediatrician pointed me in the right direction – pointed me to a preschool. I then came here, and then Andrew did, from grade 1.. he did grade 1 and 2 in one year. He did grade 6; he was working with the grade sevens. The grade sevens then, were supposed to go to grade 8, and they wouldn't put Andrew up to grade 8 because he was too young. So I needed to find something... I needed to do something with the year, productively. So, I went down the road to ... School. After having had a psychological evaluation, the lady that did the test told me that he had to stay in a manual environment, and I wouldn't accept that. That's one thing that Andrew has taught me – to question authority, not badly, not rudely – but to question it. To stand up for my rights and to stand up for his rights. Actually, more his rights than my rights, really.. So the principal of that school also taught at this school. She also taught Deaf Education, and then she came to study Remedial Education. I didn't move Andrew to mainstream; I moved him to remedial education – small classes, where he would cope. They had a challenge in that he was the first deaf child that they had had. So, it worked out very well. At the end of last year, he was their top grade 7 pupil. He got a merit award for being academically first, he got a merit award for what he had done, for what he had achieved as a deaf child. Erm, we're going to have to find a high school for him, and here we have to redo the whole thing: "where do we go from here?" ...And we're going to have to redo it again when he finishes grade 12. Because there's so little open or available to the deaf, and because they can cope in so few environments, (erm) they cannot cope in a lecture-hall of 200



students. So your options become limited. He's no longer dependent on sign language, but for those that are dependent on sign language, there are very few interpreters. So, that cuts down what options a child can do. He's very clever. He's very bright, and he loves Science. I don't know where he's going to end up. He would like to do something scientific. We're going to hit a lot of brick walls when we get there, and I don't know how we're going to overcome them, but we'll get there. We seem to have done very well so far. Erm, the interview to get him into Remedial School was a nightmare. They just couldn't cope with the fact that they couldn't timetable Afrikaans – Andrew needed something different for Afrikaans. And (erm), down the road from us is another school, and they run something called ..., which is a small class inclusion programme. Erm, – it's been running since last year – it's initially was from grade 7 through to matric. It has actually been such a success, that from next year, they'll be running it for the whole school. So they've obviously found out that it's a very valuable service to children who can't cope in big classes. And when I went to the interview, their principal was so accepting of the fact that Andrew was different, not abnormal, but different. He just said, "You'll do what you're doing now. You'll sit in the front, you'll lip-read, if you can't understand, you'll make the teachers repeat", and then he patted him on the shoulder and said, "Don't worry my boy, we'll take good care of you". And Andrew's been very, very happy there. He's made friends with hearing children, which he's always done. He's got a couple of deaf friends, and although he associated very well and fitted in very well here, he has got a lot of hearing friends. He seems to have a very good way of.. well he seems to be very bilingual. He'll switch off his voice in this school, when he comes and visits here, and he'll switch off his hands up there. So he's very bilingual. Erm, almost like you switch Afrikaans and English. You can't have a working.. but you're either Afrikaans or English, you don't kind of speak a mix of both. He does exactly the same thing.

*What is your advice to other hearing parents of hearing impaired children?*

My advice to other parents is that they don't sit back and they don't accept what people tell them in terms of the fact that, "Oh no, don't worry, there's nothing wrong with your child". If you live with your child long enough, and your child doesn't respond to something, and you think that there's a problem, pursue it, because we see children coming in here that are 3, 4, 5 – by which time it's so late that you cannot make up for the first three years of a child's life. And, the disadvantage you place your child in can never be made up. If you know your child well enough, and you feel in your heart there's something wrong, go and see another person. And go and see another person. But, don't jeopardise your child's future by accepting it if somebody else says that there's nothing wrong – if you really, really believe that there is something wrong. I learnt to question things that people told me, and I once had a really big argument with an audiologist from America who told me that my son had a high frequency hearing loss, which he doesn't have. He's actually got extremely good high frequency hearing. And the man told me I was wrong; and I wasn't wrong, I actually was right. But it took many years before we could actually get a perfect audiogram from him, because he was just not ..... And that's all I can say – it's hard, it's tough, it's a slog, and who wants to do it? None of us want to do it. I don't know why we're given deaf children, I don't know why we're given things that we can't cope with or that we fear we can't cope with, but the fact that you've got it

doesn't mean that you must now 'sit in a corner' and leave your child. You have to, at the end of the day, do what you did for your hearing child – and that is: the best you can. And, sometimes that means that you've got to send your child to a school that's further than what the school down the road is; in my case, it's not. I've lived in my house for 20 years; this is one of the closest schools. It just happened like that. Again, it's one of the things that happened. It's very odd – almost like something had been planned. Erm, the rewards as a mother of a deaf child are very, very small, and they come after a lot of very hard work. A child will absorb a lot and it will seem like you're getting nowhere – absolutely nowhere – and then, all of a sudden, you get a response. Like, your child will turn around and say, when you're walking past, "That's a waterfall". And you will have worked and worked and worked, and all of a sudden that spark of recognition will be your little reward. And it will be such a brilliant moment that you have to enjoy those bits, because they don't come often – they're like, few and far between – but they're actually very valuable. They're kind of a reward for all the hard work that you did.

Q 3) *So, Amy – from what I gather, it's been a really tough go, but there have been these moments of rewards, when you really appreciated the positive signs that came through from your child. Now, in terms of parents benefiting from one another's experiences, do you think it's necessary to set up a support network for parents? What do you think about that idea?*

A: I think that it's very, very important – worth trying even in our own school, to set up some kind of parental support group, so that the parents ...feel that they're not alone, and they don't feel that they're the only ones that have this problem. I think that's your initial problem. When your child is diagnosed as being deaf – you actually feel isolated, and that you're the only person in the world that's ever had this problem. Once you realise, and once you start coming to school and you see that there's all these other kids and they're kind of at school and they're at high school, and other parents have survived this, and their kids have gone onto tertiary education – and stuff like that, then you tend to realise that there is, kind of, 'life after death'... this is what we're trying to get going here, but it's very, very difficult to join people into it. We've had 2 parent workshops this year; and the parents actually did come, and our biggest shock was how many parents had not as yet, even if their children were in the high school, accepted the fact that their children were deaf... And if you don't do that, where are you going to start? Because if you don't accept the fact that your children function in a different language to you, how are you ever going to overcome any of the other obstacles that are in their way? And there are.. there are *huge* obstacles, even to something like – interpreting something on TV for you child, which you have to do. It becomes a pain; it is a pain. It's annoying; "what's he saying; what's he doing; why is he doing that?".. you can't exclude your child from stuff all the time, and my biggest.. the thing that 'hits me in the face' the most is: if you don't learn sign language to communicate with your child, how do you tell your child you love him? How do you tell your child you're proud of him/her? How do you tell your child: "I'm angry with you because..."? Are you just going to have this person growing up in your house, sort of separately, but together?

Communication, *ja!* Because your child is already isolated in the community. How can you isolate your child in your own family? And then not expect the child to feel anger, or rejection, or those kind of things within their own home? And you now have to produce a person that's functional in the community, and produce a person whose capable of going out, having a laugh, being a functional part of society, and in turn, having a family.. getting married, and all those things that we do. Unless, you instill values in them, and all that kind of stuff that your parents did to you; if you can't communicate those things, it's not up to the school to do it. The school and the parent have to function as a partnership. What the parents are doing – is that they're bringing their child here and saying: "Here's my child. My child's deaf. You're doing everything". You can't, because there are cultural values and all sorts of other things which we can't possibly begin to do. If we discipline the child, there's no discipline from home. There's all sorts of other stuff that become an issue.

Parents need to accept the fact that they have to learn sign language, to communicate with their children. Erm, not many children can lip-read or understand enough of our language to be able to cope at home. And, the first level of functioning of English and sign language is in our schools. So, they're learning English, they're learning sign language, then they go home to a third language. Erm, and they battle – they struggle. They don't get support, they don't get anything.. And they become a 'dunce'. Mustn't daddy be fortunate, because he had support, he had help, he had everything he could possibly want.. And that made the difference, and that's why he was able to go out there, and keep his head above water and hold his own... because of the fact that he had all this – this whole framework in place (*ja*).. But unless – until you become – it's like an alcoholic, I think: you have to accept the fact that you are, before you start going into the programme. I think that's what they used to say about alcoholics, but unless you accept the fact that your child is deaf, you don't even start beginning to deal with all the other issues of grief and anger.. and it is a whole process that you go through – you go through grief and anger, and it is – you grieve! Because all those dreams you had are shattered. You go through anger, like me, you go through all those processes – your dreams are shattered. Until you deal with all of those things and can come to the conclusion that your child is normal, your child is functional, your child is a child and you need to mother it, you actually – people just cast these children aside and don't treat each child as a child to love, gift from God, whatever you want to call them, I don't know.. but it's a child, just like your other 5 or 6 or 2 children are. I don't know what else to say.

Q 4) *What effect if any, has the raising of a deaf child had on your relationships with others.*

I have a small family, erm, my parents are both deceased, I don't have brothers and sisters, I have a very small family, I'm doing very well with my husband's family. I have an issue with my husband – seven years ago he fell off a ladder, and he has some brain trauma, which has made him not a very nice person. So, we have issues there. Erm, I can't actually say that that's kind of a normal situation, but if you take what's normal in our school, you'll find that many of our families break up. And a lot of people who have time, they either can't take the blame or they can't take the strain, or one of them's too

busy doing stuff, and the other one goes. My husband did not accept much responsibility, and still does not accept much responsibility in terms of the education process. Erm, that's the kind of person he is.. but otherwise, in terms of getting on with my family, my mother did not accept the fact that my son is deaf. She couldn't come to terms with it.. And my husband's parents had accepted the fact, and funny enough, my mother-in-law has a great grandchild who is blind, so she actually has 2 disabled children in the greater family. I know several people who have other disabled children, CP and stuff like that. I don't know if...and I don't know if it's just his nature, I don't know.. I really don't know. He's friendly with a deaf child here who is supremely clever. He's actually one of the cleverest children who came in a very long time.. But he's also friendly with other kids who really have not much...interesting. It's been very interesting. God's given me Andrew, to teach me passion...o do anything with it, but take stuff and deal with it, and go through the motion, and accept the fact that you can't change Andrew; you have to 'go with the flow', (erm) and...other stuff, or we could have been living in a squatter camp, or we could have been 'dirt poor', or.. so as bad as things were, I still had to be faithful for my mercies, as they were, 'cause they were really not that bad – I still have some kind of access to resources. So.. and my son is really bright.

*I just want to say thank you so much Amy, for sharing your thoughts, emotions and experiences with me.*

Sure! It's basically what I lived!

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**ETHICAL CLEARANCE APPROVAL: HSS/06208A**

University of KwaZulu-Natal

Please see bound thesis for actual hard copy of Ethical Clearance Approval HSS/ 06208 A, signed by Ms Phumelele Ximba, from the Research Office at the Westville Campus, dated 08 August 2006.

122 Damorosa Crescent  
Moorton  
Chatsworth  
Durban  
4092

17 November 2005

*for att:* CIRCUIT MANAGERS / THE SCHOOL PRINCIPAL / CHAIRMAN OF THE  
SCHOOL GOVERNING BODY

Dear Sir / Madam

### **REQUEST FOR PERMISSION TO CONDUCT RESEARCH**

I am a PhD student at the University of KwaZulu-Natal and am currently engaged in a research project entitled “An ecosystemic perspective of hearing parents raising deaf children. A mixed methods study”.

This research is conducted under the supervision of Prof. N. de Lange (*tel:* 031-2601342) of the School of Education Studies, Faculty of Education.

The aims of this study:

- To explore the experiences of hearing parents raising deaf children
- To explore the various ecosystemic variables that influence the way hearing parents raise deaf children
- To generate guidelines in the form of recommendations with regard to facilitating the emotional well-being of hearing parents and in turn, the well-being of their deaf children.

In order to complete this study. I need to send questionnaires to hearing parents of deaf children attending schools for the Deaf as well as conduct interviews with some of the parents. Each interview will last approximately 45 to 60 minutes and will be audiotaped,

transcribed by myself as the researcher, and the findings will be verified by an independent coder.

The researcher will ensure the anonymity of the participants and their children's schools by omitting the names of the participants and the schools. Pseudonyms will be used instead of actual names. The researcher will ensure the confidentiality by destroying the taped information on completion of the study.

The participants (parents of deaf children attending your school) are under no obligation to participate, and reserve the right to withdraw at any stage during the research process.

Benefits of the study to participants:

- Participants will be given a chance to verbalise their experience and have their voices heard.
- The researcher will use the findings to generate guidelines in the form of recommendations to facilitate the emotional well-being of hearing parents raising deaf children.

The key question that will be asked is, "What is your experience of raising a deaf child?" Depending on the responses, further probing questions will be asked, *e.g.* :

- *What were the greatest challenges you encountered and how did you cope?*
- *What are your views regarding the establishment of a parent support group in the neighbourhood?*
- *What effect, if any, has raising a deaf child had on your relationship with others in the family, school and community?*
- *What advice would you give to other hearing parents of young deaf children?*

Permission is sought to interview at least 4 parents of learners at your school, and your assistance in scheduling interviews with parents and distribution of the questionnaires will be appreciated.

Should permission be granted to conduct research at your school, it would be appreciated if you could complete, detach and return the consent form on the following page.

Thank you for your support.

Yours faithfully

\_\_\_\_\_

Mrs. V. John

(*tel:* 031-4043973 ; *work:* 031-2603614)

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**ACKNOWLEDGEMENT OF CONSENT TO CONDUCT RESEARCH:**

Mrs. V. John

Your request to conduct research at our school bears reference. You are hereby granted consent to conduct research at our institution.

Signed at \_\_\_\_\_ on \_\_\_\_\_ 2005

Circuit Manager / School Principal / Chairman of School Governing Body

Signature: \_\_\_\_\_



122 Damorosa Crescent  
 Moorton  
 Chatsworth  
 Durban  
 4092  
 05 December 2005

Dear Parent

### **REQUEST FOR CONSENT TO PARTICIPATE IN RESEARCH**

I am a PhD student in the Faculty of Education at the University of KwaZulu-Natal. I am currently engaged in a research project entitled, "An ecosystemic perspective on the raising of deaf children by hearing parents in South Africa." This research project is conducted under the supervision of Professor N de Lange (School of Education Studies).

The primary aims of this research project are to explore how the ecosystem (family, school and community) influence the way hearing parents manage and deal with the raising of their deaf children, and to explore the experiences of parents in this regard. The secondary aim is to reflect on the data and to generate guidelines in the form of recommendations to facilitate the emotional well-being of hearing parents, and in turn, the quality of life of their deaf children.

In order to generate data, it is necessary for hearing parents of deaf children attending schools for the Deaf, to complete a questionnaire and to participate in semi-structured one-to-one interviews. Thus, you are invited to participate in this research project. The questionnaire consists of twenty-five questions and will take approximately thirty minutes to complete. The interview will last approximately thirty-sixty minutes, and will be audio-taped, transcribed verbatim by the researcher, and the data will also be coded by an independent data-coder. The audio tapes will be kept safely under lock and key and will be destroyed upon completion of the research study.

The following question will be asked, "*What is your experience of raising a deaf child?*". This will be followed by further probing questions if necessary, such as:

- "*What were the greatest challenges you encountered and how did you cope?*"
- "*What are your views regarding the establishment of a parent support group in the neighbourhood?*"
- "*What effect, if any, has the raising of a deaf child had on your relationship with others in the family, school and community?*"
- "*What advice would you give to other hearing parents of young deaf children?*"

The research project conforms to ethical guidelines and therefore, there are no risks involved with your participation. The benefits of participating in this research project are that you will be given an opportunity to verbalize your experiences, and for your voices to be heard. This will contribute to the formulation of guidelines to promote the well-being of hearing parents and consequently the quality of life of deaf children.

The anonymity of participants as well as their children will be ensured through the use of pseudonyms. Further, the name of the child's school will be omitted from the data presented. The data will be treated with respect and confidentiality. Participation is voluntary and there is no obligation to participate in this study. Participants reserve the right to withdraw at any stage during the research process.

If you are willing to participate in this study, please complete and return the consent form attached to this letter. You may use the self-addressed envelope enclosed.

Thank you for your support

Yours faithfully

Mrs. V John: Researcher

Professor N de Lange: Supervisor

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**ACKNOWLEDGEMENT OF CONSENT TO PARTICIPATE IN RESEARCH:**

I, \_\_\_\_\_, am willing to participate in this research project.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_