

CHAPTER 1: INTRODUCTION AND PROBLEM STATEMENT

1.1 INTRODUCTION

“Children are the touchstone of a healthy and sustainable society. How a culture or society treats its youngest members has a significant influence on how it will grow, prosper and be viewed by others” (Shonkoff & Meisels, 2000:10).

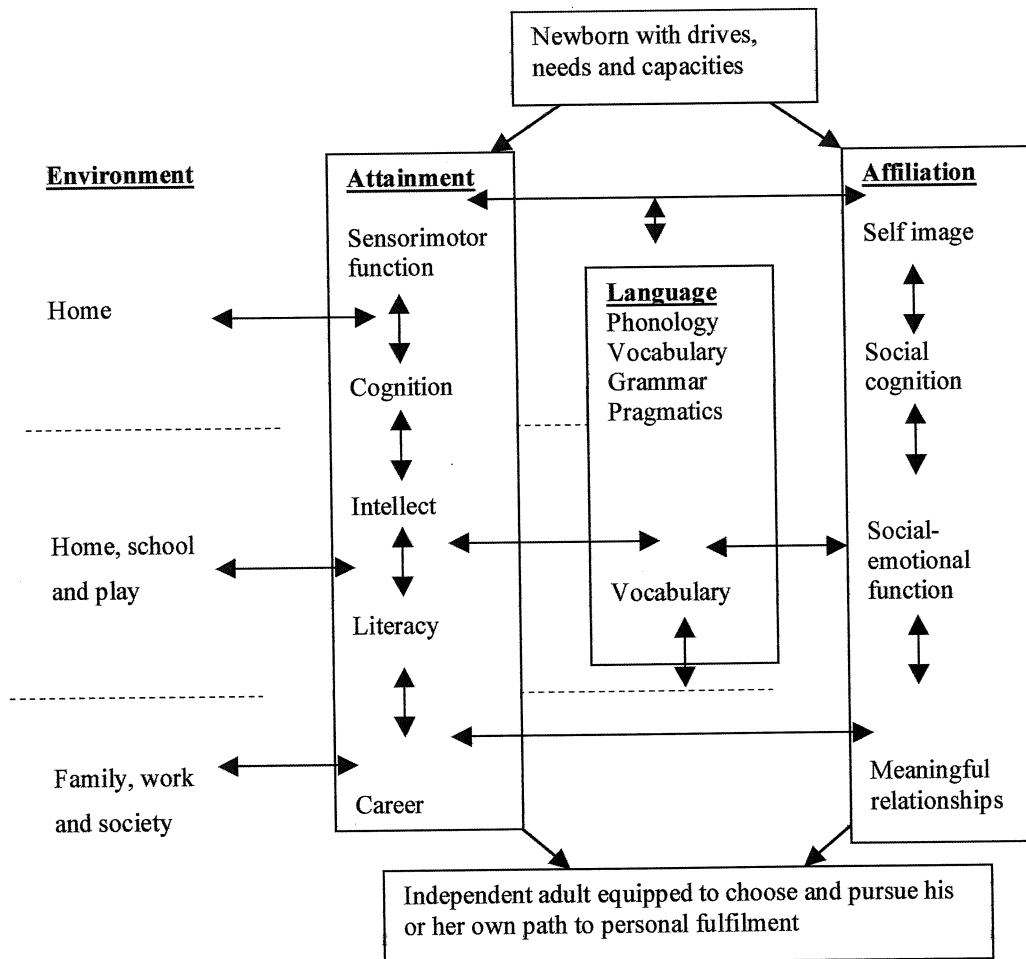
Normal hearing is the entrance to the world of sound for infants and children – a process that is necessary for normal speech and language development (Campbell, 1998). Deafness or loss of hearing is simply defined as an inability to hear (Encarta Encyclopedia, 1998). The condition affects all age groups, it may be temporary or permanent, partial or complete and its consequences range from minor to severe. Deafness is classified into two types – conductive deafness or sensorineural deafness – depending on the part of the hearing mechanism that fails to function adequately (Martin & Clark, 2000).

Deafness from birth causes severe sensory deprivation that can seriously affect a person’s intellectual capacity or ability to learn (Alpiner & McCarthy, 1993). The critical period for neurological plasticity is up to age seven (McGrath, 1998). Failure of acoustic sensory input during this period results in failure of formation of synaptic connections and possibly an irremediable situation for the child. Hearing loss that is treated late or not treated at all holds negative effects for the developing child/infant (McGrath, 1998). This includes problems among others with optimal cognitive development, communication competency, literacy- and academic skills (McGrath, 1998).

The requirement for spoken language development in infancy is normal hearing (Boothroyd, 1998). Unless provided early with special training, children with profound hearing loss are incapable of learning to speak. Their chances of optimal socio-emotional, cognitive and sensori-motor development are also severely restricted (Boothroyd, 1998).

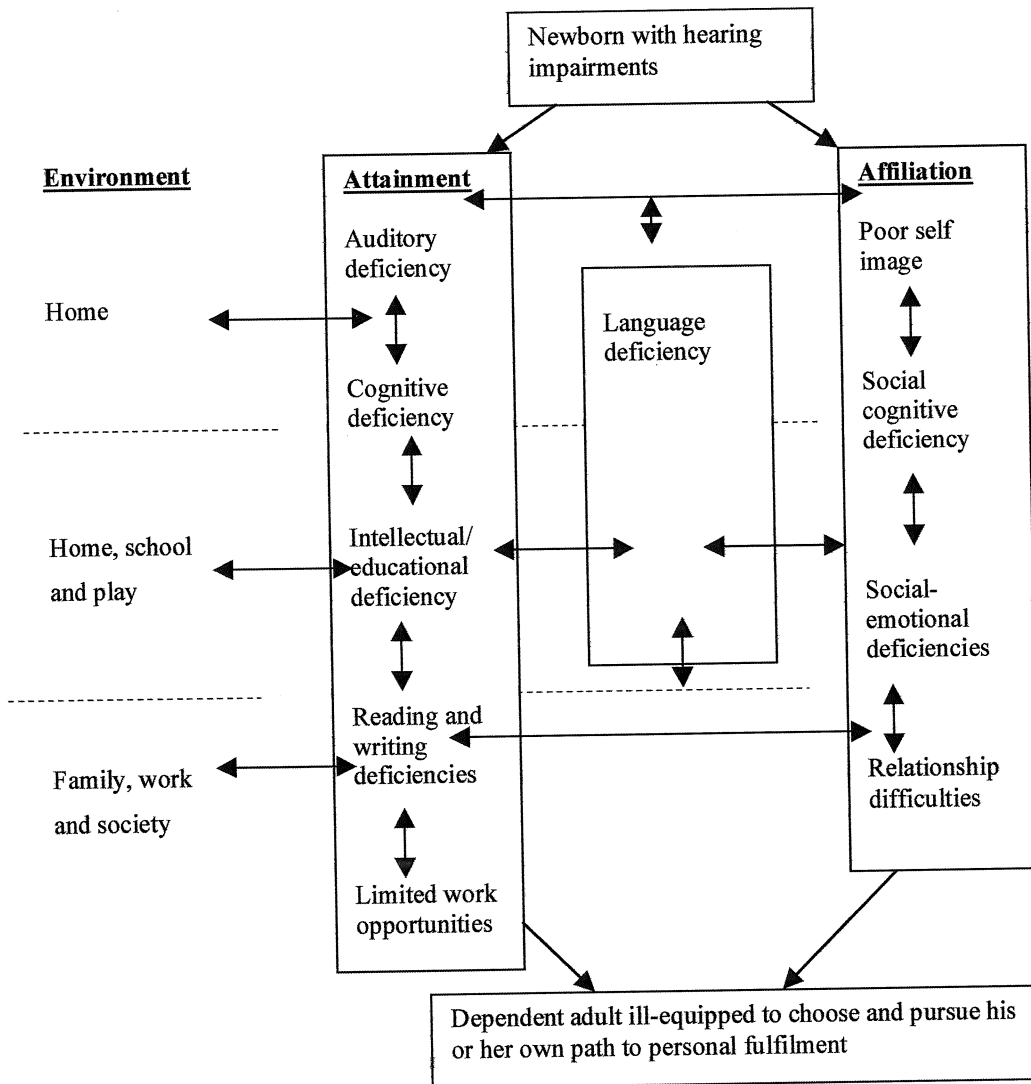
There is a limited time span during a child’s development for optimal speech acquisition. The critical time is during the first 2 years of life (Boothroyd, 1998). Hearing is important for the acquisition of vocabulary that leads to the expression of words and meaning of life. Vocabulary is the basis for learning and intellectual development. Therefore, early diagnosis of hearing loss is important. Figure 1.1 is a schematic representation of the factors and processes involved in human development, especially the key role that normal language development plays. Figure 1.2 represents the negative consequences of unmanaged hearing loss on an infant or child.

Figure 1.1: The role of hearing in normal development



Source: Boothroyd (1998) p.3

Figure 1.2: The effects of hearing impairment on development



Source: Boothroyd (1998) p.4

* In Figure 1.1 the bi-directional arrows indicate mutual enhancement or positive feedback while in Figure 1.2 it indicates mutual interference or negative feedback.

Research done by Yoshinaga-Itano (2001), Campbell (1998), Diefendorf (1997) and Alum (1996) proves hearing loss to be one of the most common birth defects. The prevalence of infants and children with loss of hearing revealed to be 1½ to 6 of all live births (Alum, 1996). According to a South African health website, deafness is considered to be the second largest disability in South Africa. In South Africa the prevalence figures according to www.health24.co.za (2004) classification of hearing impairment are as follows:

- 2\1000 – moderately severe to profound hearing loss
- 5\1000 – moderate to moderately severe hearing loss
- 150\1000 – middle ear infections.

McGrath (1998:1) states as follows: “*Hearing impairment is no longer a low incidence disability.*”

In this chapter, the problem and the need for interdisciplinary teamwork between the audiologist and the pediatrician, who are involved with the infant/child with hearing loss, is discussed. The arguments will be based on literature supporting the clinical value of early diagnosis and intervention of sensorineural hearing loss, as well as on the importance of teamwork between above-mentioned professionals working with infants/children with sensorineural hearing loss.

1.2 PROBLEM STATEMENT, RATIONALE AND OBJECTIVE OF THE STUDY

The aim of this section is to highlight the problem that occurs in the early diagnosis and intervention of infants/children with hearing loss, to develop a rationale and to set the objectives for this study.

The problem that occurs during the early diagnosis and intervention of infants and children with hearing loss is caused by the need for holistic and integrated teamwork of professionals. This statement has its origin in the need for extended knowledge that stems

from the concepts that surround hearing loss and rapidly developing technology that is available for intervention. The context refers to the clinical setting where an infant/child is in need of the positive attitude and proficient knowledge needed for appropriate intervention by pediatricians, who deal with sensorineural hearing loss.

The rationale for this study is to investigate the reason for late diagnosis and intervention and the need for pediatricians to contribute to a more effective intervention strategy for infants/children diagnosed with sensorineural hearing loss. The objectives of this study, as mentioned, are to analyse relevant literature in order to establish a theoretical baseline for the study and to analyse the overlapping patterns in previous studies that may support the underlying aims of this study.

1.2.1 Problem statement

This section will outline the problems that may be experienced by pediatricians in the diagnosis and intervention of infants/children with sensorineural hearing loss, especially in the South African context.

1.2.1.1 Establishing the relationship between hearing loss and early screening/diagnosis and intervention

The importance and value of early identification of hearing loss through hearing screening of infants and children is being emphasized worldwide and is well reported in the literature (Geal-Dor, Levi, Elidan & Arad, 2002). The earlier identification of hearing loss in infants and children may lead to an increase in the provision of early intervention and educational services. Amplification, special methods of providing language input and counseling of parents are aspects of early intervention programmes for hearing-impaired infants and children that have the potential for optimizing the child's language development (Northern & Downs, 2002; Alpiner & McCarthy, 1993). With the identification and diagnosis of hearing loss at birth and appropriate intervention within six months after birth, the prognosis for intellectual, emotional, language and speech development in the hearing impaired child is improved. Yoshinaga-Itano's (2001) study

proved that infants with hearing loss (and normal cognitive development) who were identified before the age of 6 months, and received immediate intervention, showed normal speech and language development. Identification of hearing loss, followed by relevant intervention, has proved to be the most effective strategy for the normal development of speech and language.

Previously the usual diagnosis of severe to profound hearing impairment was at the age of at least between 18-30 months (or even later in cases of milder hearing impairment) and where no screening programmes existed (Harrison & Roush, 1996). The ultimate goal currently is to allow as little time as possible to elapse between the onset of a hearing disorder, and its detection and subsequent management (Yoshinaga-Itano, 2001). Effective programmes for early identification and management are highly dependent on a well-coordinated interdisciplinary strategy involving pediatricians, audiologists and other medical specialists (Hall, 2000). A study in Ireland confirmed the importance of early screening: an increase of 39.9% was achieved in the identification of infants, between ages 3 to 6 months, with a congenital hearing loss (Nekahm, Weichbold, Welz-Meuller, Hirst-Stadlmann, 2001).

1.2.1.2 An integrated approach towards teamwork

Pediatric audiology, in particular, is a growth area of practice and will continue to be into the new century (Boswell, 2001). The success, efficiency and effectiveness of early hearing detection and intervention (EHDI) programmes require the support and expertise throughout the health care system and especially that of pediatricians (Finitzo & Crumley, 1999). Information is the key to developing a shared commitment for the EHDI programmes.

According to Wactel and Compart (1996) the pediatrician's primary task is to identify infants and children with atypical development and to make the relevant referrals for further evaluations or services (Tharpe & Bess, 1999). Research indicates that the average pediatrician will encounter approximately a dozen children with a severe hearing impairment in the course of a practice lifetime (Tomaski & Grundfast, 1999). By

understanding the concepts surrounding hearing loss and by understanding the process and importance of early identification and intervention, the pediatrician is in the ideal position to support and assist the family in the necessary referral process to relevant services and sources (Cherow, Dickman & Epstein, 1999; Lutherman & Kurtzer-White, 1999).

In partnership with other healthcare professionals, the pediatrician must assure that an audiological assessment is conducted on all infants who do not pass the screening and initiate referrals for medical evaluation to determine the etiology of the hearing loss. Middle-ear status should be monitored, since the presence of otitis media can further compromise hearing (Hall, 2000). The infant's history should be reviewed for the presence of risk indicators that require monitoring for delayed onset and/or progressive hearing loss. Periodic audiological evaluation of infants at risk should be ensured since 30-40% of infants/children with confirmed hearing loss will demonstrate developmental delays or other disabilities (Hearing loss is a component of more than 200 inherited syndromes) (Tomaski & Grundfast, 1999). Interdisciplinary assessment and intervention is essential in order to address all the developmental needs of infants and children who are hearing impaired.

1.2.1.3 Typical clinical setting

The goal is to identify hearing loss between 1 and 3 months of age and to start the intervention services before infants are 6 months of age (Yoshinaga-Itano, 2001). Although hearing screening has been both recommended and even routine in many countries, some pediatricians remain unfamiliar with the rationale for universal hearing screening of all newborns (Finitzo & Crumley, 1999). This problem is confirmed if one compares it to the results of the study done by Boswell (2001). In 1997, the "*Centers for Disease Control and Prevention*" (CDCP) monitored the prevalence of children with hearing loss between the ages of 3 years and 10 years. The results were shocking. Of the 413 children identified, only 8% were identified in their first year of life, 47% were not diagnosed before 3 years of age (or older), and 29% showed one or more additional developmental disorders (Boswell, 2001). Another study done in Pretoria showed that the

mean age of hearing loss onset of children who received amplification through hearing aids or a cochlear implant was 4 years and 2 months (Slabbert, 2002). No legislation for hearing screening in the neonatal period and effective follow-up, diagnosis and intervention exists in South Africa (Finitzo & Crumley, 1999).

1.2.1.4 Factors that may lead to late diagnosis and intervention

All professionals involved with pediatric audiology need to enhance their knowledge and skills in order to serve the population in need of service. “*A unique set of competencies is required to provide pediatric assessment, rehabilitative and consultative services as well as to be competent to support families at different stages in their child’s development*” (Boswell & Cherow, 1999:3). An audiologist should provide professional assistance to the rest of the professional team members because of the continuous technological advances in procedures in diagnostic testing of young children and amplification options (White, 2002).

In current medical practices, the professional personnel are under constant pressure to provide ways of increasing the efficiency of patient care, as well as maintaining a high standard of care (Vowles, Jefferis & Smith, 1997). Hearing loss is a ‘silent, hidden’ impairment in a highly heterogeneous population (Joint Committee on Infant Hearing, 2000). If the hearing loss goes undetected and untreated it can lead to many infants/children experiencing a delay in diagnosis from the time of the first suspicion of hearing loss (Kittrell & Arjmand, 1999). Inconsistent evaluation/assessment by team members lead to the late diagnosis of children with sensorineural hearing loss, while the alert pediatrician can eliminate this time lag by utilizing the screening techniques (Kittrell & Arjmand, 1999). During their study Kittrell and Arjmand (1999) also found that many infants/children with a risk factor for sensorineural hearing loss are diagnosed no earlier than infants/children with no risk factors. (This is presented in Table 1.1) This leads to the average age of diagnosis of infants/children with sensorineural hearing loss to remain unacceptably high.

Table 1.1: Median age, in months, for an age of suspicion, diagnosis and hearing instrument fitting for children with and without known risk factors. Also included are lag times between diagnosis and hearing instrument fitting.

Children with no known risk factors				
Hearing loss	Suspicion	Diagnosis	Hearing aid fitting	Delay between diagnosis and fitting
Mild to moderate	15 Months	22 Months	28 Months	6 Months
Severe to profound	8 Months	13 Months	16 Months	3 Months
Children with known risk factors				
Mild to moderate	8 Months	12 Months	22 Months	10 Months
Severe to profound	7 Months	12 Months	15 Months	3 Months

Source: Harrison and Roush (1996)

In some areas, where extensive otologic and audiological services may be lacking, the family pediatrician can be an important resource person for assisting and supporting parents in their search for appropriate professionals. Unfortunately it has been said by the parents that the pediatricians do not always follow up, on their suspicions and concerns regarding their child's hearing loss (<http://www.oraldeiafed.org/library/devices/> 1998-2003). A general rule to be taken into account is that the mother will usually be the first person to become aware of the hearing problem and any parental concern about hearing status or speech-language delay should prompt further referral and evaluation, regardless of the developmental screening outcome (Kittrell & Arjmand, 1999).

Yet another problem is the fact that pediatricians displayed questions with regard to the effectiveness of EHDI, and audiologists must be able to provide convincing feedback, in order to ensure increased participation of the pediatrician (Finitzo & Crumley, 1999). The following issues are often questioned by pediatricians:

- Pediatricians' primary concern is whether infants really benefit from early hearing detection and intervention (Finitzo & Crumley, 1999).
- Is early-hearing detection and intervention standard care? Standard care is defined as "what reasonably prudent practitioners do". Current government and professional agencies have recognised the importance and benefits of early detection, diagnosis and intervention of hearing loss in infants through the implementation of EHDI programmes (Finitzo & Crumley, 1999).
- Does a failure of the birth admission screening cause undue parental anxiety? Counseling the parents of these infants is challenging, but pediatricians have an important role in communicating screening results to parents. After discharge, the pediatrician's offices become the medical home for infants. Pediatricians are the experts parents seek and are often the source for referral for these services. Parents seek guidance from their pediatrician and programmes which can prove good outcomes and have strong pediatric advocacy. One needs to provide the necessary information in order to make the parents sufficiently aware of the importance of a follow-up screening (Finitzo & Crumley, 1999).

Additional factors exist which contribute to the delay from diagnosis to the fitting of the correct amplification (Sjoblad, Harrison, Roush & McWilliam, 2001). In Table 1.2 and Chapter 2 (Section 2.8) factors are described that influence early identification and intervention.

Table 1.2: Reasons for not detecting hearing impaired children (birth-contingent 1995-1999)

Reason for non-detection
Born in a hospital without a hearing-screening programme
Parental failure to keep the appointment for a final audiological assessment
Delay of hearing loss confirmation due to more urgent intensive care treatment
Progressive hearing impairment
Acquired hearing loss, for example ototoxic therapy

Source: Stephens, Stephens & von Eisenhart-Rothe (2000)

Adopting universal newborn hospital screening (UNHS) in developing countries is doubtful, due to poor public healthcare facilities at all levels. Not only do a significant number of births occur outside the hospitals, but current attitudes, customs and superstitious beliefs in many communities cause parental denial of impairments. Economic implications in developing countries in terms of funding, personnel training and administration are beyond the resources and capacities of most governments (Stephens, Stephens & von Eisenhart-Rothe, 2000). Families who live in under-served areas may have less accessibility and fewer professional resources available to assist them (White 2002). These factors underscore the necessity of providing comprehensive, culturally sensitive information to families – information that fulfils their needs and that results in informed choices.

1.2.1.5 How audiologists are viewed by other professionals

Audiologists are on the verge of a fundamental shift in service delivery as they prepare to meet the needs of the increasing number of infants now being identified through EHDI (Boswell, 2001). Audiologists have a growing role of service delivery in partnership with children and their families and related professionals to optimize development, language learning and life choices for children with deafness and hearing loss. Providing age-

appropriate, efficient and accurate services combined with decision-making synchronised with a family's culture and preferences is a difficult balancing act.

Speech and hearing professionals are well aware that communication disorders can restrict a child's learning and/or social-emotional development. Unfortunately the general public and policy makers cannot always be convinced of the critical importance of communication skills and remedying of communication disorders (Loggemann, 2000). In research, physicians indicated that they did not know the type of intervention children received and remained limited in their understanding of which specific intervention programmes were available for children with significant hearing loss (Smith, 1994; Calderon, Bargones & Sidman, 1998).

Audiologists are involved with infants and children with sensorineural hearing loss on a daily basis and fulfil an important role during the diagnosis and intervention of this population (White, 2002). Audiologists' role is to act as service coordinators, facilitating the tracking and follow-up of infants who fail the birth admission screening or who are at risk of delayed-onset of progressive hearing impairment. Audiologists teach, train and supervise the staff with regard to hearing loss in infants. Without audiologic involvement and pediatrician advocacy EHDI programmes fail either in quality or altogether (White, 2002).

1.2.2 Rationale underlying the study

When the pediatrician is not aware of the audiologist's potential role, the client may not receive optimal diagnosis and intervention during the critical first 6 months. For optimal identification, diagnosis and intervention it is essential to realize that pediatricians be aware of the audiologist's extensive knowledge in this particular field and the existing problems surrounding effective identification and intervention of a hearing loss. Thereafter emphasis is placed on the positive contributions both the audiologist and the pediatrician can make in an infant's or child's life.

1.2.3 Objective of the study

The importance of developing effective health teams in order to implement primary health care for infants/children in developing countries cannot be overemphasized. The objective of this study is to improve the skills and knowledge of participating team members. Improved teamwork skills and knowledge lead to more optimistic attitudes among members as well as to the delivery of more coordinated planning and management of problem issues at hand. Motivating team members also enhances effectiveness of services. Further improvements will rely on actions taken by the involved team members and at national level (Conn, Jenkins & Touray, 1996).

In order to reduce delays in diagnosis and intervention of pediatric sensorineural hearing losses there is a need to identify the factors responsible for such delays as well as the assessment of the effective medical evaluation of these infants/children (Kittrell & Arjmand, 1997). There is a need to enhance pediatrician's awareness of infancy and childhood deafness and to develop guidelines during the diagnosis and intervention of these infants/children.

1.3 DISCUSSION OF RELEVANT TERMINOLOGY

Different professionals have different perspectives regarding approaches to the identification and intervention of an infant/child with sensorineural hearing loss. In order to avoid confusion of terminology and for the sake of clearness, some of the terms used throughout the study are defined.

1. **Attitude:** a settled opinion of a way of thinking (Encarta Encyclopedia, 1998).
2. **Children:** one year to twelve years (Berkow, Fletcher & Beers, 1992).
3. **Deafness:** ¹ denoting one in whom the sense of hearing is nonfunctional, with or without amplification, for the ordinary purposes of life;

² loss of ability to hear, without designation of the degree of loss or the cause stimulus (Nicolosi, Harryman & Kieheck, 1996).

- **Congenital:** ¹ loss of hearing sensitivity existing at or dating from birth.
² born either totally deaf or sufficiently deaf to prevent the establishment of speech and natural language stimulus (Nicolosi et al., 1996).

- **Acquired:** ¹ loss of hearing sensitivity occurring after birth and due to injury or disease.
² became deaf in childhood before language and speech were completely established (prelingual deafness);
³ or became deaf after having acquired speech and language skills (postlingual deafness), thus significantly impairing communication skills stimulus (Nicolosi et al, 1996).

4. Degrees of hearing loss:

- **Profound hearing loss:** 90+ dB
- **Severe hearing loss:** 71 – 90 dB stimulus (Nicolosi et al, 1996).

5. **Diagnosis:** identification of a disease, abnormality, or disorder by analysis of the symptoms presented (Nicolosi et al, 1996).

6. **Disorder:** occurs as a result of some type of disease process or malformation of the auditory system (Nicolosi et al, 1996).

7. **Electrophysiologic testing:** procedure using various types of objective audiometry designed to measure an individual's response to a sound stimulus (Nicolosi et al, 1996).

- **Auditory Evoked Response (AER)** is a type of electrophysiological assessment in which electrical activity, evoked by sounds arising from the auditory portions

of the peripheral or central nervous system, is recorded with electrodes stimulus (Nicolosi et al, 1996).

- **Auditory Brainstem Response (ABR)** in which electrical activity is evoked by very brief sounds from the VIII cranial nerve and brainstem; findings allow inference of hearing level and identification of site of lesion as the cochlea, VIII cranial nerve, or brainstem stimulus (Nicolosi et al, 1996).
- **Otoacoustic emissions:** sounds generated within the normal cochlea, either spontaneously or in response to acoustic stimulus (Nicolosi et al, 1996).

8. **Hearing:** the sense, receptive in nature through which spoken language is received by response to sound pressure waves. The ears, the auditory nerve and the brain are involved in the process of hearing (Nicolosi et al, 1996).

9. **Impairment:** any loss or abnormality of psychological, physiological or anatomical structure or function (Nicolosi et al, 1996).

10. **Infants:** birth to one year (Berkow, Fletcher & Beers, 1992)

11. **Intervention consists of:**

- **Habilitation:** act or process of developing a skill in order to be able to function within a given environment (Nicolosi et al, 1996).
- **Rehabilitation:** restoration to normal, or to as satisfactory a status as possible, of impaired functions (Nicolosi et al, 1996).

12. **Knowledge:** ¹ awareness or familiarity gained by experience.

² a person's range of information.

³ theoretical or practical understanding of a subject, etc. (Encarta Encyclopedia, 1999)

13. **Screening:** any gross measure utilized to separate those who may require specific help in a specific area, such as hearing (Nicolosi et al, 1996).

14. **Sensorineural hearing loss:** hearing impairment resulting from a pathological condition in the inner ear or along the nerve pathway from the inner ear to the brain stem. In sensorineural hearing loss, the sound waves are transmitted to the inner ear, but they are not translated into nerve signals that are interpreted by the brain as sound sensations. The defect can lie in the organ of Corti or the auditory nerves. (Berkow et al, 1992)

1.4 DIVISIONS OF CHAPTERS

Chapter 1

Chapter 1 consists of an introduction that highlights the problem statement and the rationale of the study. The motivation and the importance of this study are also highlighted. A discussion follows of terminology and definitions that will be used throughout the study.

Chapter 2

In chapter 2 an overview and discussion of the literature of the role of the audiologist and the pediatrician regarding the diagnosis and intervention on infants and children with a sensorineural hearing loss is presented.

Chapter 3

The research methodology is described in this chapter. It includes the following:

- Research aims: the aims will be viewed and discussed.

- **Research design:** decision and motivation for the specific type of study is explained. A discussion ensues of how the research aims will be achieved, as well as the planned process that will follow until the solution for the problem statement has been found.
- An overview on the respondents who participated in this study is given.
- **Apparatus and material** includes a discussion on the background and the use of the questionnaire that is used to collect the data. A discussion follows on the type of questions used in the questionnaire as well as motivation thereof.
- A discussion following the course of the study, namely the pilot study, the main study and the data analysis.
- **An analysis of the collected data by using conventional statistical methods up to the point where it is represented as the results of the study.**

Chapter 4:

The results and a discussion of the study are presented. The most important/main results will be interpreted, evaluated and comparisons with similar research will be made.

Chapter 5

This is a conclusive chapter providing a summary, evaluation and clinical implications of the study. The chapter will answer the theoretical and clinical aspects of the research problem.

References

This will indicate the primary sources used throughout the study.

Appendices

The appendices include, among others, the questionnaire that was used during the data collection. Other information deemed important during the study is also available for explanation of the research.

1.5 SUMMARY

A lack of skills and proficient knowledge is a major constraint during the implementation of efficient primary health care services in developing countries (Kane-Berman, Henderson & De Souza, 2001). Issues of inefficient staffing, budgeting, planning and a lack of skills and motivation necessary for strengthening health management limit the effectiveness of these services (Conn et al., 1996). These are common problems despite growing advocacy for more effective services for early diagnosis and intervention of children with hearing loss.

Knowledge appears to be the key to prevention, identification and intervention of infants and children with hearing loss. The importance of knowledge and skills regarding research and findings thereof, as well as the rapid, changing technology, specific amplification selection and fitting procedures that are used for infants and children cannot be overestimated. Technology develops at a rapid rate and it is each professional person's role and responsibility to keep up with the latest intricacies. By showing a greater understanding of the different family systems, cultural beliefs and diversity in terms of knowledge and attitude, audiologists and pediatricians can make a difference in the life of infants and children with hearing loss (Guralnick, 1997).

The purpose of this study is to increase the pediatrician's general awareness of the significance of hearing loss in children. As the gatekeepers for children's health care, pediatricians are typically the primary recipients of parental expressions of concerns and the initiators of evaluations or referrals to address these concerns (Tharpe & Bess, 1999).