

CHAPTER 4

EARLY INTERVENTION FOR INFANTS WITH HEARING LOSS IN SOUTH AFRICA: A CRITICAL EVALUATION

Aim: This chapter provides a critical review of the present South African context and the infrastructure of audiological services for implementing widespread EHDl

4.1. INTRODUCTION

A review of the accumulated knowledge in a field of study is an essential step in the research process. It serves to delineate a study from the existing body of knowledge and to integrate the contribution into a wider framework of relevant theory (Neuman, 1997:88). In the current study, examining different knowledge domains pertaining to early identification of hearing loss in South Africa will provide a path of prior research and should stimulate new ideas in developing strategies for establishing effective and relevant systems.

Early detection of, together with intervention for infants with hearing loss is rapidly being established as the standard of care for infants with hearing loss in developed countries (JCIH, 2000:11; Lin et al., 2002:217; Olusanya et al., 2004:288). It is clear, however, that developing countries may not be able to follow this trend and will have to be resourceful in finding ways for providing contextually relevant services in an effective and accountable manner through local research and systematic planning (Gopal et al., 2001:100; Mencher & DeVoe, 2001:20). The wealth of international research and expertise provides an indispensable body of knowledge for implementing Early Hearing Detection and Intervention (EHDl) systems, but the unique characteristics and challenges of

developing countries demand that contextual research be done in conjunction with these international resources.

The South African Government recognises this need for contextually relevant health research when it states that the “lack of reliable health information is one of the major obstacles to the effective planning of health services in South Africa” (Department of Health, 1997:25). The government furthermore identifies health systems research as an essential research field that should be aimed at informing health planning, effective delivery, management and policy (Department of Health, 1997:25). Developing EHDI services in South Africa should therefore embrace evidence-based decision making, guided by established international practice and directed by the specific context.

The Professional Board for Speech, Language and Hearing Professions of the HPCSA (HPCSA, 2002:3) recently accepted the international benchmark specified by the Joint Committee on Infant Hearing (JCIH, 2000:10) for delivering services to infants with hearing loss through the implementation of UNHS programmes as part of an EHDI system. Acceptance of this benchmark, however, has placed an important responsibility on the hearing healthcare profession in South Africa. A priority has been created to analyse the broader South African context and assess service delivery models in the healthcare system to ensure evidence-based contextual implementation of EHDI services.

The purpose of this chapter is therefore to critically review the present South African context and the infrastructure of audiological services for implementing widespread EHDI programmes as proposed by the South African Hearing Screening Position Statement (HSPS). Figure 4.1 provides an outline and flow of the chapter contents.

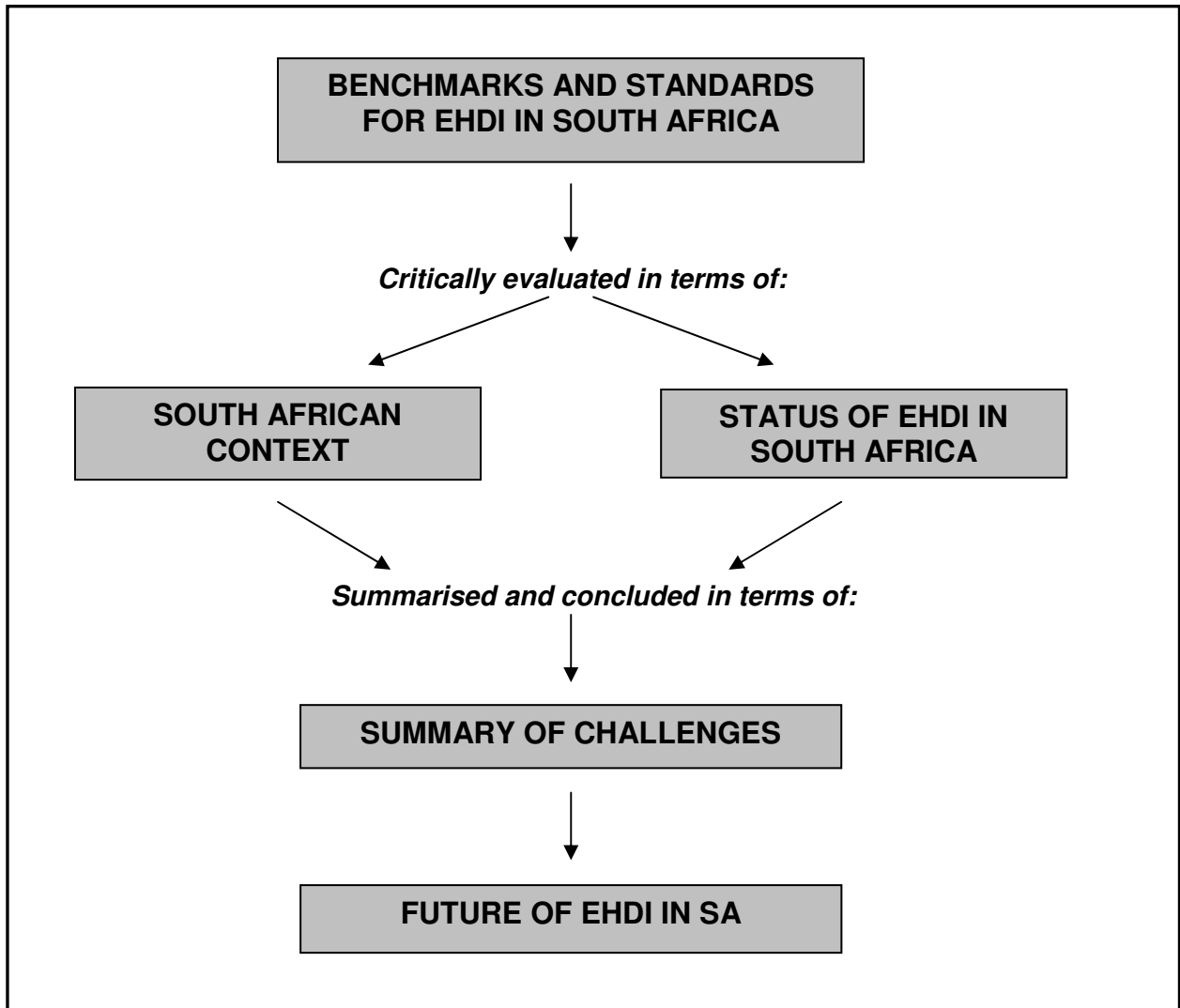


FIGURE 4.1 Outline of Chapter 4

4.2. BENCHMARKS AND STANDARDS FOR EHDl IN SOUTH AFRICA

The goal of providing UNHS to all children recommended by the JCIH year 2000 position statement is reaching beyond the borders of developed countries such as the USA and UK, and is now also becoming evident in developing regions of the world (Mencher & DeVoe, 2001:19). It is also apparent in South Africa through the recent release of a Hearing Screening Position Statement by the HPCSA in which it acknowledges the JCIH Year 2000 position statement as the

definitive document in delivering services to the infants and children with hearing loss in South Africa (HPCSA, 2002:1). In developing countries, like South Africa, where there are currently no standards for delivering services to infants with hearing loss (Mencher & DeVoe, 2001:19), a statement like the JCIH Year 2000 Position Statement provides a standard of care that can serve as a benchmark against which to measure existing services. This provides a body of knowledge that will serve as a point of departure for the implementation of future contextual research in countries like South Africa.

The South African position statement advocates early detection of infants with hearing loss by using objective electrophysiological measures for Targeted Newborn Hearing Screening (TNHS). This is followed by early intervention consisting of a diagnostic evaluation and family-centred intervention programmes provided through integrated interdisciplinary healthcare services by the Provincial and District Health Systems (DHS) (HPCSA, 2002:1). The rationale underlying these recommendations for EHDI programmes is to ensure optimum, cost-effective solutions for individuals identified with hearing loss. It is to “enable persons to communicate effectively, thereby allowing maximum habilitation or rehabilitation of the individual’s capabilities and potential, to secure their full participation in, and contribution to, society and the country’s economy” (HPCSA, 2002:1). The programmes are intended to reduce the average age of identification, diagnosis and intervention.

An evaluation of the South African HSPS in terms of the principles, as well as the roles and responsibilities specified, will be presented next, followed by a discussion regarding the importance of contextually relevant benchmarks and standards.

4.2.1. Principles of the South African Hearing Screening Position Statement

The principles specified by the SA position statement are summarised from the JCIH Year 2000 Position Statement and provide direction for the development

and implementation of successful EHDI programmes (JCIH, 2000:11). The position statement contains eight principles that support the goals of universal access to hearing screening, evaluation and intervention for newborns and infants embodied in Healthy People 2000 and 2010 produced by the US Department of Health and Human Services (US Department of Health and Human Services, 1990 in JCIH, 2000:11; US Department of Health and Human Services, 2010, in JCIH, 2000:11).

The South African year 2002 HSPS document summarises the goals for EHDI programmes in four statements (HPCSA, 2002:3,4). First, screening for hearing loss should identify infants who are at risk for hearing loss that impacts on development. Secondly, the types of hearing loss targeted by these programmes are unilateral or bilateral, conductive or sensori-neural, and greater than 30 dB in the speech frequencies (0.5 – 4 kHz). Thirdly, through developmental screening programmes at Primary Healthcare clinics, all infants should receive ongoing monitoring of the development of auditory behaviour and communication skills, as well as other sensory and motor milestones. The last guideline specifies that quantifiable goals and quality indicators need to be determined for the monitoring and evaluation of EHDI programmes with periodic reviews to assure the quality of such programmes.

The Professional Board for Speech, Language and Hearing Professions of the HPCSA assessed and compiled the principles and benchmarks for each principle specified by the JCIH year 2000 position statement in such a way that it is suited to the South African primary healthcare system. The principles, as well as a critical assessment of the limitations thereof, are summarised in Table 4.1.

TABLE 4.1 Summary and evaluation of principles and benchmarks specified by the South African HSPS

PRINCIPLES	SOUTH AFRICAN BENCHMARKS	LIMITATIONS
<p style="text-align: center;">1 ACCESS TO HEARING SCREENING</p>	<ul style="list-style-type: none"> - Neonatal hearing screening of all “at-risk” infants should take place prior to discharge from a hospital or other facility - Objective electrical and electrophysiological methods (OAE’s and AABR) are the only acceptable tests. Acknowledge that test protocols for combinations of procedures that are appropriate for the local context need to be developed - Strongly recommend use of nurses and lay volunteers as personnel trained to conduct hearing screening. Training should take place according to SAQA accredited training modules and should be presented by audiologists or speech therapists - Audiologist should supervise screening programmes in any context in the capacity of programme manager - Public institutions should invest in appropriate technology for targeted neonatal hearing screening to ensure all socio-economic levels of society have access to hearing screening and the benefits of early intervention - Hearing screening should take place in the well-baby nursery, at discharge from the NICU or at 6-week immunisation clinics - By 2005 there should be technology at MCH clinics in the community to enable infants who attend for their first immunisation to have their hearing screened as part of the package of services at that time - By 2010 – 98% of neonates/infants should be screened for hearing loss - All babies not previously screened should be screened at the 6 week immunisation clinics - Diagnosis of hearing loss should take place by age 3 months - Parent education regarding options for communication should take place by age 3-months. This should occur within a multiprofessional team framework of parents and professionals in collaboration with the designated case manager. - Referral and intervention should take place by age 6 months - Regardless of prior hearing screening outcomes, all infants who are at risk for delayed onset or progressive hearing loss should receive ongoing audiological and medical monitoring for 3 years and at appropriate intervals thereafter to ensure prompt identification and intervention - High risk questionnaires and behavioural observation audiometry are not recommended as stand-alone screening methods but must only be used in conjunction with electrophysiologic tests such as OAE and AABR - Use of noise-emitting devices such as rattles, whistles or other instruments are not endorsed and should be discontinued if currently being used 	<p>No mention or consideration is given to home-births</p> <p>Specify follow-up at ‘appropriate’ intervals but do not specify what these intervals are</p> <p>Clarity regarding multidisciplinary or interdisciplinary or transdisciplinary teamwork is needed. The terms seem to be used interchangeably. Best practice should consist of a transdisciplinary service-delivery model (Fair & Louw, 1999:14).</p>

TABLE 4.1 Continued

PRINCIPLES	SOUTH AFRICAN BENCHMARKS	LIMITATIONS
	<ul style="list-style-type: none"> - Community based developmental screening incorporating communication milestones should be implemented at primary care level within the District Health Services model. Results should be recorded on the Road to Health Card. Follow-up systems should be aggressively instituted to ensure that hearing-impaired infants are enrolled in appropriate rehabilitation programmes. Road to Health Card lends its self to utilization as first level record of hearing screening and districts should be encouraged to adapt it to meet local needs - There should be adequate supporting infrastructure and services at regional levels for diagnostic audiological assessments and therapeutic interventions. There should be access at this level to the necessary assistive device technology: selection, prescription, delivery and maintenance 	
<p style="text-align: center;">2</p> <p style="text-align: center;">CONFIRMATION OF HEARING LOSS IN INFANTS BEFORE 3 MONTHS OF AGE</p>	<ul style="list-style-type: none"> - Infants who fail a hearing screening should be referred for comprehensive audiologic assessments and specialist medical evaluations - Benchmarks and quality indicators need to be developed 	<p>No recommendations is made for a generally accepted diagnostic protocol</p>
<p style="text-align: center;">3</p> <p style="text-align: center;">EARLY INTERVENTION BEFORE 6 MONTHS OF AGE FOR CONFIRMED HEARING LOSS</p>	<ul style="list-style-type: none"> - Goal: facilitation of developmentally appropriate language skills and empowerment of families to assume the prime role in the habilitation process - Principles expressed in the integrated National Disability Strategy, National Rehabilitation Policy, DEAFSA’s Early Intervention Policy and relevant policies for inclusive education are endorsed - These are: Early intervention should be family oriented; Assistive device technology should be readily and immediately accessible; Medical and surgical intervention for otitis media and cochlear implantation should be available; primary focus of early intervention should be development of a communication mode suited for the individual - “Free health care for children under six year old” must also include rehabilitation and provision of assistive devices - Without prompt intervention neonatal hearings screening is unethical and should not be undertaken 	<p>Responsibilities are not specified for aspects of early intervention service-delivery.</p> <p>No early intervention protocol or standard procedure is recommended.</p>

TABLE 4.1 Continued

PRINCIPLES	SOUTH AFRICAN BENCHMARKS	LIMITATIONS
<p style="text-align: center;">4</p> <p style="text-align: center;">CONTINUED SURVEILLANCE OF INFANTS AND TODDLERS WITH RISK INDICATORS</p>	<ul style="list-style-type: none"> - Continued surveillance of infants and children under the age of six years specifically those presenting with known risk indicators and in environments where neonatal hearing screening is not yet available - Risk indicators, both those present at birth and those that may develop later, should be widely publicised especially in the Primary Health Care context - It is equally important to detect and monitor progressive and delayed onset hearing loss 	<p>Continued surveillance is recommended but the mechanism for conducting this is not specified.</p>
<p style="text-align: center;">5 - 6</p> <p style="text-align: center;">GUARANTEED INFANTS' AND FAMILIES' RIGHTS</p>	<ul style="list-style-type: none"> - The right to choose a preferred communication mode is protected by the SA constitution. - Various charter and bill protect the rights of children and the rights of persons with disabilities - Client and parent autonomy should be respected at all times 	<p>Right to preferred communication mode is granted but no guideline for ensuring unbiased sharing of information is stated.</p>
<p style="text-align: center;">7 - 8</p> <p style="text-align: center;">INFORMATION INFRASTRUCTURE; AND QUALITY ASSURANCE PROGRAMS</p>	<ul style="list-style-type: none"> - A national database should be developed which requires the implementation of a standardized methodology, reporting, and program evaluation - Each province should report the number of live births and the number of newborns that have been screened for hearing loss during birth admission - Important information to collate include: number of birthing hospitals in each province; number of live births in each province; number of infants screened for hearing loss before discharge; number of infants referred for audiologic evaluation before one month of age; number of infants whose hearing has been evaluated before 3 months; number of infants with permanent congenital hearing loss; mean, median, and minimum age of diagnosis of hearing loss for infants identified in a newborn hearing screening program; number of infants with permanent hearing loss receiving intervention by 6 months - Development of a mechanism for further identification and follow-up of infants who are missed in the screening programme who may then be included in the data set - Ongoing monitoring of high risk infants will make identification of late onset congenital hearing loss or those losses that are associated with meningitis and tuberculosis - This data will provide for estimations of hearing loss prevalence by province and region which will provide national benchmarks and quality indicators 	<p>A national database is recommended but the mechanisms for developing and implementing this is not specified nor are any suggestions made.</p>

The principles and benchmarks presented in Table 4.1 demand an active response from the audiological profession in South Africa. The pursuit towards hearing screening for all neonates/infants in the footsteps of developed nations such as the USA and the UK is marked with challenges in a developing country like South Africa. An important step toward reaching this goal is the establishment of a national database for contextual research regarding Infant Hearing Screening (IHS) programmes and the prevalence of hearing loss. This type of data will provide scientific support for the development and implementation of widespread IHS programmes.

4.2.2. Roles and responsibilities of EHDI role players in South Africa

Another essential aspect of an EHDI programme, which requires careful consideration in the initial phases of its implementation, is the different role players involved in the process. The success of a programme relies heavily on the role players and their individual and team responsibilities. A description of the suggested roles and responsibilities involved in implementing EHDI programmes in South Africa has been proposed by the HSPS. These roles and responsibilities are summarised in Table 4.2.

According to Bamford (2000:365) multidisciplinary teamwork between the different role players is vital to ensure satisfied families and confident children. Although other authors specify a transdisciplinary approach to be more effective especially in primary healthcare contexts, the important emphasis is on collaborative teamwork as a key to successful programmes (Fair & Louw, 1999:16; Moodley et al., 2000:37).

TABLE 4.2 Roles and responsibilities of role players in EHDI programmes (HPCSA, 2002:4)

ROLE PLAYERS	ROLES AND RESPONSIBILITIES
<p>Families and Professionals</p>	<ul style="list-style-type: none"> - Key partners in a family-centred, transdisciplinary team model. - Members include families, paediatricians, audiologists, otolaryngologists, speech-language therapists, educators and other early intervention professionals. - Case manager should coordinate services in consultation with family. - Individualised family plan should be designed to meet unique needs of infant and family.
<p>Institutes and Agencies</p>	<ul style="list-style-type: none"> - Those involved in hearing screening should assume responsibility for particular components. - A lead agency should be appointed to coordinate the various components. - Performance of hearing screening programmes should be audited through the formally commissioned evaluation of a designated pilot programme. - Community-based projects should be explored in order to implement and comply with Primary Healthcare objectives.
<p>Provincial Directorates of Finance</p>	<ul style="list-style-type: none"> - Accept full responsibility for ensuring that an adequate, dedicated allocation of funds is made to enable screening to take place, using appropriate technology. - Allocation of funds to ensure that “free healthcare for children under six years”, as specified by the Government, includes rehabilitation and the provision of assistive devices is an urgent priority. - Funding must also be made available to train personnel in the use of equipment and in the administration of screening programmes at hospitals and in the community.

Although the list provided by the HPCSA is comprehensive, some important role players are omitted. Nurses and lay volunteers are not mentioned although they are reported to play an important part in many screening programmes internationally (Messner et al., 2001:123). The HSPS does, however, recognise their role in recommending that they be trained to conduct hearing screening (HPCSA, 2002:4). Important state institutions that should be included are also omitted. The Department of Health has a significant role to play in enforcing the

implementation and maintenance of such programmes and specific responsibilities are also required for the primary, secondary and tertiary healthcare centres. Another state department that needs to be specified as an important role player is the Department of Education. The educational changes toward an inclusive educational system requires that children with hearing loss be included in the mainstream school system. The ultimate goal of EHDI programmes is therefore to ensure successful inclusion of children with hearing loss (Van Dijk, 2003:14).

The specific roles and responsibilities in addition to the benchmarks and standards specified by the HSPS are a helpful guide but their contextual relevance to the South African situation requires further investigation with more comprehensive recommendations.

4.2.3. Contextually relevant benchmarks and standards

The Professional Board for Speech, Language and Hearing Professions' year 2002 HSPS provides valuable direction regarding the development and implementation of EHDI programmes in accordance with its mission of guiding the professions and protecting the public in South Africa (HPCSA, 2002:1). Although there are many aspects that still require in-depth consideration, the position statement has provided a general direction for infant hearing screening (IHS) in South Africa (Swanepoel et al., 2004:634). Charting a course at a national, provincial and district level, it provides a set of standards and benchmarks where none previously existed.

The implementation and evaluation of these standards, however, require that the principles and benchmarks *be evaluated against the unique characteristics of South Africa*. The fact that the South African year 2002 HSPS is based on the JCIH year 2000 position statement, which was developed in and intended primarily for the USA, makes it necessary for these benchmarks to be assessed within the South African context. This is essential because of the vast difference between the needs of developed (e.g. USA) and developing countries (e.g.

South Africa), and even between the needs of different developing nations (Madriz, 2001:91). The unique features of the South African context in terms of demographics, policies and services must therefore be investigated alongside with the current status of audiological services to infants and toddlers in the country. This will ensure evidence-based planning and implementation of appropriate early intervention services for infants with hearing loss in South Africa.

The following section, therefore, provides a critical evaluation of the challenges posed by the South African context to the implementation of widespread hearing screening. After this section a more specific assessment will be made of the current status of audiological EHDl services to infants and toddlers in South Africa.

4.3. EVALUATION OF THE SOUTH AFRICAN CONTEXT

Sub-Saharan Africa has an estimated population of 518 million people, which constitute almost 10% of the world's population (McPherson & Swart, 1997:18). The health and related socio-economic indicators put the continent of Africa among the least developed regions of the world (Dennill et al., 1999:29). Examples of these indicators in the continent of Africa are an infant mortality rate of 111 per 1 000 compared to 9 per 1 000 in developed countries; a life expectancy at birth of 51 years compared to 76 years; an adult literacy rate of 51% compared to 95%; a safe water supply of 43% compared to nearly 100%; and a gross national product of \$505 compared to \$18 884 (Dennill et al., 1999:29).

Although two-thirds of the world's least developed nations are in sub-Saharan Africa, the country of South Africa, which occupies the southern tip of the African continent, has a comparatively well-developed infrastructure (McPherson & Swart, 1997:18; Children in 2001, 2001:26; Woolard & Baberton, 1998:15). The South African population is heterogeneous with mixed sections of developed and

developing contexts (Fair & Louw, 1999) that are classified collectively as a developing nation. The country of South Africa has been described as a “world in one country” – not only because it has four or five relatively different climates and a vastly contrasting geography, but also because it has a diverse collection of peoples and cultures (Tuomi, 1994:6). These facts contribute a variety of challenges to the widespread implementation of IHS in South Africa and will be considered in the following sections (Swanepoel, 2004:11).

4.3.1. General characteristics of the population

It is essential that healthcare professionals such as audiologists should familiarise themselves with the general characteristics of a population since they have a significant impact on the service-delivery approach and strategy to follow (Louw & Avenant, 2002:145). The estimated South African population in 2002 was 45,1 million compared to 40,6 million for the 1996 census (Statistics South Africa, 2003:9; Census Key Elements, 2003:10). Almost half (44%) of the current population is younger than 20 years of age, with 10% of the total population between 0 and 4 years old (Census Key Elements, 2003:10). According to the Government report on *Children in 2001* (2001:28) children of 18 years and younger will dominate the age distribution of the population of South Africa in the short to medium term, at least. Most young children (55%) live in rural areas where poverty is most rife and the infrastructure least developed. More than half (62%) of children residing in rural areas are 10 years or younger (Children in 2001, 2001:29).

The country is grouped into nine provinces, with the largest population found in KwaZulu-Natal (9,4 million people) followed by Gauteng (8,8 million people). The population is comprised of a mixture of races. Figure 4.2 illustrates the distribution of South Africans according to race as identified by Census 2001 (Population Census Key Results, 2003:6)

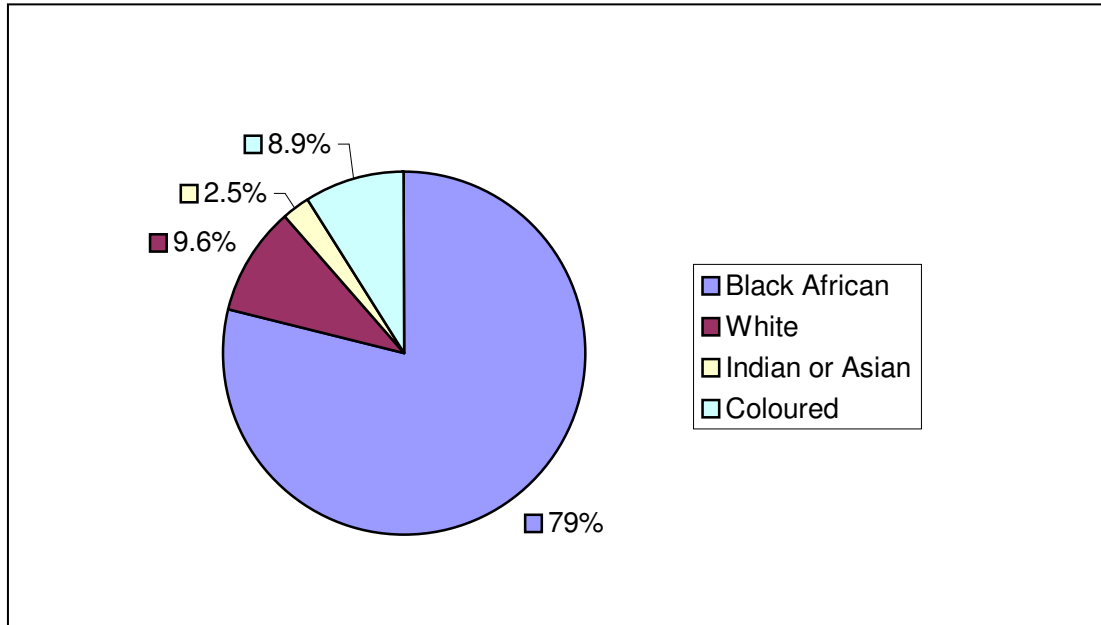


FIGURE 4.2 Distribution of South African population according to race (Population Census Key Results, 2003:6)

This race diversity is even further diversified by different cultures within these race groups, each with their own language or dialect. South Africa, often referred to as the “rainbow nation”, has eleven official languages of which Zulu is spoken most commonly (24%) with Afrikaans third (13%) and English fifth (8%) (Population Census Key Results, 2003:8). Although half of the South African population lives in rural areas, the distribution of people in urban and non-urban areas varies according to race. Almost two-thirds (63%) of Africans live in non-urban areas, as against a far smaller proportion of coloureds (16%), Indians (5%) and whites (9%) (Central Statistics, 1998:9). The diverse characteristic of race and language poses a significant challenge to delivering culturally sensitive early intervention services to infants with hearing loss in their home language. This is compounded by the distribution of race between urban and non-urban areas, which means that services are least accessible to those disadvantaged communities most in need of services.

The distribution by age among Africans resembles the typical age-pyramid of developing countries where a large proportion of people are infants and young children, and among those aged 15 years or more, the proportion of people in different age categories decreases steadily (Central Statistics, 1998:7). Among coloureds and Indians there emerges a transitional profile of age distribution that depicts a situation which lies somewhere between developing and developed countries. The picture of age distribution for whites is typical of developed countries. There are proportionately fewer infants, pre-school children and children of school-going age, compared to the other population groups, while the proportion of older people is increasing. Approximately one in every seven (15%) white females and one in every eight (12%) white males in the country are aged 60 years or more (Central Statistics, 1998:7,8).

These figures demonstrate that national EHDI services will have to be directed primarily toward the African population since this population comprises the largest percentage of the population, have the most children in relation to other races, and are the most disadvantaged. The multiracial and multilingual characteristics of South Africa and the geographical distribution of young children with special needs present as significant challenges to the implementation of effective early intervention services to children with disabilities in South Africa.

4.3.2. Disability in South Africa

Approximately one in every 20 people in South Africa is reported to be disabled, with a similar proportion across race and gender (Central Statistics, 1998:38). The prevalence of disabilities in South Africa as determined by the Census 2001 is represented in Figure 4.3.

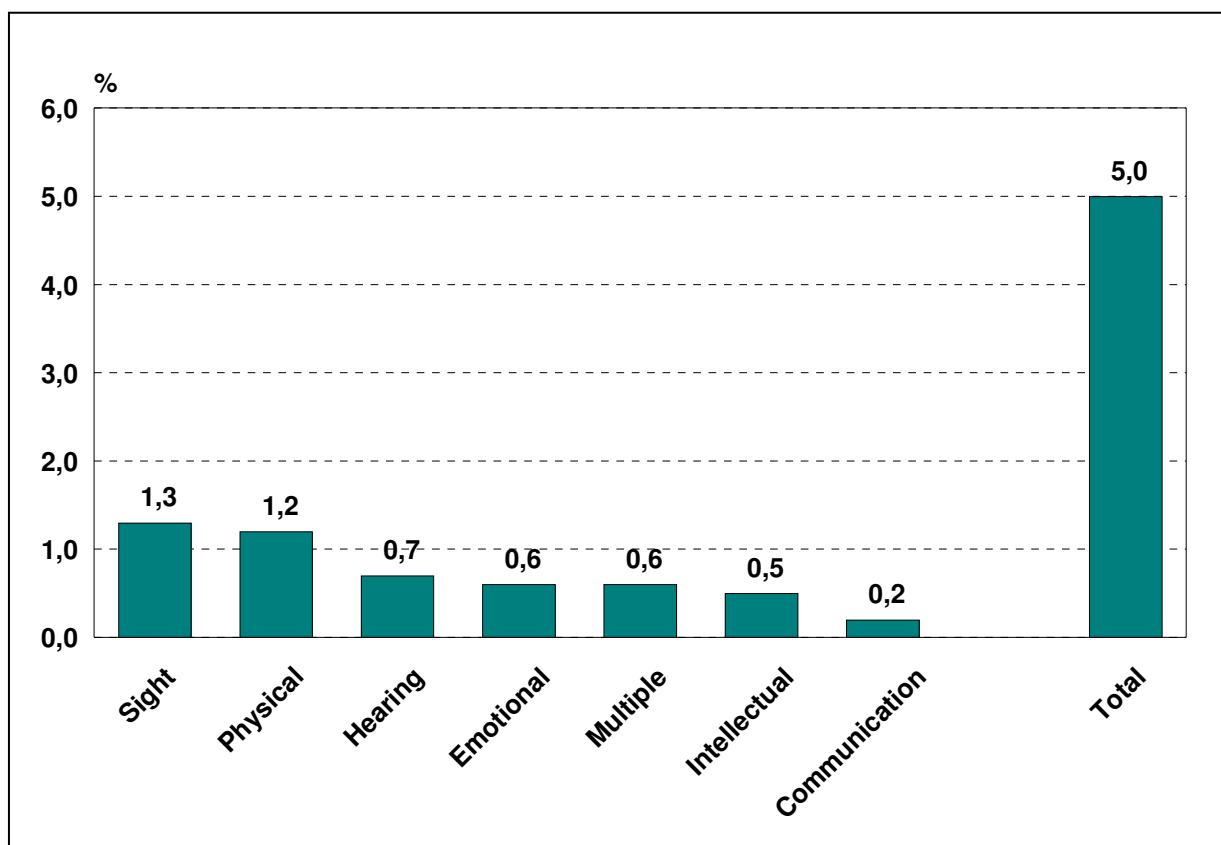


FIGURE 4.3 Prevalence of disabilities in South Africa (Population Census Key Results, 2003:6)

A total of 5% of South Africans suffer from some type of disability, with hearing loss making up 0.7% of the total figure. According to the Central Statistical Services (Central Statistics, 1998:38) this is probably a gross undercount due to the social stigma related to disabilities especially among the African population, as well as due to the fact that the definitions of disability in the census often differ and are not always explicit. Consequently, the accuracy of these prevalence studies have been questioned by some within the disability movement since the figures are considerably lower than the previous estimate of 10% of the population estimated by international agencies (Children in 2001, 2001:116). The international prevalence of disabling hearing loss, as estimated by the WHO, is much higher than the estimated South African figure at 2.2% (Mencher, 2000:180). This percentage does not, however, account for different regions in

the world and a survey done in South Africa indicated an even higher prevalence of 10% sensori-neural hearing loss (Sellars & Beighton, 1997:15).

Of the total population who present with disabilities, children between 1 and 15 years of age comprise approximately 9.4% (Children in 2001, 2001:114). Even though there is some controversy regarding the percentage of disabilities because international agencies estimate it higher at 10% of the total population, it is agreed that there are at least over half a million children with disabilities who are in need of appropriate services (Statistics South Africa, 1999:15). Although figures differ across provinces, rural children between birth and 10 years are twice as likely to have three or more disabilities than their urban counterparts. Hearing loss is reported to comprise approximately 22% of disabilities in South African children and is second only to impairments of sight. An additional 4% have multiple disabilities of which hearing loss probably constitutes an additional number of cases (Statistics South Africa, 1999:15). This figure, however, also seems to be a gross underestimation of congenital hearing loss prevalence since it is the most prevalent major birth defect in the USA (White, 2003:79). There is no doubt that hearing loss comprises a large proportion of disabilities in children. Despite the need for widespread EHDI services as part of the public healthcare system the misrepresented prevalence and impact of hearing loss in South African children, due to limited and poor quality statistical data, have resulted in a lack of legislative support and subsequent service delivery.

According to the report on *Children in 2001* (2001:116), South African child disabilities such as hearing loss were mainly caused by illness, prenatal and perinatal problems such as genetic disorders and birth trauma, injuries, accidents and violence. Children living in poverty are also much more vulnerable to disability as poverty-related factors lead to many preventable impairments which in turn perpetuate poverty. It is also true that the majority of children with disabilities in South Africa live in extreme poverty in inhospitable environments. Harmful, negative and discriminatory attitudes are probably the most significant barrier to development for these disabled children. Many children with disabilities are hidden in backrooms and often given no stimulation as they are deemed

worthless and available money is invested in the education of other siblings (Children in 2001, 2001:116). The perception of disability among African families is often characterised by an attitude of fatalism, which leads to an accepting, passive stance toward hearing loss in infants. This may have a negative effect on caregivers' decision to participate actively in the screening and early intervention process (Louw & Avenant, 2002:146,147).

The prevailing attitudes, ignorance of society and the protectiveness of their parents limit the rights of children with disabilities to participate and typically result in them growing up to be dependent, disempowered adults, unable to take initiative (Olusanya et al., 2004:301; Children in 2001, 2001:116). These attitudes pose a significant challenge in the form of cultural-based and ignorance-based resistance to the implementation and maintenance of successful EHDI programmes (Louw & Avenant, 2002:147). It will require implementation to occur in conjunction with educational awareness programmes to establish positive supportive attitudes in communities.

The following section focuses on epidemiological information that is available to describe the disability of hearing loss in the paediatric population of South Africa.

4.3.2.1. Epidemiology of childhood hearing disability in South Africa

An increasing world population and better survival rates for high-risk newborns will progressively and substantially increase the number of infants and young children with disabling hearing loss if decisive public health action is not taken. The first step in the implementation of such action is a thorough knowledge of the prevalence and aetiology of hearing loss in specific geographical regions for specific populations, in other words, community-based data (Olusanya, 2000:168). Few such studies have been conducted in South Africa, and those that have been completed are limited to small groups that are unrepresentative of the diverse South African population. In developing countries like South Africa, studies on children are typically of screening programmes for young school-aged children. These often reflect conductive losses and therefore are not a true

indicator of the incidence of congenital sensori-neural impairment (Mencher, 2000:179). Notwithstanding, such research is of value and some of the most prominent studies will be reviewed in the following section.

A number of studies have been conducted to ascertain the incidence of middle-ear pathology among young children from various South African communities, including black, white and coloured groups. The incidence varied between 13,4 and 29,4% (Celliers et al., 1988:35; Oosthuizen, 1986:26; Nel, 1988:25; Meyer & Van der Berg, 1985:73; Pretorius, 1984:22; Meyer et al., 1987:43), which indicates that the prevalence of middle-ear dysfunction in South Africa is higher than in First World countries, lower than in other Third World countries outside Africa and very comparable to other countries in Africa. The prevalence rates according to race and geography indicate it to be lower among black groups and higher in urban areas. Bhoola and Hugo (1995:22) evaluated 728 subjects aged between 4 and 5 years (315 black; 413 Indian) with a Middle-Ear Screening Protocol (MESP) and established a prevalence of 13% failures for black subjects and 14,3% for Indian subjects. Excessive cerumen caused 38,4% of the black and 49.9% of the Indian children to fail the outer ear tests.

In 1985 Meyer and Van den Berg (1985:73) found a 15,2% incidence of ear and hearing pathology in a group of children between 1 and 12 years old in an isolated community in Venda, Tshikunda-Malema. Altogether 13,4% presented with middle-ear conditions and 1,8% presented with sensori-neural hearing loss. A similar study, using immittance and pure tone screening procedures, was performed with grade one pupils (201) in the Eersterust community, which represents a developing context with primarily coloured children. All in all 15,7% did not conform to hearing within normal limits, with 2% presenting with sensori-neural hearing losses and 13,6% with middle-ear conditions (Meyer et al., 1987:45). A summary report on otitis media in South Africa concluded that there is a higher prevalence of otitis media in South Africa than in developed countries with difference across gender (less among black citizens) and geography (less in rural areas) (Hugo, Louw & Meyer, 1991:20). The high prevalence of middle-ear

and outer-ear disorders in South African children emphasises the need for effective national hearing healthcare services.

More recently the incidence of hearing loss in very low birth weight infants born at Kalafong hospital was determined for a small sample of 98 subjects. The incidence at discharge was found to be 4,1% and for a follow-up evaluation at 12 months chronological age, 41 of these infants were retested. An incidence of 16,3% hearing loss (6,1% sensori-neural; 10,2% conductive) was indicated (Van der Watt, 2002:14). This increased incidence is probably due to later onset conductive and sensori-neural hearing loss and draws attention to the urgent need for effective EHDI services providing routine follow-up for high-risk infants.

A comprehensive project to establish aetiologies of hearing loss for children at schools for the deaf in South Africa was performed between 1975 and 1983 (Sellars, Napier & Beighton, 1975:1136; Sellars, Groeneveldt & Beighton, 1976:1196; Sellars, Beighton, Horan & Beighton, 1977:311; Sellars & Beighton, 1978:812; Sellars & Beighton, 1983:888; Beighton, Sellars, Goldblatt & Beighton, 1987:210). Acquired hearing loss was identified in 25% of cases, with one third of acquired losses caused by meningitis and 19% by maternal rubella. In South Africa meningitis is responsible for 1.1% of deaths for children under five years of age (Solarsh & Goga, 2004:112). A genetic cause was identified in 18% of the study population with the most common aetiologies being Waardenburg, Treacher-Collins, Pendred, Usher and Branchial Arch syndromes. These results indicate a variety of causes for childhood hearing loss, including a large number of acquired losses due to environmental and disease-based causes and a smaller range of genetically based hearing disorders.

Prevalence studies for children in Southern Africa have consistently shown higher rates of severe to profound bilateral hearing loss when compared to those in the developed world (McPherson & Swart, 1997:7). There is, however, still a great paucity of prevalence and aetiological data for infant hearing loss throughout the South African population. The high prevalence of HIV/AIDS in South Africa emphasises the importance of investigating hearing loss in infants,

which may be related to HIV/AIDS infection or exposure (UNAIDS, 2003:1,2). Intra racial differences exist for outer-ear, middle-ear and inner-ear pathology, making it necessary to ascertain the prevalence of various types of hearing loss for the different ethnic groups according to age, geographical region and socio-economic status.

The current lack of true prevalence data for all regions in South Africa makes future hearing health service planning and provision difficult (McPherson & Swart, 1997:7). The underestimated prevalence of childhood hearing loss by inadequate means such as a census also renders political lobbying for legislative support in South Africa mostly ineffective. These factors are further complicated by a resource poor South African socio-economic infrastructure when compared to developed countries.

4.3.3. Socio-economic infrastructure

A small proportion of the population in South Africa represents the developed world, with a much larger proportion representing the developing world (Tuomi, 1994:6). South Africa is an upper-middle-income country with a *per capita* income similar to that of Botswana, Brazil, Malaysia or Mauritius (Woolard & Barberton, 1998:13; Children in 2001, 2001:26). When measured against other sub-Saharan African countries on the basis of socio-economic indicators such as the Human Development Index and Child Risk Measure, South Africa demonstrates low risk, but when compared to other countries with similar resources the measures are high (Woolard & Baberton, 1998:15; Children in 2001, 2001:31). The country is considered to exhibit a medium level of human development despite the fact that there are great disparities in human development levels in different regions and across different races (Woolard & Baberton, 1998:15). Certain provinces such as the Western Cape and Gauteng display high levels of human development whilst the Northern Province exhibits a low human development level. Large racial disparities further point to great inequality, with the black population's human development level on par with the

Congo and the white population on a level with Canada (Woolard & Baberton, 1998:15).

Extreme income inequality is evident in the form of destitution, hunger and overcrowding side by side with affluence. The experience of almost 50% of South Africa's population is that of outright poverty or of continued vulnerability to becoming poor (Children in 2001, 2001:26). The poorest 10% of households amass less than 1% of total household income in South Africa, in contrast with the wealthiest 10% who reap over 40% of household income (Woolard & Barberton, 1998:13). More than half the households living in poverty are found in rural areas where remittances and state social grants are relied on as the primary sources of income (Savage, 1998:67). According to Woolard and Baberton (1998:27) only 1% of African households earned more than R5 000 a month in 1993, compared to 51% of white households. Although poverty is not confined to one racial group in South Africa, it is concentrated among blacks, particularly Africans. A full 66% of Africans are poor compared to less than 2% of white households, whilst 8% of Asian households and 25% of coloured households are poor (Woolard & Barberton, 1998:27). The inequality is not only between racial groups, however, since the gap between rich and poor within the black community is also widening (Children in 2001, 2001:26). Poverty is an ever-present obstacle that will impede the delivery of EHDI services to the majority of South Africans and must therefore be carefully considered for future implementation of services.

Inequality is also evident in the provision of education in South Africa as low levels of income are strongly related to low levels of education (Louw & Avenant, 2002:147). There is a large discrepancy in the level of education across race and gender. One in every five (20%) African women have received no education at all, compared to one in every seven (14%) African males. On the other hand, only one in every 500 (0,2%) white males and females has received no education at all. At the upper end of the educational scale, almost all whites aged 20 years or more (99%) have received at least some secondary school education (Standard 6 or higher), while 30% of white males and 24% of white

females in this age category have obtained post-school qualifications. Among African males and females, however, only 6% have attained post-school qualifications (Central Statistics, 1998:11). Among the economically active, the proportion of unemployed is 34% or higher for those who have attended but have not completed school. However, the unemployment rate drops to 18% among those who have completed at least Grade 12 (Central Statistics, 1998:18).

The large percentage of poorly educated mothers or caregivers, primarily from low-income families, often lacks the knowledge to confirm suspicions of a disorder such as hearing loss and may not be able to access appropriate forums for guidance or concrete referrals early on (Louw & Avenant, 2002:147). Mothers and caregivers are at a disadvantage due to this lack of knowledge, which often causes confusion regarding developmental expectations for their children. This has important implications for the early detection of hearing loss in South Africa (Louw & Avenant, 2002:147) and emphasises the need for comprehensive EHDI programmes with a strong focus on empowerment through education, especially for those communities hardest hit by poverty and low levels of education. Unfortunately, additional socio-economic strains such as widespread unemployment diminish the priority for such services in healthcare systems.

Employment opportunities in South Africa are extremely limited, and many unemployed people have ceased to seek work actively. Transport and other costs entailed in job seeking, often with negative results, have however discouraged people from going out and seeking work (Central Statistics, 1998:17). The unemployment rate varies considerably across provinces, race and gender. On average, African women who are in the age group of economically active people are most likely to be unemployed (47%), followed by African males (29%), and then by coloured women (28%). White females (8%) and males (4%) are least likely to be unemployed. Comparisons of unemployment in urban and non-urban areas in the various provinces of South Africa show that, with some exceptions such as the Western Cape (which in any case is largely urbanised) unemployment tends to be higher in non-urban rather than in urban areas (Central Statistics, 1998:17,18). This is also related to race,

as 63% of Africans live in non-urban areas as against a far smaller proportion of other races (Central Statistics, 1998:9). The strain of finding employment may well cause parents of infants with hearing loss to demonstrate passivity toward EHDI. A negative socio-economic situation causes individuals' priorities to move away from habilitation to the more basic needs of daily provision and stability.

The above-mentioned socio-economic aspects of depravity such as poverty, unemployment and low levels of education have also demonstrated a significant relationship with the prevalence of congenital hearing loss as reported in a recent study (Kubba et al., 2004:123). This means that the more socio-economically deprived sections of South Africa will have an increased prevalence of hearing loss, and that the situation will be aggravated by the compounding factor of limited resources. The limited availability of resources creates barriers to the acquisition of equipment and the provision of appropriate training as well as supporting equipment and personnel for EHDI programmes. *The extensive poverty and inequality evident throughout the general population must spur efforts to provide hearing services to those who can least afford it, who need it most, and who are often furthest from hearing healthcare services.*

4.3.3.1. Socio-economic effects on children

The growth, development, well-being and safety of children depend largely on the ability of their caregivers to provide for them. In South Africa, however, six out of every ten children live in poverty (Children in 2001, 2001:33) and the children in rural areas are more likely to be poor than those in urban centres because seven out of every ten poor people live in rural areas (Central Statistics, 1998:39). The Department of Health estimated in 1995 that about 16% of babies were of a low-birth weight, 16% of children under five years were underweight for their age and the growth of between 20% and 30% was stunted as a result of chronic malnutrition (Savage, 1998:67).

Two measures frequently used to measure the vulnerability of a country's children are the Infant Mortality Rate (IMR) and the Child Risk Measure (CRM).

According to a Demographic Health Survey conducted in 1998, the IMR in South Africa is 45 per 1 000 live births, which means that one in every 22 babies born dies before reaching his or her first birthday (Children in 2001, 2001:31). This rate differs significantly across race with 11 and 47 per 1 000 for whites and Africans respectively. The Under-5 Mortality rate was at 59 per 1 000 and has been showing an upward trend since 1990, which is probably associated with the HIV/AIDS pandemic. Due to AIDS-related deaths it is projected that the child mortality rate for 2010 will be 99.5 per 1 000 (Children in 2001, 2001:31). These figures demonstrate why, in healthcare priorities, there is a move away from disability issues such as hearing loss, toward the more pressing need to address life-threatening conditions.

The socio-economic challenges evident in South Africa are also environmental risk factors that place young children at an increased risk of developmental disabilities and specifically hearing loss (Fair & Louw, 1999:14; Kubba et al., 2004:123). Despite an emphasis on life-threatening conditions, the risk factors emphasise the need for preventive measures that will minimise the use of more expensive rehabilitative measures. This may prevent the burden on society of an economically inactive group, such as individuals with hearing loss who do not receive appropriate early intervention.

The socio-economic pressures on families with infants with hearing loss also result in a priority shift within the family from attending to the rehabilitation of a disability to dealing with the more basic needs of stability and nutrition. This pressure also creates an increased passivity in families and prevents them from becoming active participants in the early intervention process, which ultimately undermines the efficacy of EHDI programmes. It is therefore essential that innovative models of service delivery such as those suggested by Louw and Avenant (2002:149), which “mobilizes caregivers and combats passivity” and “meets the needs of low-income populations” are investigated to ensure that accountable services are provided.

An additional factor affecting the whole of South Africa across all peoples and within all sectors of the economy, social life, healthcare and education is the HIV pandemic so rife in sub-Saharan Africa and also in South Africa.

4.3.4. Effect of HIV/AIDS

Worldwide, the HIV pandemic is showing no signs of abating, with 5 million new infections in 2003 and 3 million deaths due to AIDS-related illnesses. Southern Africa is home to only 2% of the global population but comprises 30% of global HIV cases. South Africa presented with an estimated 5.3 million HIV cases at the end of 2002 – the highest of any country in the world (UNAIDS, 2003:1,2). This rapid progression of HIV/AIDS is already impacting on every aspect of social and economic life in South Africa and is taking a heavy toll on the lives and well-being of all citizens, especially children (Children in 2001, 2001:85). The impact thereof will have a profound effect on family structures and the economy (Children in 2001, 2001:26). At the end of 2002 an estimated HIV prevalence rate of 26.5% was reported among sexually active women aged between 15 and 49 (Mngadi, 2003:1). Surveys by the Department of Health indicate an estimated HIV prevalence rate of 11.4% across the general population (Department of Health, 2002:4), which means that one in every nine South Africans and one in every five adults are living with HIV (UNAIDS, 2003:2).

South Africa is one of the countries with the highest number of children living with HIV/AIDS (UNAIDS, 2003:2). The greatest threat to South African children at birth is contracting HIV from infected mothers. Approximately one-third of children (14-39%) born to HIV-positive mothers are infected and an estimated one in seven will acquire it through breast-feeding (Singh, Georgalas, Patel & Papesch, 2003:240; Children in 2001, 2001:86). Most of these children develop AIDS and die within a few years after birth. This has been the main reason for a steady increase in child mortality, with 40% of deaths for children under five years of age due to the infection (Solarsh & Goga, 2004:112). It is estimated that the child mortality rate in South Africa will double due to HIV/AIDS by 2010 (Children in 2001, 2001:86).

The magnitude of the HIV/AIDS pandemic in South Africa is totally overshadowing disability and quality of life priorities such as hearing loss. It is therefore not surprising that hearing loss is not receiving the attention and support it deserves as a serious disability with devastating effects on individuals and far-reaching societal consequences. Healthcare priorities have furthermore been aligned toward life-threatening conditions in South Africa by the resurgence of tuberculosis, which is now on the rise in developing countries alongside HIV. These two diseases are known for activating and reactivating each other and tuberculosis accelerates the progression of HIV infection to reach the AIDS defining stage (*Department of Health Statistical Notes, 2000:2*).

Infants born of HIV/AIDS-infected mothers are at an increased risk for hearing loss due to significantly lower birth weights and the fact that HIV can affect virtually every organ in the body (Spiegel & Bonwit, 2002:128,129). Infants living with HIV/AIDS are also susceptible to other opportunistic infections and neurological complications that can compromise auditory function such as meningitis and cytomegalovirus (Matkin, Diefendorf & Erenberg, 1998:144; Spiegel & Bonwit, 2002:128). It is therefore no surprise that infants born to HIV positive mothers are at risk for a congenital hearing loss and for developing a hearing loss shortly after birth (Druck & Ross, 2002:4).

According to Matkin et al. (1998:153) approximately 90% of children with AIDS display developmental delays and, more importantly, many of them have a persistent problem with otitis media. Singh et al. (2003:2) report that otitis media was found to be the second most common ear, nose and throat disease in a group of children with HIV, and that 46% of the sample presented with it. Furthermore, HIV/AIDS is related to congenital hearing loss due to ototoxic medications taken prenatally for the treatment of HIV-related diseases. These medications may cross the placenta and damage the foetal ear structure development (Bankaitis, Christensen, Murphy & Morehouse, 1998:178). A recent study in South Africa indicated that for a group of 10 infants with HIV/AIDS between the ages of 6-12 months, 85% of the ears (n=20) indicated abnormal middle-ear functioning (Bam, Kritzinger & Louw, 2003:40). This was in

conjunction with a high prevalence of excessive wax in the external ear canal. It is clear that auditory development may be significantly impacted by the presence of HIV/AIDS.

Projections suggest that by the year 2005 there will be one million and by 2010 two million orphaned children due to HIV/AIDS (UNAIDS/UNDP, 1998:14). These figures suggest far-reaching consequences for children and the possible increase in hearing loss. Family life and the composition of the household are also profoundly affected by HIV/AIDS. It is inevitable that caring for sick family members and participation in ongoing economic activities will fall increasingly to the elderly and the very young (Children in 2001, 2001:88). The lack of dedicated caregivers for the children poses a significant threat to effective caregiver-focused early intervention services for the infants with hearing loss. Furthermore, children orphaned by AIDS face not only trauma of bereavement, but also the likelihood of poverty due to the loss of a breadwinner (Children in 2001, 2001:88). The impact of HIV/AIDS has surpassed an epidemic scale and has reached pandemic proportions in South Africa. This means that it is so widespread that it is starting to (and will continue to) affect all aspects of life in South Africa in a more prominent and observable manner. It is having a significant effect on healthcare system priorities, with the result that non-life-threatening conditions such as hearing loss does not receive adequate support and advocacy.

The fact remains, however, that the increasing number of infants and young children living with HIV/AIDS in South Africa will also increase the prevalence of hearing disorders across the population. This is due to complications of the central nervous system and increased middle-ear and outer-ear disorders caused by HIV/AIDS, which adversely affect hearing ability (Druck & Ross, 2002:4; Bam, Kritzinger & Louw, 2003:40). Paediatric HIV/AIDS in infants who have access to quality healthcare is not viewed as a critical short-term disease anymore but rather as a chronic condition (Davis-McFarland, 2002:10; Chan et al., 2002:73). This means that the paediatric population of infants with HIV/AIDS is an important and growing patient group that will require EHDI services. These

services are important to ensure a better quality of life and to improve the potential for development and education for these infants (Bam, Kritzinger & Louw, 2003:36). Although HIV/AIDS is shifting healthcare priorities primarily toward life-threatening conditions at the cost of disabling conditions such as hearing loss, the need for EHDI services to this very population is clearly indicated. A discussion of healthcare priorities in South Africa is presented in the following section.

4.3.5. Healthcare system for children

South African health services are based on a primary healthcare philosophy that aims to decentralise services with the principal emphasis on community care. The aim of the primary healthcare plan was “to ensure the provision of cost effective primary healthcare to all the inhabitants of South Africa” (Department of National Health and Population Development, 1992:6). The goal of the South African health policy, therefore, is to meet the health needs of the whole population by implementing an intersectoral approach. The emphasis is on healthcare rather than on medical care, with consensus that all South Africans have the same right to that care (Kritzinger, 2000:88).

Within this approach the health of children is recognised as a priority and the Government has legislated free healthcare services for all children under the age of six years (*White Paper on Integrated National Disability Strategy*, 1997:80). The White Paper (1997:84) also states that all children with disabilities who are under six years old have free access to assistive devices and that the Department of Health is responsible for assistive devices that improve the independent functioning in these children. In spite of the efforts to provide healthcare for these vulnerable sections of society, specific policies for the disabled and at-risk population are lacking in South Africa (Moodley et al., 2000:26).

The new health system in South Africa clearly specifies child health as one of the priority components of the primary healthcare (PHC) package but a basic component like screening services, although in agreement with current

healthcare priorities and legislation, has not yet been realised in practice (Baez, 2003:1). This is despite former president Nelson Mandela pledging his government's commitment to children in June 1994 by stating that they would be put first (Children in 2001, 2001:21). The South African context poses several significant challenges to the implementation of EHDl services and the country's children are still in need of intensive efforts to nurture, develop and protect the future of South Africa. Table 4.3 reflects the status of children in the South African context.

TABLE 4.3 Key indicators for South African children (*Children in 2000, 2001:27*)

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- Six out of every 10 children live in poverty, mostly in rural areas.
 - The Infant Mortality Rate in 1998 was 45.4 per 1 000 live births. For Africans it was 47, coloureds 18.8 and whites 11.4.
 - The Under-Five Mortality Rate was 59.4 per 1 000. For Africans it was 63.6, coloureds 28.2 and whites 15.3
 - 63% of children were fully immunised and only 2.2% had received no immunisations.
 - Nearly a quarter of children under 5 years old are stunted in their growth, and one in 10 is underweight for his/her age.
 - One third of children under 5 years have a Vitamin A deficiency and 1 in 10 is anaemic.
 - 21% of children under five die from diarrhoea, and 10% from acute respiratory infections.
 - In 1998, 22.8% of women attending antenatal clinics in public health facilities were HIV positive. The rate of increase among teenagers between 15 and 19 years was 65.4% from the previous year. At the end of 2001 an estimated HIV prevalence rate of 24.8% was reported among sexually active women aged from 15 to 49 (Department of Health, 2002). This percentage grew to 26.5% at the end of 2002 (Mngadi, 2003).
 - 180 000 children under the age of 15 were estimated to have lost their mother or both parents to AIDS.
 - School enrolment is high at primary and secondary levels but an estimated 5% of children between the ages of 10 and 16 are not in school.
 - In 2000, there were 226 631 children in state-supported reception year classes for 5-year olds.
 - The pass rate for the Grade 12 examinations in 2000 was 57.9%.
 - At least half a million children have moderate to severe disabilities and need access to specialist services.
 - 42% of children under 7 years of age live only with their mother and 20% do not live with either parent.
-

It is clear from these key indicators that despite policy and programmatic interventions by the government, prevailing socio-economic conditions do not support the normal, healthy development of many of the country's children (Children in 2001, 2001:26). These factors constitute significant challenges to EHDI services in South Africa and need to be integrated and addressed in prescribed benchmarks and standards of service delivery.

The South African Hearing Screening Position Statement (HPCSA, 2002:1-9) provides benchmarks and guidelines for the implementation of screening services in the healthcare system in order to identify infants with hearing loss. In the previous discussion these benchmarks and recommendations were set against the background of the South African context, but they also need to be viewed within the existing framework of hearing healthcare services for infants and young children in South Africa. The next section therefore reviews the current status of audiological services in South Africa.

4.4. EVALUATION OF EHDI SERVICES IN SOUTH AFRICA

4.4.1. Introduction

Pienaar, the father of Speech-Language Pathology and Audiology in South Africa wrote as early as 1962 that “[a] young country, with a comparatively small percentage of wage earners, keen on expansion in every sphere of life, with no endowments and handicapped by a lack of funds, has had to march forward on faith, hope and charity and its youthful idealism. We are jealous of our standards of training, of research and therapeutics... We realise the vastness of the field still lying fallow; the great task still ahead of us to cater to the needs of the whole population of South Africa and through South Africa to the whole of the awakening Southern Africa” (Pienaar, 1962 in Cilliers, 1980:1). Almost 40 years later with a new government and new healthcare system, the main aim of audiology in South Africa has remained the same: availability of accountable services to all peoples of the country.

During the last decade large-scale changes have occurred in the South African socio-political arena. These developments have not only been political but have also brought about changes in national health, education and welfare policy (Kritzinger, 2000:86). An ongoing paradigm shift in the profession of speech-language therapy and audiology in South Africa has mirrored these political changes in order to improve imbalanced service delivery, redress teaching programmes and focus its research endeavours on the specific needs of the context. According to Kritzinger (2000:85), the shift has not only been reflective of the national changes in South Africa, but it has also been stimulated by international trends and developments in healthcare, education for learners with special needs, and views on people with disability.

The use of traditional institution-based models of service delivery in the field of speech-language therapy and audiology has proved to be ineffective in reaching the majority of vulnerable and disadvantaged communities in South Africa (Moodley et al., 2000:25). A resultant transformation is occurring towards a community-based service delivery model for speech-language pathology and audiological services to meet the unique needs of the broader South African community (Uys & Hugo, 1997:27). This type of model matches the South African government's current policy for a comprehensive, equitable and integrated National Health System. The restructured National Health System mandates the transition in service delivery from institution-based to community-based services to provide for the health needs of the whole South African population (*White Paper on an Integrated National Disability Strategy*, 1997:22,26).

Two recent initiatives from the HPCSA have reaffirmed these objectives, thereby providing a continued impetus for bringing services to the entire population. The first is the publication of a South African year 2002 Hearing Screening Position Statement (HSPS) by the Professional Board for Speech, Language and Hearing Professions of the Health Professions Council of South Africa (HPCSA, 2002). This document acknowledges the Joint Committee for Infant Hearing (USA) Year

2000 Position statement as the definitive document on infant hearing screening and admits that it forms an integral part of the South African position statement (HPCSA, 2002:1). The primary benchmark states that by 2010, 98% of neonates/infants in South Africa should be screened for hearing loss. The intermediate step in the pursuit of universal neonatal/infant screening is a targeted screening approach (HPCSA, 2002:5). These benchmarks reflect the commitment to the delivery of services to all South Africans and, according to the HSPS, “Primary Health Care principles need to be adopted in order to respond to the escalating need for community based and family oriented early intervention programmes” (HPCSA, 2002:7).

The second initiative was the decision to implement a community service year for all speech-language therapy and audiology graduate students. This legislation was implemented in 2002 and the graduate class of students began the first year of community service in January 2003 (Padarath et al., 2004:302). This community service year will not only provide in-service training to the new graduates, but more importantly, it aims to bring services to the communities where they were not previously available. Although there are still many challenges in terms of equipment and disposable supply shortages, this initiative is a step towards more community-based speech-language therapy and audiology service delivery. It also provides an infrastructure of audiologists and therapists to manage and oversee the delivery of new services such as EHDI programmes. To permit realistic planning, the infrastructure of audiological manpower in the public health sector needs to be ascertained alongside with the status of audiological services in this context.

The following section therefore reviews the available audiological manpower and the status of the professional functions of audiologists in South Africa as they relate to EHDI.

4.4.2. Audiological manpower in South Africa

Approximately 2 113 speech-language therapist audiologists are registered at the HPCSA (HPCSA, 2003:1). Traditionally, speech-language therapy and audiology constituted a combined qualification offered by South African universities and therefore, HPCSA registration was done as therapists and audiologists. Recently, university courses have changed, allowing qualification as either a therapist or audiologist or both. Since this change, 35 audiologists have been registered with the HPCSA (HPCSA, 2003:1).

According to projections made in 1993 there would already be a shortage of 10 000 speech-language therapists/audiologists in the year 2000 (Uys, 1993:4). There is also a limited awareness of the services offered and the relevance and need for services are subsequently not recognised (Malherbe, 1999:25). The recent initiative to add a compulsory community service year for audiology graduates may increase the awareness of services offered, due to an increased visibility of the profession. The number of community service positions and of permanent audiology positions in the national healthcare system is presented in Table 4.4.

A total of 128 community work placements were allocated for 2004 (Tau, 2003). However, the majority of these placements are not only for audiologists but are in fact dual posts for speech-language therapists/audiologists. This implies that these professionals are not dedicated solely to providing audiological services. Also, although speech-language therapists may conduct hearing screening as a professional function, they cannot manage an EHDI programme without being qualified as an audiologist too (Hugo, 2004:6). Disparities in distribution also become evident when the placements are related to the population per province. For example, the Free State with a population of 2.7 million received 17 placements, whilst the Eastern Cape with a population of 6.4 million only received 4 placements.

TABLE 4.4 Number of community service* audiologists and permanent audiologists employed by the Department of Health in each province

PROVINCE	POPULATION (Census Key Results, 2003:7)	NUMBER OF COMMUNITY SERVICE PLACEMENTS 2004 (Tau, 2003)	NUMBER OF COMMUNITY AUDIOLOGISTS FOR 2004
Eastern Cape	6.4 million	4	8
Free State	2.7 million	17	18
Gauteng	8.8 million	20	Info unavailable
KwaZulu-Natal	9.4 million	33	Info unavailable
Limpopo	5.3 million	7	28 (Only 2 are trained audiologists)
Mpumalanga	3.1 million	19	Info unavailable
Northern Cape	0.8 million	2	1
North West	3.7 million	16	Info unavailable
Western Cape	4.5 million	5	Info unavailable
SA Military Health Service	-	6	-

* Community service audiologists are audiology graduates busy with their compulsory year of community service.

From a national perspective, disparities also exist between private and public audiological services. The vast majority of audiologists are in private practice and provide services to a small minority of the country – primarily to people from developed contexts who can afford the services. The majority of the population however, with a higher prevalence of congenital hearing loss due to socio-economic depravity (Kubba, 2004:123), cannot afford audiological services in private practice and rely on the national healthcare system. This problem is exacerbated by the fact that many of the national healthcare positions for audiologists and speech-language therapists are filled by community speech and hearing workers who are not adequately qualified to implement and maintain EHDI services (Doctoroff, 1995:340; Centner, 2000:42). Previously audiologists preferred not take up these positions because of a more lucrative market in the private sector. It is the healthcare system's responsibility to reassess these positions as a competitive proposition to qualified audiologists.

According to the data contained in Table 4.4 (number of audiology /speech-language therapy posts) there is an obvious shortage of audiological manpower in the public health sector of South Africa. Based on the international estimated prevalence of congenital hearing loss of 2.2% there must be approximately one million individuals with hearing loss in South Africa (Mencher, 2000:180). If a South African prevalence estimate of 10% is used (Sellars & Beighton, 1997:15), the number of individuals with sensori-neural hearing loss is approximately 4.5 million. According to these prevalence estimates, if only half of the registered audiologists /speech-language therapists in South Africa provide dedicated audiological services, each of these audiologists are required to serve between 903 and 4 103 individuals with hearing loss. However, the vast majority of these audiologists are in private practice. This significantly increases the ratio of individuals with hearing loss per audiologist in the national healthcare system, which serves the largest proportion of the population. These figures indicate an overwhelming number of individuals with hearing loss who require audiological services from a very small number of professionals.

A final manpower challenge lies in the multilingual and multicultural characteristics of a country such as South Africa where the minority of people are mother tongue speakers of English and Afrikaans. So far, only a small percentage of mother tongue speakers of an African language have qualified as audiologists (Uys & Hugo, 1997:24). Delivering linguistic and culturally appropriate EHDI services to the vast majority of the population is a significant challenge to the audiological community in South Africa. The audiological manpower available in South Africa is insufficient, culturally and linguistically misrepresented, and unequally distributed between the private and public sector. The following section will review the status of audiological service provision to infants and young children in the public healthcare system.

4.4.3. Status of audiological services to infants and young children

The infrastructure of audiological services available in the public health sector must be ascertained to allow for reliable planning of widespread EHDI

programmes. Although the number of audiologists in each region provides an indication of human resources, providing services to infants and young children is heavily dependent on available equipment, effective referral mechanisms and teamwork. An inventory of this type of information is essential to the planning, implementation and execution of widespread audiological services such as infant hearing screening. Unfortunately no comprehensive South African study has as yet been conducted to ascertain the status of audiological services in the public healthcare sector. This neglect of audiology in the public healthcare sector is also evident in the national primary healthcare facilities survey of 2003 where no mention is made of audiology positions (Reagon et al., 2004:1-96). This emphasises the need for urgent action to provide a profile of the current status of audiological service in the South African healthcare system.

To provide an interim overview of local audiological services, an evaluation of the status of specific professional functions of audiologists in South Africa is provided in the following section. These professional functions include research, prevention, screening, assessment and intervention selected as those primary functions that are essential for an EHDI programme (Hugo, 2004:7).

4.4.3.1. Audiological research in South Africa

A science is built on the research it generates (Hugo, 1998:4). This is no different in the field of audiology where research is an essential cornerstone that underlies all aspects of the profession. It is a basic and inseparable part of all the other professional functions in audiology. According to Hugo (1998:4) a profession is established, sustained and developed by generating research. Audiological training and services in South Africa have always incorporated and used international research to guide service delivery to infants and children. The necessity for local research to sustain and develop the profession of audiology in South Africa has, however, become more prominent with an increased emphasis on providing relevant and accountable services for the entire population. Future activities must therefore be guided by findings of past research (McPherson & Swart, 1997:3)

Although research has always been an important part of audiological service delivery for infants and young children in South Africa, it has occurred on a small scale with limited application to the whole population. An urgent need exists for comprehensive research endeavours toward the improvement and development of audiological services to infants and young children in South Africa. Despite limited resources for research in developing countries, the research endeavours must mix the ideal formal research protocol with the reality of the nation and then problem solve to make it work (Mencher, 2000:180). Research efforts should be aimed at addressing two main aspects, namely determining the prevalence and aetiology (epidemiology) of hearing loss in infants and young children across the whole South African population, and establishing the status of the audiological service infrastructure of South Africa in terms of personnel, work setting, functions, collaborations and equipment as it relates to infants and children.

Currently there is a paucity of knowledge regarding both of these aspects (McPherson & Swart, 1997:5). Effecting the necessary changes in South African healthcare is dependent on context-specific research initiatives reporting both specific characteristics and needs based on representative research reports (Gopal et al., 2001:100; White, Behren & Strickland, 1995:12). Epidemiological data on childhood hearing loss in South Africa is scarce and those studies available are limited to small regions – mostly reporting on school-aged children – and are often not comparable due to methodological differences. Information regarding the status of audiological services for EHDI programmes throughout the country is even more difficult to come by. This information is, however, essential to the planning of widespread EHDI programmes based on accurate knowledge regarding existing infrastructures and service provision. The following section provides a summary of audiological services rendered to infants and young children.

4.4.3.2. Audiological prevention and screening for infants in South Africa

Prevention of hearing loss is an important professional function of the audiologist and a role that is supported by the South African Department of Health. The lack

of awareness among healthcare professionals and the lay public regarding audiology services is a continued obstacle toward prevention of hearing loss in South Africa. This includes a lack of awareness about the profession of audiology, risk factors for hearing loss, the effect of hearing loss and the importance of early intervention (Centner, 2000:40; Kathrada, 2000:54; Kopp, 2000:37; Malherbe, 1999:24).

The only studies reporting on the status of prevention and screening of infants in South Africa are unpublished undergraduate research projects, which provide fragmented information but are nonetheless useful in light of the lack of available published reports. A study investigating speech-language therapy and audiology services in the Western Cape identified an inadequate awareness of audiological services among nurses, parents and the general public (Centner, 2000:40). Studies indicate that nurses possess relatively limited knowledge about the role of the audiologist for providing services to infants (Kopp, 2000:37) and it seems that community rehabilitation workers also have a restricted, and in some cases misguided, perception of the profession (Malherbe, 1999:24). This lack of awareness among important team members leads to poor knowledge of the services audiologists can offer. The majority of health professionals (health administrators, neonatal nurses and paediatricians) surveyed in the Durban metropolitan area in KwaZulu-Natal had not heard of neonatal hearing screening programmes before (Kathrada, 2000:54). These reports, although regional, imply a general lack of knowledge regarding audiological services and remain a stumbling block to exercising the professional function of prevention.

The lack of preventive audiology in the public health sector is despite the fact that child health is a priority component of the primary healthcare package in the new South African health system. The latter includes comprehensive curative and preventive services for children younger than 6 years of age. Currently, however, preventive care seems limited to immunisation against diseases and growth monitoring, when it should also include developmental screening, which incorporates hearing screening (Baez, 2003:1). Since the introduction of free health services for children under the age of 6, which led to a dramatic increase

in demand for services, the focus of nursing staff training has shifted to curative rather than preventive care. It is unfortunate, therefore, that the implementation of any programme or policy for developmental screening, including hearing screening, has thus far been overlooked (Baez, 2000:1). Late identification of hearing loss in South Africa is therefore not surprising, and children are identified as late as four and eight years of age (Centner, 2000:43). This leads to irreversible delays in language development, speech and cognition, with far-reaching social and economical ramifications (Yoshinaga-Itano, 1998:1161; JCIH, 2000:10; Mohr et al., 2000:2).

The relationship between early recurrent otitis media and poor language and central auditory processing has already been established by research and clinical findings (Campbell et al., 1995:73). The Department of Health has made an attempt at preventing hearing loss caused by otitis media in the form of a guiding document constituting part of the Primary Healthcare Package for South Africa (Department of Health, 2000:1). The document provides norms and standards for health clinics and specifically includes the prevention of hearing loss due to otitis media. A guideline that specifies the procedure and protocol for the prevention of hearing loss due to otitis media was also published at clinic level (Department of Health, 2001:4). Apart from this document, however, there is no other legislation regarding the prevention of hearing loss in South Africa. A broader approach to prevention has been suggested considering that other preventive strategies to reduce the prevalence of meningitis, measles, rubella, ototoxic drugs, congenital syphilis and some familial aetiologies may also reduce the number of cases of acquired childhood hearing loss (McPherson & Swart, 1997:18).

Limited studies have been conducted that document infant hearing screening services in South Africa. A study investigating neonatal hearing screening practice in two private and three public hospitals in the Durban metropolitan area indicated that no neonatal hearing screening programmes existed (Kathrada, 2000:54). Another survey by Höll (1997:51) regarding neonatal hearing screening practice in 13 well-baby nurseries and 7 NICUs in six state-subsidised

hospitals provides some indication of audiological neonatal screening services. The results indicate that at least 15% of the hospitals in the study did not perform any neonatal hearing screening. Of those hospitals that implemented hearing screening, 85-86% used behavioural observation screening techniques. The study concluded that neonatal hearing screening was unsatisfactory due to the following reasons: a lack of standardised procedures for conducting neonatal hearing screening; trained personnel and nurses not being used to conduct screening; shortage of training programmes for nurses; no efforts to make screening more reliable; no definite control over follow-up of screening results; and limited collaboration between audiologists and nurses. If the private hospitals that offer more advanced and structured screening programmes are excluded, the reported results should provide a fair reflection of neonatal hearing screening in the national healthcare system.

These types of surveys need to be conducted on a larger scale to ascertain the standard and scope of audiological screening on a national basis in South Africa. Currently the ability to perform neonatal hearing screening is limited to audiologists as they are the only professionals trained to perform IHS screening (Kathrada, 2000:54). Although it is recommended that nurses do IHS (HPCSA, 2002:4), this practice has not realised thus far. In addition, electrophysiological hearing screening is primarily confined to private hospitals with only a small number of audiologists in tertiary state-subsidised hospitals having access to such equipment. In general, however, the state neonatal screening programmes in South Africa are fragmented and lack standardised criteria for testing, referral and follow-up (Höll, 1997:27-29). It is clear that significant improvements in audiological prevention and hearing screening for infants in the public healthcare sector are necessary. Once an infant at high risk for having a hearing loss is identified by means of prevention or screening programmes, a thorough audiological assessment is essential.

4.4.3.3. Audiological assessment in South Africa

As mentioned earlier, audiological services are distributed unequally in South Africa with services mostly confined to metropolitan areas whilst other areas experience a dire need of services (Uys & Hugo, 1997:24; Centner, 2000:41). Although assessment protocols and procedures for infants and young children are well developed, they are not freely available in the South African context. A further concern regarding audiological service provision is that in certain cases unqualified persons were employed in the past due to a lack of qualified personnel. This has obviously resulted in poor and fragmented service delivery (Doctoroff, 1995:340; Centner, 2000:42).

A study by Centner (2000:39) investigating speech-language therapy and audiology services in the Western Cape indicates that audiological services have not been integrated into the primary healthcare structure. The study reveals that rehabilitative audiological care was not accessible in its complete form to the population and many children were unable to receive the required intervention due to inaccessibility and financial constraints (Centner, 2000:42). There were no audiological services at primary healthcare level or at secondary healthcare level. All identified cases were subsequently referred to tertiary healthcare levels (Centner, 2000:49). This poor referral system – with no audiological services at secondary level – causes excessive numbers of cases to report at tertiary hospitals (Centner, 2000:42). The over-referral to the limited number of personnel at these hospitals causes long waiting lists, which make service provision inefficient especially in light of the importance of immediate action for infants with hearing loss.

Accessible audiological services require a strong, effective and well-coordinated referral system that ensures easy and logical movement between primary, secondary and tertiary services (Kopp, 2000:3; Centner, 2000:42). The limited number of referrals unfortunately reflects the fact that only a few audiologists are present at primary and secondary healthcare centres and that nurses demonstrate a relatively limited knowledge of audiology (Kopp, 2000:37). Some

clinic nurses feel that it is senseless for them to conduct infant hearing screening since diagnostic facilities are not locally available (Centner, 2000:44). It must be noted, however, that the implementation of a community service year in 2003 for audiology graduate students may begin to address this persistent problem, provided that appropriate equipment is also made available.

Diagnostic audiology centres for infants and young children in the South African healthcare system are primarily based at tertiary hospitals and university clinics, making them less accessible to the majority of the population in rural areas (Kopp, 2000:3; Centner, 2000:42). Surveys are necessary to ascertain the audiological infrastructure throughout the healthcare system. This information will allow for future planning, development and implementation of audiological services. Once an infant is diagnosed with a hearing loss, the intervention process must commence as soon as possible to ensure optimal outcomes.

4.4.3.4. Audiological intervention in South Africa

A limited number of studies have documented the current status of early intervention service delivery to infants and young children with special needs such as hearing loss in South Africa (Fair & Louw, 1999:14). It is, however, generally accepted that infants and young children in the developing contexts of South Africa are not receiving adequate intervention services (Fair & Louw, 1999:14). Speech therapy and audiology service delivery to the developing rural population groups has specifically been shown to be inadequate (Seef & Bortz, 1994:73). This is detrimental to the eventual outcomes of those infants, since the first intervention step in treating hearing loss in infants involves the efficient and timely fitting of appropriate amplification devices (Diefendorf, 2002:473).

No state subsidy is allocated for cochlear implants although three private implantation centres are established throughout South Africa. The South African healthcare system does, however, provide hearing aids to individuals with hearing loss at minimal costs although the availability thereof is questionable (Wansbury, 2002:26). A recent study by Wansbury (2002:20) investigating the

availability of these hearing aids in six state-subsidised hospitals revealed an unequal distribution of available amplification devices. In 50% of the hospitals the demand for hearing aids exceeded the supply and waiting lists of between 2 and 9 months for up to 48 patients were reported. In the other half of hospitals hearing aid demand was adequately met and supply even exceeded demand in one hospital. These results indicate poor coordination and distribution of resources and emphasise the need for large-scale surveys addressing all aspects of audiological service delivery, inventory of equipment and availability of supplies (Wansbury, 2002:24,25). It is essential to optimise the intervention process, beginning with amplification as the first step, since early identification benefits are lost when there are long waiting lists. Neonatal or infant hearing screening without prompt intervention is also considered unethical (HPCSA, 2002:6).

Due to a shortage of qualified personnel, audiologists' use of traditional institution-based models of service delivery has proven to be ineffective in reaching the majority of the vulnerable and disadvantaged communities of South Africa (Moodley et al., 2000:26). The restructured National Health System mandates a transition in service delivery from institution-based services to community-based services (*White Paper on Integrated National Disability Strategy*, 1997:86). Implementation of community-based services has not been without persisting problems. Poor coordination of early interventions is a continuing problem especially in South Africa in the light of the country's history of limited resources, fragmentation and lack of coordination in health service systems (Moodley et al., 2000:26).

Educational intervention for infants and young children with hearing loss in South Africa has not been conducive to the inclusion of individuals into society. Children with hearing loss have primarily been placed in special schools for the deaf of which there are 35 nationwide (Van Dijk, 2003:17). These schools are not enough for the conservative estimate of approximately 169 550 school-aged children with hearing loss (Van Dijk, 2003:21). It is only more recently that the government policy started to stress more inclusive practices to allow

accommodation of children with hearing loss into mainstream schools (Department of Education, 2001:4). Although this approach is aimed at the better integration of hearing disabled persons into society, it faces many challenges in the current South African context, such as overcrowding of classrooms and large teacher/child ratios (van Dijk, 2003:21). A change of focus in South African education toward more inclusive practices is a positive change for children with hearing loss since the outcomes of an effective EHDI programme should be inclusive school placement. Challenges to the comprehensive implementation of this inclusive educational system are therefore also possible barriers to the desired outcomes for infants with hearing loss enrolled in EHDI programmes.

The discussion of audiological manpower and the current status of audiological services in the above paragraphs has highlighted a significant number of barriers and persisting challenges to the delivery of effective and widespread EHDI services to all South Africans. These challenges are summarised in the following section.

4.5. SUMMARY OF THE CHALLENGES TO EHDI IN SOUTH AFRICA

A review of the South African context and EHDI services in South Africa has revealed that there are many challenges to the implementation of the recommendations made in the South African HSPS (HPCSA, 2002:1-8). The challenges that require consideration for implementing widespread EHDI programmes in South Africa (as discussed in paragraphs 4.3 and 4.4) are summarised in Table 4.5.

TABLE 4.5 Summary of challenges to EHDI in South Africa

CHALLENGES OF THE SA CONTEXT	CHALLENGES OF SA AUDIOLOGY SERVICES
<ul style="list-style-type: none"> - Multicultural, multilingual, and multiracial nature of SA population - Geographical distribution of infants and young children with special needs - Large third world sections and small first world section coexist - Large racial disparities in human development - Extensive poverty and inequality - Large discrepancies in levels of education across race and gender - Prevailing socio-economic conditions do not support the normal healthy development of many of the country's children - Most young children (55%) reside in rural areas where poverty is rife and the infrastructure least developed - Majority of children with disabilities live in extreme poverty in inhospitable environments - Prevailing attitudes and ignorance hinder prevention of and early intervention for hearing loss - South African socio-economic challenges are environmental risk factors which place infants at and increased risk of developmental disabilities - HIV pandemic: High prevalence of infected infants and orphaned infants and children - HIV infected infants are prone to ear disease and disease and deterioration of the auditory system - There is a crowding out of non-HIV related illnesses - Demands on health sector are increasing while the capacity is undermined through losses of staff owing to HIV/Aids - Lacking in policies and legislation for disabled and at-risk infants 	<ul style="list-style-type: none"> - Paucity of neonatal / infant hearing screening programs - Importance of hearing screening largely overlooked - Only audiologists are currently trained to perform neonatal / infant hearing screening - Limited collaboration between audiologists and nurses in terms of screening - Limited hearing screening with OAE and AABR screening technologies - Unequal distribution of audiology services – mostly confined to metropolitan areas making accessibility difficult for large portions of the population - Unqualified persons are delivering audiological services in certain cases - Audiological services have not been adequately integrated into the primary health care structure yet - Diagnostic audiological centres are primarily based at tertiary hospitals and are often far and inaccessible to large portions of the population - Shortage of audiologists in the public health sector - Shortage of audiologists who are fluent in African languages and familiar with African culture - Unequal distribution of audiologists across provinces as measured against their population size - Limited audiological equipment and supplies - Small scale research endeavours with limited application to larger sections of the population - Limited information regarding the audiological infrastructure and standard of care for infants and young children in the health care system - No large-scale prevalence and aetiology studies for infant hearing loss in South Africa - Lack of awareness amongst health care professionals and the lay public regarding the audiology profession, risk factors for hearing loss, the effect of hearing loss and the importance of early intervention - Few preventative strategies to reduce no. of acquired childhood hearing loss (e.g. for meningitis, measles, rubella, ototoxic drugs, congenital syphilis, and some familial aetiologies) - Poor coordination of early intervention services - Absence of structured early identification programs and well-organized referral systems causes fragmented early intervention services - Unequal distribution of funds for hearing aids: long waiting lists are common

Although the challenges summarised in Table 4.5 have been extrapolated from the South African context and EHDI service delivery status, these challenges are not uncommon throughout the developing world. Early identification of and intervention for infants with hearing loss in developing countries are hampered by similar barriers in all developing countries – including lack of trained personnel and equipment, supply shortages, and the overburdening of understaffed health units (Newton et al., 2001:230; Gell et al., 1992:645). The challenges have not, however, discouraged efforts globally to implement EHDI programmes in developing contexts. Despite these difficulties, reports of UNHS programmes are continuing to emerge from developing countries as the desire to implement UNHS is spreading from developed countries to other regions (Chapchap & Segre, 2001:33; Psarommatis et al., 2001:25; Lin et al., 2002:209; Mencher & DeVoe, 2001:19; Rouev et al., 2004:805). The growth in UNHS programmes in countries outside the developed world emphasises the need for the development of feasible and effective EHDI service delivery models suited to the unique challenges of developing countries.

This aspiration to implement widespread EHDI services in South Africa is evident in the year 2002 HSPS, which provides direction in the development of UNHS programmes (HPCSA, 2002:1-8). The document specifies First World screening goals for the South African context in an attempt to provide first-class clinical services in a developing country. The South African healthcare system is relatively well developed compared to other developing countries (Children in 2001, 2001:116,117), which allows the possibility to provide quality audiological services despite the prevailing challenges. This has proved to be possible in other developing regions but also in the development of neonatal hearing screening programmes in the late 1960s in Colorado, USA, when very limited resources were available (Silverman & Moulton, 1997:5-7; Downs, 2002). Such services require a thorough knowledge of the prevailing challenges so that a contextually relevant EHDI system may be developed in the future.

4.6. FUTURE OF EHDI SERVICES IN SOUTH AFRICA

EHDI programmes are consistent with South African primary healthcare priorities (Fair & Louw, 1999:17) and should constitute an essential part of services to infants and young children if these priorities are to be met. The guidelines specified by the year 2002 HSPS provide a valuable set of standards to direct the future of EHDI in South Africa (HPCSA, 2002:1-8). These standards should be used for advocacy purposes at national level and with administrators at management level.

The HSPS specifies neonatal hearing screening in well-baby nurseries and NICUs (HPCSA, 2002:5), which are screening contexts similar to those in developed countries such as the USA and UK. A significant pool of information and resources is available to guide and measure service delivery in these contexts (Mencher & DeVoe, 2001:18). A third screening context is also recommended, namely at 6-week immunisation clinics. These clinics are part of the Maternal and Child Health (MCH) clinics and they are not specified as screening contexts in developed countries (JCIH, 2000:13,14). The HSPS has put forward a benchmark of having screening equipment available at all MCH clinics in 2005 to allow hearing screening for all infants attending their first immunisation visit (HPCSA, 2002:5).

The rationale for including this third screening context is the fact that the South African healthcare system is based on a primary healthcare approach which aims to provide an accessible service to the whole population. A unique problem in developing countries like South Africa is that a significant number of births do not take place in hospitals but either at home or in clinics. Reports indicate that the majority (70%) of South African children are born in hospitals, but the actual percentage varies greatly across regions. In the Central Karoo, for example, all births were reported to have occurred in a hospital, compared to the Tambo district where 51% of births were in a hospital, 2% were in clinics, and the other 40% were home births (Statistics South Africa, 2002:65). The use of 6-week

immunisation clinics at MCH clinics therefore provides a means of reaching the entire population with infant hearing screening.

The Maternal and Child Health clinics are specifically suited to the delivery of community-based services by providing extensive coverage of all newborn and maternal health services in South African communities. The 6-week immunisation clinics provide comprehensive coverage since only 2% of South African children aged 12 to 23 months do not receive vaccinations (Children in 2001, 2001:75). This also means that the use of immunisation clinics for hearing screening could provide coverage of 98% of children younger than 23 months of age. There will obviously be a large discrepancy between the recommended 3-month age of identification specified in the HSPS and the potential 23-month age of actual identification (HPCSA, 2002:5). However, a recent report indicated that 79% of all infants in South Africa were fully immunised by one year of age (Solarsh & Goga, 2004:121). If this is true, it would ensure an almost 80% coverage for hearing screening before an infant is six months old. Although the recommended 95% coverage is not achieved in this way yet, it should be remembered that the 6-week immunisation clinic is but one of three screening contexts recommended by the South African year 2002 HSPS (HPCSA, 2002:5).

A concern, however, is the screening age at these MCH 6-week immunisation clinics. The HSPS recommends identification of hearing loss before three months old (HPCSA 2002:5), but a baby's first immunisation may well occur any time during the first year of life even though it is scheduled for six weeks after birth (Children in 2001, 2001:75). The Department of Health has recently put forward a strategic plan to ensure that full immunisations are realised for all infants by one year of age with an intermediate step of 90% national coverage by 2005 (Solarsh & Goga, 2004:113,122; Children in 2001, 2001:75). Even when infants are screened at exactly six weeks of age on their first immunisation visit, however, it allows limited time for follow-up and confirmation of hearing loss before 3 months of age (JCIH, 2000:15). The 3-month benchmark has originated in the United States, where almost all hearing screenings take place within 48 hours after birth. For hearing screening in well-baby nurseries and the NICU this

may be a reasonable benchmark for South Africa, but it might prove very difficult to attain at MCH clinics. A further concern at these clinics is the fact that older infants are more difficult to test than newborns and this may result in less successful infant screens (Palmu et al., 1999:210).

Timely and efficient confirmation of hearing loss for infants screened at 6-week immunisation visits at MCH clinics will require an integrated multi-disciplinary follow-up system. An essential component will be the education of mothers/caregivers regarding the importance of returning for follow-up appointments, the effect of late-identified hearing loss, and the benefits of early identification and intervention. According to *Children in 2001* (2001:75), mothers who are better educated are more likely to return for the full set of vaccinations and probably also for the follow-up hearing screenings and evaluations. A large-scale initiative of this nature must, however, be carefully considered, evaluated and planned within an appropriate model of EHDI service delivery in MCH clinics (Fair & Louw, 1999:14).

It is also essential that appropriate screening technology be selected and the best screening protocols be developed for the varying screening contexts in South Africa. This will require applied research methodologies implemented at pilot sites to investigate the various possibilities. In addition to investigating the screening technology and protocols for South Africa, the Year 2002 HSPS provides future challenges as priority aspects to be considered. These challenges are summarised in Table 4.6 (HPCSA, 2002:7).

TABLE 4.6 Priority challenges to developing EHDl programmes in South Africa

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- Principles of primary healthcare must be fully adopted in order to respond to the escalating need for community-based and family-oriented early intervention programmes.
 - Research is needed to differentiate between truly congenital and perinatally acquired hearing loss.
 - Strategies for the optimal management of auditory neuropathy need to be identified and implemented.
 - Consideration should be given to the way in which technological advances in the measurement of hearing acuity, amplification and cochlear implantation will affect services delivery.
 - Genetics of hearing loss and patterns of inheritance should be investigated.
 - Benchmarks and quality indicators need to be developed and established to evaluate the effectiveness of neonatal and infant hearing screening programmes.
 - Health, social service, and education organisations associated with early intervention must continually monitor progress to ensure that EHDl programmes are timely, effective and beneficial to the whole South African population.
-

Important aspects to consider for the future implementation of early intervention services in South Africa are also highlighted by Moodley et al. (2000:37,38). These authors remark that adoption of a transdisciplinary team approach is essential to increase the accessibility of hearing screening services; collaboration is important at different levels of the healthcare system to ensure advocacy at and access to different levels; marketing of audiological services are necessary to increase awareness among professionals and the lay public; and the training of audiologists must be directed at the current and projected demand for EHDl services. In addition to this, recruitment efforts must be made to enrol students from culturally and linguistically diverse backgrounds to reflect the composition of the South African population.

The dire need for EHDl services for infants and young children with hearing loss in South Africa necessitates the proactive collaborative efforts of audiologists in conjunction with legislative support and funding from the government. This challenge needs to be met by consistent efforts from audiologists on all levels

including management, research, service delivery and training in order to ensure effective and accountable early intervention service delivery to the maximum benefit of infants and toddlers with hearing loss in the developing communities of South Africa.

4.7. CONCLUSION

The priority of implementing a national system of EHDI is aimed at ensuring good hearing as a basic human right for all infants. The desire to develop and implement EHDI programmes for children in developing countries such as South Africa is therefore just as intent, humane and appropriate as it is for developed countries (Mencher, 2001:19). Unfortunately the lack of standards, equipment, staff, facilities and other resources are persistent obstacles to developing contexts. These challenges of infrastructure and contextual characteristics must be considered and addressed by systematic planning and legislative support.

Despite the many challenges toward the implementation and maintenance of effective EHDI services, there have been a number of positive changes to support the cause of providing quality services to infants with hearing loss in South Africa. These changes include the following:

- Health and education policies are in support of early identification and appropriate timely interventions for disabilities such as hearing loss (*An Integrated National Disability Strategy*, 1997:22; Department of Education, 2001:4).
- The South African Year 2002 HSPS gives valuable direction by providing a set of standards where none previously existed.
- A compulsory community service year for audiology graduates will raise the awareness of audiological services by giving it better visibility, as well as increase the manpower to implement widespread EHDI programmes.
- An existing MCH immunisation clinic infrastructure provides an important platform for thorough screening and follow-up coverage with 98% of

children receiving at least one immunisation before 23 months of age and 79% of infants being fully immunised by one year of age (Solarsh & Goga, 2004:112; Children in 2001, 2001:75)

- Technological developments leading to reduced costs of electrophysiological hearing screening measures (Oto-Acoustic Emission and Auditory Brainstem Response screeners) and minimal false positive rates (~ 100% screening sensitivity and specificity as low as 98%) make this type of screening a feasible option (Mencher & DeVoe, 2001:18; Mehl & Thomson, 1998:2)

The positive changes provide guidelines, support and a platform for EHDI services in South Africa. The assessment of real cost and efficiency on the basis of pilot studies remains essential prior to the widespread implementation of such services. This is especially relevant in South Africa – a resource-poor country with low literacy levels – where a non life-threatening yet debilitating condition such as hearing loss is not receiving the institutional support, research funding and political advocacy which it deserves. The ability to identify hearing loss at birth does not mean we in South Africa are ready to deal with the responsibilities and consequences of UNHS (Mencher & DeVoe, 2001:19). Contextual research regarding epidemiology and prevalence, especially for unique populations such as HIV-infected infants, is crucial alongside surveys assessing hearing healthcare services. This data is necessary to ascertain the nature and impact of hearing loss in infants and the standard and scope of otological and audiological services in South Africa so as to ensure a relevant course of action. A UNHS programme should be incorporated into primary and secondary healthcare services to ensure that it becomes an integral part of a health and education programme.

South Africa needs to access international resources to guide and support innovative, context-specific research endeavours for the planning of screening programmes that improve hearing healthcare for all infants in a cost-effective and accountable manner.

4.8. SUMMARY

This chapter provided a critical evaluation of EHDI services in South Africa. The benchmarks and standards for EHDI services in South Africa were discussed first as proposed by the year 2002 HSPS. These benchmarks and standards were subsequently evaluated against the current South African context and status of EHDI services in South Africa. The South African context was evaluated in terms of its population characteristics, disability prevalence, socio-economic infrastructure, effect of HIV/AIDS, and the healthcare system for children. The status of EHDI services was also discussed in terms of the available audiological manpower and the status of audiological services for infants and children. The challenges posed by the South African context and the status of EHDI services were summarised together before the focus of the discussion turned to the future direction of EHDI in South Africa. The chapter was drawn to a close by an appropriate conclusion.