

## CHAPTER 2

# PRINCIPLES AND CURRENT PRACTICE OF INFANT HEARING SCREENING

**Aim:** This chapter evaluates the principles of newborn hearing screening as a societal responsibility and assesses the current practice thereof in the developed world

### 2.1. INTRODUCTION

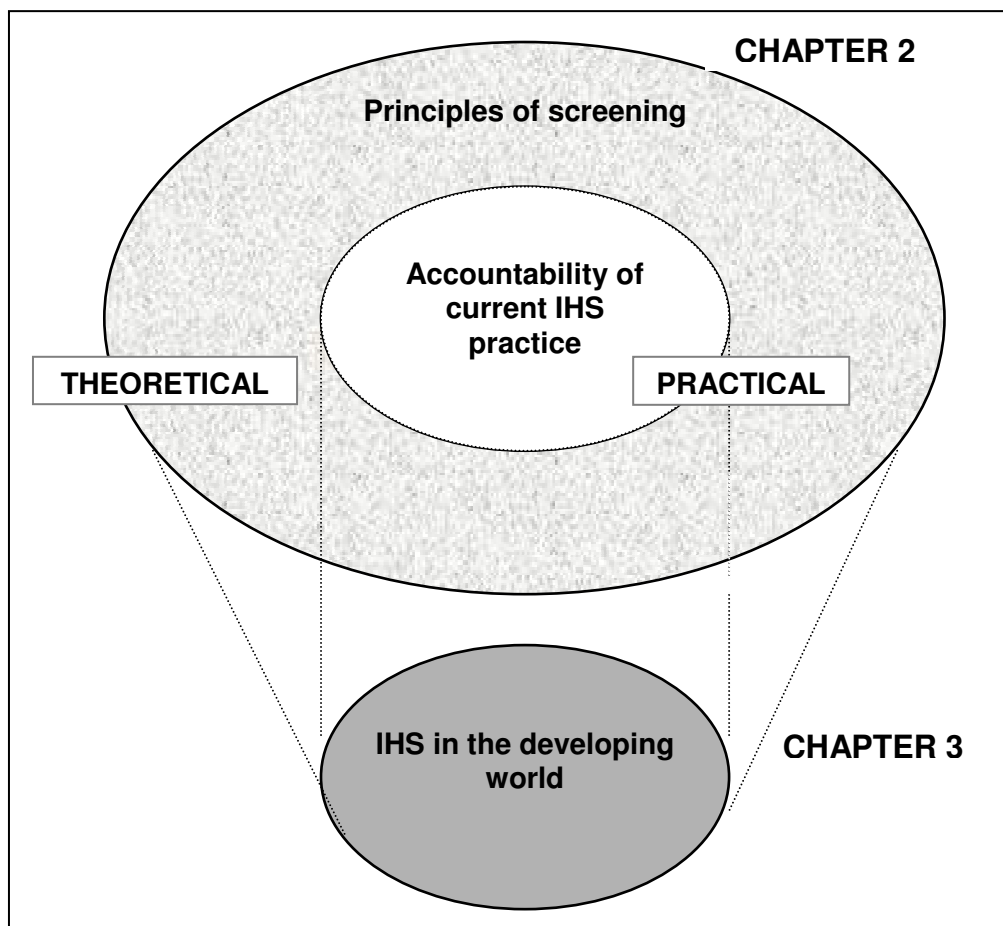
It is estimated that every day, on average, 33 babies are born with congenital hearing loss in the USA, making it the most prevalent major birth defect in that country (White, 2003:79). The fact that these hearing-impaired infants miss out on critical periods of exposure to adequate auditory and language stimulation creates a sense of urgency, emphasising the need for early intervention. Although it is only over the last 20 years that early intervention has developed into an internationally accepted means of delivering services to infants and toddlers with special needs, audiologists have been intent on early identification of hearing loss for at least the past 60 years (Northern & Downs, 2002:259; Widerstorm et al., 1997:17). This commitment to the identification of hearing loss as early as possible was based on the premise that the earlier habilitative/rehabilitative measures could be implemented, the better the outcomes would be.

In recent years the above sentiment has been proved correct by various research reports (Yoshinaga-Itano, 2003:205). Infants who are identified with hearing loss soon after birth and who receive early intervention have an important and measurable advantage over later-identified peers and many children with hearing loss who receive comprehensive early intervention services

before six months of age achieve language abilities similar to hearing peers (Yoshinaga-Itano, 1995: 129; Yoshinaga-Itano & Apuzzo 1995:124; Carney & Moeller, 1998:78-79; Moeller, 2000:6-7).

The continued growth in research evidence that reports the importance and benefits of early intervention for hearing loss has resulted in neonatal hearing screening becoming the *de facto* medical/legal standard of care in the USA (White, 2003:85). The UK and increasing numbers of European countries have also introduced universal newborn hearing screening (UNHS) and are in the process of implementing it as standard practice for newborn healthcare (Parving, 2003:154; Davis & Hind, 2003:194). These large-scale healthcare initiatives to provide early intervention services to very young hearing-impaired infants represent a major, but welcome challenge to paediatric audiological services (Parving, 2003:154). According to the International Society on Early Intervention (1999:1), addressing this challenge should be one of the most important priorities for contemporary societies.

Although the principles underlying this practice appear to be universal, the practices across countries vary greatly (Mencher et al., 2001:8). **The purpose of this chapter is therefore to evaluate the principles of Infant Hearing Screening (IHS) as a societal responsibility and to assess current practice in the developed world as a background to considering IHS in the developing world (Chapter 3).** This chapter provides two constructs, one theoretical and one practical (as depicted in Figure 2.1), which provide the foundation for Chapter 3. The philosophy, theory and principles of screening are investigated to ensure its validity as a societal practice. In a more practical sense, the current status of such programmes in developed nations, such as the USA, is assessed to determine the accountability and direction of these initiatives.



**FIGURE 2.1 Theoretical and practical construct (Chapter 2) for evaluating IHS in the developing world (Chapter 3)**

## **2.2. PHILOSOPHY OF SCREENING**

Defined in general terms, screening may be considered as a process of filtering cases into two groups. The first group has an adequately high probability of having a given disease or condition to warrant referral for further testing. The second group has an adequately low probability of having the disease or disorder and therefore does not merit the expense, inconvenience or risk of diagnostic testing (Lutman, 2000:367). The goal of a screening programme is therefore to identify asymptomatic individuals with an increased likelihood of presenting with the target disorder, so that diagnostic testing procedures can be applied only to that subset of individuals (Roush, 2001:33).

Screening for disorders is an important component of all the health sciences, and general principles serve to guide an accountable screening process. For the audiologist, identification through screening has been identified as a primary professional role by the HPCSA (Hugo, 2004:7). The American Speech-Language-Hearing Association (ASHA) provided an outline of essential elements to be considered in any screening programme (ASHA, 1995:26-27). These elements are summarised in Table 2.1.

**TABLE 2.1 Elements of a screening programme (ASHA, 1995)**

<p style="text-align: center;"><b>1. PURPOSES OF SCREENING</b></p>	<p style="text-align: center;"><i>To separate from among apparently healthy individuals those for whom there is a greater probability of having a disease or condition and then refer them for appropriate diagnostic testing.</i></p>
<p style="text-align: center;"><b>2. IMPORTANCE OF THE DISEASE</b></p>	<p style="text-align: center;"><i>Every disease has a cost to society; the greater the burden to society, the greater the reason to screen for the disease. Factors that must be considered include the prevalence, morbidity and duration of the disease, as well as the cost of screening, diagnosis and treatment.</i></p>
<p style="text-align: center;"><b>3. DIAGNOSTIC CRITERIA</b></p>	<p style="text-align: center;"><i>For a screening programme to be successful, there must be a clear and measurable definition of the disease being screened for. In addition, measurable and acceptable criteria for diagnosis must be available.</i></p>
<p style="text-align: center;"><b>4. TREATMENT</b></p>	<p style="text-align: center;"><i>Before a screening programme is implemented, it is necessary to demonstrate that treatments are available, effective and shown to alter the natural history of the disease. It should also be shown that treatment early in the disease process results in greater benefits than when treatment is begun in the symptomatic patient.</i></p>
<p style="text-align: center;"><b>5. THE PROGRAMME MUST REACH THOSE WHO COULD BENEFIT</b></p>	<p style="text-align: center;"><i>It is important that screening programmes be administered so that those who would most likely benefit from early identification are included easily. Mechanisms for outreach to the targeted population should be in place. Education and public policy can influence how well screening programmes succeed in reaching those it should reach.</i></p>

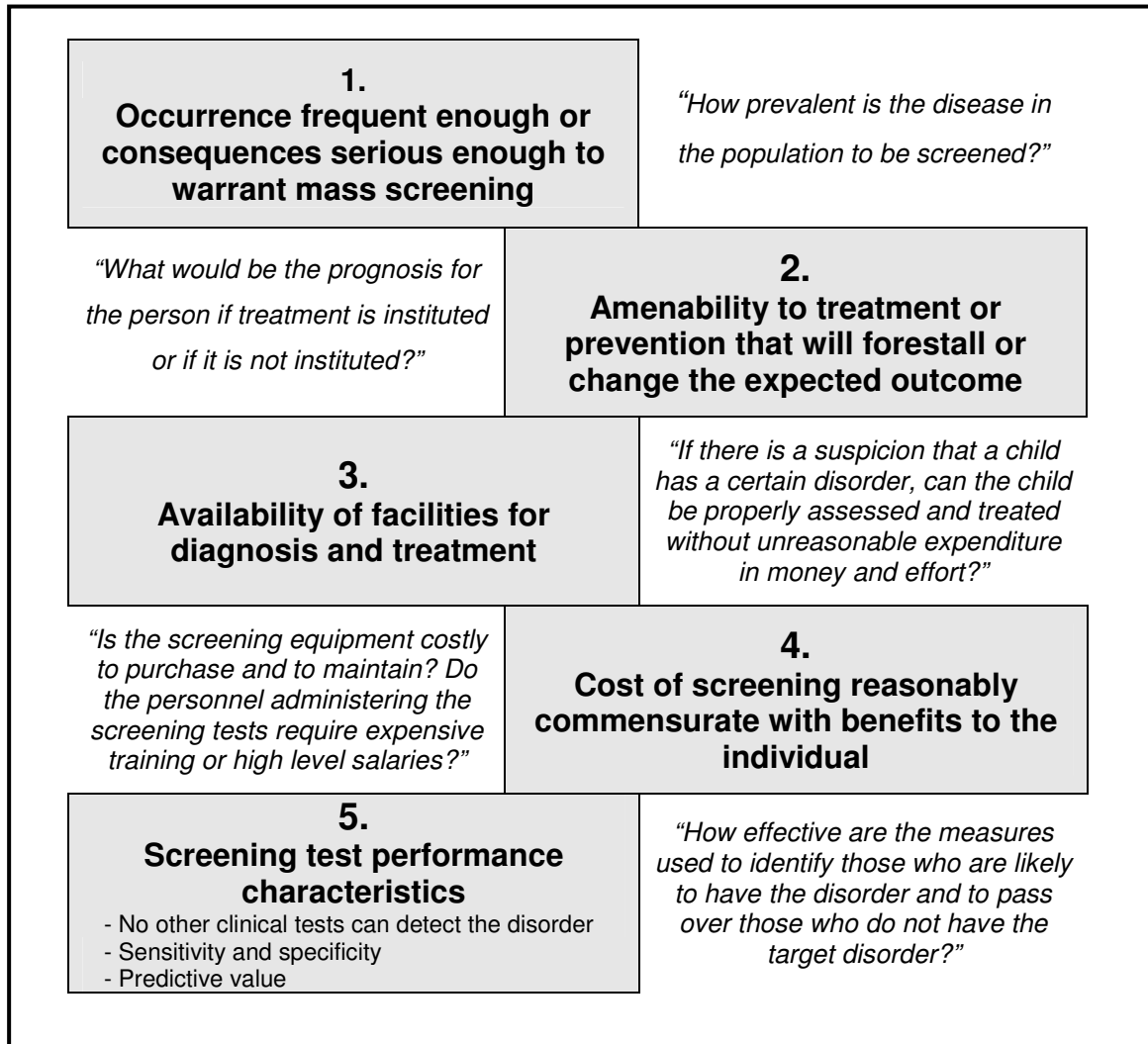
**TABLE 2.1 Continued**

<p><b>6.</b> <b>AVAILABILITY OF RESOURCES AND COMPLIANCE OF THOSE IDENTIFIED</b></p>	<p><i>Diagnostic and treatment resources appropriate for the population being served must be available before a screening programme can be managed successfully. After identification, those identified must comply with follow-up components of the screening programme. Diagnostic and treatment resources must be able to accommodate the influx of clients who are referred after the screening.</i></p>
<p><b>7.</b> <b>APPROPRIATENESS OF THE TEST</b></p>	<p><i>A screening test should be simple and preferably easy to administer, comfortable for the patient, short in duration and inexpensive. It must also meet performance criteria. It must be sensitive, specific, precise and accurate.</i></p>
<p><b>8.</b> <b>SCREENING PROGRAMME EVALUATION</b></p>	<p><i>Screening programmes must be evaluated. Protocols must be based on data that demonstrates that individuals identified through screening have better outcomes than those not screened. Direct monetary costs can be computed and such costs can be modified through administrative decisions.</i></p>

According to Roush (2001:24), these elements set benchmarks against which screening initiatives should be evaluated. A disorder to be screened for must first be a problem that is significant to the individual and to society. There must be good evidence of effective treatment once the problem is detected and the screening test must be properly evaluated and shown to be acceptable in the setting where screening is to be performed. It is also essential that there be evidence that a screening programme resulting in treatment is of greater benefit than waiting until symptoms develop. Cost issues should furthermore be considered and judged to be reasonable. Lastly, care must be taken to ensure that there are plausible strategies and sufficient resources to facilitate implementation (Roush, 2001:24).

Deciding on whether or not to screen for a disorder is an important societal and public health priority that requires careful consideration. A useful outline for evaluating a disorder according to the principles of screening philosophy is summarised from Northern and Downs (2002:260-265) and the American

Academy of Pediatrics (AAP, 1999:527-528). These criteria are summarised in Figure 2.2 below.



**FIGURE 2.2 Criteria for evaluation of a disorder according to principles of screening** (based on Northern & Downs, 2002:260-265 and AAP, 1999:527-528)

The above criteria are essential in determining if screening is warranted and, if so, for which type of disorder or disability. They may also assist in determining which screening procedures and protocols are to be used for specific disorder types. Consideration of these criteria constitutes the cornerstone for the development of a screening programme. An accountable process of screening

must therefore be measured within the general philosophy of screening against the specified principles thereof.

### **2.3. PRINCIPLES OF INFANT HEARING SCREENING**

The implementation of newborn hearing screening programmes worldwide has led to the development and refinement of screening principles. The latter adhere to the general screening philosophy and criteria but should be specifically stated for the population to be screened (ASHA, 1995:27-29). It is therefore logical that the first aspect that requires consideration and that influences the entire screening process, is what type of hearing loss to screen for. In other words, the specified or targeted condition needs to be defined (Davis et al., 2001:4). The target hearing loss to be screened for should be selected based on whether it proves to be a significant health problem (Davis et al., 1997:8). Distinguishing between hearing losses that may lead to a significant health problem and those that do not, is very difficult and has led to a number of different target disorders having been specified.

The European Consensus Development Conference on Neonatal Hearing Screening (Lutman & Grandori, 1999:95) recommended the targeted hearing loss in terms of “a permanent bilateral hearing impairment of at least 40 dB averaged over the frequencies 0.5, 1, 2, and 4 kHz”. The Joint Committee on Infant Hearing (JCIH, 2000:11) defined the targeted hearing loss for screening programmes as “permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 – 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000 Hz).” The American Academy of Pediatrics specifies a more simplistic target disorder of bilateral hearing loss, namely  $\geq 35$  dB HL (AAP, 1999:527). Despite differing statements regarding which hearing losses constitute significant health problems, once an operational objective of specifying the target hearing loss has been clearly defined, an evaluation of the justification of screening can be performed (Lutman, 2000:368).

Davis et al. (1997:8) provide a comprehensive set of screening principles for evaluating the justification that underlies screening for congenital hearing losses (see Appendix A). These principles, although thorough, are lengthy and a simpler yet comprehensive list could be evaluated more readily. A shorter comprehensive list that condenses a number of specific principles into fewer general principles has subsequently been compiled from the literature reviewed (Davis et al., 1997:8; White, 2002:1; Mehl & Thomson, 1998:3; Northern & Downs, 2002:260-267; Bamford, 2000:359-365; Mencher et al., 2001:1-10).

Six principles that underlie the practice of IHS have been identified as inclusive of the major aspects necessary for the justification of the screening procedure. These principles can be divided into two broad categories – principles relating to the disorder and those relating to the screening process. Principles relating to the disorder involve aspects such as the prevalence of the disorder, the effect of the disorder on development and the effect of intervention on development. The principles that concern the screening process include aspects such as accuracy of screening methods, efficiency of screening programmes and the costs involved. The disorder-related principles are fundamental in the justification of screening by investigating the need for and effect of screening for the disorder. The principles pertaining to the screening process, on the other hand, are more concerned with the accountability of the screening process to make it a justifiable healthcare practice.

The six principles extrapolated from the literature that constitutes the foundation of IHS as a justified healthcare practice are listed in Table 2.2.



**TABLE 2.2 Principles underpinning the practice of IHS**

<b>DISORDER-RELATED PRINCIPLES</b>
1. Prevalence of congenital hearing loss
2. Consequences of neonatal hearing loss
3. Effects of earlier versus later identification and intervention

<b>PROCESS-RELATED PRINCIPLES</b>
4. Accuracy of infant hearing screening methods
5. Efficiency of early identification programmes
6. Costs of infant hearing screening

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*(Extrapolated from Davis et al., 1997:8; White, 2002:1; Mehl & Thomson, 1998:3; Northern & Downs, 2002:260-267; Bamford, 2000:359-365; Mencher et al., 2001:1-10).*

Evaluating IHS to determine its status as an accepted healthcare practice requires a framework such as the principles listed in Table 2.2. These principles will be used as an outline for the evaluation of IHS as a justified healthcare practice in the following section. Since NHS programmes are the main source of research reports on infant hearing screening, the discussion is primarily based on data from NHS programmes.

### **2.3.1. Disorder-related principles of infant hearing screening**

As indicated earlier, the three principles underpinning IHS from a disorder-related perspective are prevalence of the disorder, effect of the disorder on development, and effect of intervention on development. These principles are of crucial importance in the justification of hearing screening as they investigate both the need for and the effect of screening. The following paragraphs will not only summarise the findings discussed in Chapter 1 regarding the rationale for

IHS based on the disorder-related principles, but will also focus on providing additional supportive information.

#### **2.3.1.1. Prevalence of congenital hearing loss**

The prevalence of hearing loss is significantly higher than that of other birth defects (Mehl & Thomson, 1998:2). According to Mehl and Thomson (1998:2), screening for bilateral sensori-neural hearing loss will identify 260 out of 100 000 afflicted newborns compared to 50 out of 100 000 with congenital hypothyroidism – the most common congenital condition routinely screened for in the USA.

The prevalence of newborn hearing loss was reported to be 1 in 1 000 live births for many years. This figure, however, referred only to congenital bilateral profound hearing loss (Carney & Moeller, 1998:63). Neither hearing loss of mild, moderate or severe degrees, nor unilateral hearing losses were then taken into consideration because it was so difficult to accurately characterise hearing loss in infants prior to the advent of OAE and ABR screening (Northern & Downs, 2002:266). Furthermore, early surveys did not include newborns at risk for developmental disabilities in which the presence of hearing loss is now known to be significantly higher than in the well-birth infant population (Northern & Downs, 2002:266). More recent studies have estimated a bilateral permanent newborn and infant hearing loss of 1.5 to 6 per 1 000 live births (Vohr et al., 2001a:238; Northern & Downs, 2002:267; Finitzo et al., 1998:1452). Apart from bilateral hearing loss, studies also indicate a significant prevalence of unilateral hearing loss. While Brookhauser, Worthington and Kelly (1991:1269) state that 37% of sensori-neural hearing loss is unilateral, Watkin et al. (1990:849) maintain that this figure is 35%. Whatever the case may be, it means that unilateral hearing loss affects a significant number of individuals, which further increases the prevalence of hearing loss.

Table 2.3 provides a summary of prevalence rates reported for bilateral permanent childhood hearing loss in population-based studies with children

between 6 and 12 years of age to demonstrate the prevalence of hearing loss when different target hearing losses are specified.

**TABLE 2.3 Prevalence rates reported for bilateral permanent childhood hearing loss in population-based studies**

Author and number of subjects	Threshold criterion for hearing loss (dB HL)	Prevalence per 1 000
Martin (1982), n=4 126 268	50 dB	0.9
Davis and Wood (1992), n=29 317	50 dB	1.1
Hadjikakou and Bamford (2000), n=188 583	50 dB	1.6
Feinmesser et al. (1986), n=62 000	40 dB	1.7
Kankkunen (1982), n=31 280	40 dB	1.3
Parving (1985), n=82 265	35 dB	1.4
Sehlin et al. (1990), n=63 463	30 dB	2.4
Sorri and Rantakallio (1985), n=11 780	30 dB	2.1
Fitzland (1985), n=30 890	25 dB	1.9

Increasing numbers of research studies are under way to provide further answers aimed at establishing the true prevalence of hearing loss in newborns and children (Northern & Downs, 2002:266). The answer is not a simple one, due to confounding factors such as the specific description of the target population; the definition of the hearing loss in terms of type, degree, bilateral and unilateral presence; protocols used; pass/refer criteria; and the success of follow-up and diagnostic procedures (Stein, 1999:103). A recent review of prevalence literature for permanent childhood hearing losses larger than or equal to 40 dB indicated a range of 0.78 to 1.8 per 1 000 (Fortnum, 2003:157). Other reports from UNHS programmes, however, suggest a prevalence of 2 to 4

babies with congenital permanent hearing loss (Barsky-Firsker & Sun, 1997:E4; Prieve, 2000:105; Mehl & Thomson, 1998:2; Finitzo et al., 1998:1456; Johnson et al., 1997:354). If unilateral hearing losses of 30 dB or greater are included, the prevalence will be closer to 4 per 1 000 live births, which significantly increases the prevalence of congenital hearing loss.

Although little is known about late-onset hearing loss within the first year of life, the JCIH (2000:21) estimated that only 2% of children with permanent hearing loss by 12 months of age had normal hearing at birth, based on data from a large multi-centre longitudinal study reported by Norton et al. (2000a). According to Davis et al. (1997:83), an estimated 10% of permanent childhood hearing loss is either progressive or *late-onset*. In a recent multi-centre study among 81 children who were survivors of neonatal respiratory failure (with or without diaphragmatic hernia) and who passed neonatal hearing screening at the time of hospital discharge, a high incidence of sensori-neural hearing loss was reported at 4 years of age. Altogether 53% of the children presented with sensori-neural hearing loss, of whom 70% had hearing loss at the age of 2 and of these, 60% was progressive between 2 and 4 years of age (Robertson et al., 2002:355).

*The prevalence of hearing loss in newborns and infants is therefore adequately high to justify hearing screening, especially when compared to existing screening programmes with much lower prevalence rates.*

### **2.3.1.2. Consequences of neonatal hearing loss**

When the second disorder-related principle is considered, it is clear that undetected hearing loss leads to irreversible language, speech and cognitive delays, with far-reaching social and economic ramifications (Yoshinaga-Itano & Gravel, 2001:62; JCIH, 2000:10; Yoshinaga-Itano et al., 1998:1161-1162; Mohr et al., 2000:3). Hearing loss in children impacts significantly on aspects such as language and literacy development, speech perception and production, and on socialisation and family dynamics (Carney & Moeller, 1998:63-S64).

Significant delays in language development and academic achievement have been reported widely for the majority of children with sensori-neural hearing losses, including those with mild degrees (Carney & Moeller, 1998:63). These delays are documented for numerous aspects such as vocabulary development, grammatical skills, concept attainment, social conversational skills and development of literary skills. Children with congenital bilateral severe-to-profound hearing loss who leave the educational system at the age of 18 years demonstrate an average middle-third to middle-fourth grade reading level and language abilities that are 50% to 90% of their chronological age, equivalent to a 9 and 10-year-old (Yoshinaga-Itano & Gravel, 2001:62). On average, children with a hearing loss who are identified late (after 12 months) exhibit a discrepancy of 40 to 50 points between nonverbal performance test scores and language ability. Even for the children who score in the top 10% of this distribution, the nonverbal/language discrepancy average is 20 points (Yoshinaga-Itano, 2003:200). These reports provide conclusive evidence of the serious negative effect of late identification of a hearing loss.

Mild or moderate degrees of hearing loss are also more likely to cause academic difficulties that can create significant delays in literacy development such as reading comprehension and other language-based academic skills (Davis et al., 1986:59; Bess et al., 1998:347). Bess et al. (1998:342) studied children with minimal sensori-neural hearing loss, which included children with unilateral hearing loss, bilateral sensori-neural hearing loss between 20 and 40 dB and high frequency hearing loss of greater than 25 dB at two or more frequencies above 2 kHz. The results indicated that 37% of these children had failed at least one grade and that they exhibited significantly greater dysfunction than children with normal hearing on aspects such as behaviour, energy, stress, social support and self-esteem (Bess et al., 1998:339). The deduction that is made from these results is that even minimal hearing loss categories have a significant impact on development and performance.

Speech perception ability is significantly reduced for children with all degrees of hearing loss, with increasing reduction as the hearing loss increases (Carney &

Moeller, 1998:64). This can cause difficulties in using their hearing in simple daily-life situations. The decreased ability to perceive differences in sound typically leads to a significant delay in speech production. For children with severe-to-profound hearing losses, all the aspects of speech may be disrupted – including articulation, voice, prosody, and timing of speech – whilst children with mild degrees of hearing loss may suffer far less disruption (Carney & Moeller, 1998:64).

Self-esteem and socialisation are other aspects that can be affected severely by early delays in communicative development. Davis et al (1986:55) report that half of the deaf or hard-of-hearing school-aged subjects expressed concerns about making friends or being accepted by classmates, compared to a 15.5% incidence of such problems among hearing grade-mates. These children also scored significantly higher than the norm on scales of aggression and somatisation, and parents rated them to have difficulties in the areas of aggression, impulsivity and immaturity (Davis, 1986:56). Family adjustment is also a challenge, which often leads parents to experience grief reactions and feelings of “a loss of control” when a child is diagnosed with a hearing loss. A considerable amount of evidence indicating the negative consequences of such parental stress on child development is available (Carney & Moeller, 1998:64).

*It is clear that undetected hearing loss in infants has serious negative consequences that impact on language, speech, academic and social spheres, even in the case of children with minimal losses.*

### **2.3.1.3. Effect of earlier versus later identification and intervention**

Analysis of the third principle proves that IHS yields dramatic benefits, since infants whose hearing loss is identified before 6 months of age have significantly better language abilities compared to those whose hearing loss was identified later (Yoshinaga-Itano et al., 1998:1164-1166; Moeller, 2000:5; Calderon & Naidu, 2000:53). The reason for this is that intervention (hearing aid fitting and supportive services) before the age of 6 months, enables infants to develop and

maintain normal language skills on a par with their cognitive development (Yoshinaga-Itano et al., 1998:1169). This is in stark contrast with the persistent language delay of two to four years for infants identified after 6 months of age (Yoshinaga-Itano et al., 1998:1169).

Theoretical arguments on auditory and cognitive plasticity have suggested that earlier auditory stimulation is better for developing the individual child's auditory and cognitive potential (Davis et al., 1997:83-84). These arguments have been supported by a number of more recent reports (Moeller, 2000:5; Yoshinaga-Itano, 2003:199-206). A study in the Trent Regional Health Authority UK, lately reported by Davis and Hind (2003:194), produced substantial data on the cognitive performance of children with moderate to severe permanent hearing loss and quality of life indicators. Results were based on linear regressions controlling for potentially confounding variables (e.g. age, severity, presence of other disabilities, etc.) and indicated that the age of first hearing aid fitting was a significant predictor of verbal and non-verbal reasoning as well as overall IQ. Age at diagnosis was identified as a significant predictor of working memory. The most important outcomes associated with early identification as described by Yoshinaga-Itano (2003:199-204) are summarised in Table 2.4.

**TABLE 2.4 Compelling benefits of early identification versus later identification (Yoshinaga-Itano, 2003:199-204)**

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**COMPELLING BENEFITS OF EARLY IDENTIFICATION VS LATER IDENTIFICATION**

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- Children with hearing loss born in UNHS hospitals had an 80% probability of having language development within the normal range of development.
  - Children with hearing loss born in UNHS hospitals were 2.6 times more likely than children with hearing loss born in non-screening hospitals of having language development within the normal range of development.
  - 76% of children with hearing loss in the screened group had language quotients that were 70 or greater – whilst only 32% of the non-screened group had language quotients of 70 or greater.
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**TABLE 2.4 Continued**

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- Early-identified children in the screened group had a 10-point discrepancy between their language and cognitive quotients – whilst later-identified children in the non-screened group displayed a 35-point discrepancy.
  - The vocabulary of children at the 75<sup>th</sup> percentile of the non-screened group contained fewer words than that of the children at the 25<sup>th</sup> percentile of the screened group.
  - The 75<sup>th</sup> percentile of the screened group had speech that was “always or almost always understandable” – whilst the 75<sup>th</sup> percentile of the non-screened group had speech that was “hard to understand”.
  - Early-identified children maintained language development in the same vein as their non-verbal cognitive symbolic play development, while later-identified children demonstrated a greater than 20-point discrepancy between their non-verbal cognitive development and their language development.
  - Children with additional disabilities who were identified early and provided with immediate early intervention services also had symbolic play quotients that were similar to their language quotients – whilst children with additional disabilities who were identified later displayed significant discrepancies between their cognitive and language quotients.
  - Early-identified children with hearing loss had significantly higher personal-social skill development than children whose hearing losses were identified later.
  - The first six months of life appear to be a particularly sensitive period in early language development as young children identified with hearing loss and placed in intervention by 6 months of age present with significantly higher language development than later-identified children with hearing loss.
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It is also important to mention that reports demonstrate that UNHS programmes do succeed in identifying hearing loss early. This provides the opportunity for timely intervention so that access may be gained to the benefits of early auditory stimulation. In its first four years, the UNHS programme in Rhode Island decreased the mean age at which hearing loss was detected from 20 months (prior to implementing UNHS) to 5.7 months (by year four) (Vohr et al., 1998:355). The Hawaii UNHS programme reduced the average ages of identification and amplification from 12 and 16 months to 3 and 7 months respectively (Johnson et al., 1997:354). In Colorado, the average age for hearing aid fitting is 5 weeks (Yoshinaga-Itano, 2004:454). Research outcomes provide evidence that hearing screening programmes reduce the age of hearing loss identification, lower the age of intervention initiation, and produce significantly



improved outcomes for both the child and his/her family (Yoshinaga-Itano, 2004:464).

*It is clear that there are enough examples in the literature demonstrating the benefits of NHS programmes toward early identification and intervention (which provide infants with an opportunity to reach optimal outcomes) to justify its role as an important part of neonatal care.*

The disorder-related principles provide a strong case for IHS by indicating the need for screening because of the number of affected infants, the detrimental effect of late identification and the dramatic benefits of early identification. The discussed evidence provides adequate justification for implementing IHS as it significantly improves the disorder outcomes. However, accountability with regard to the means of conducting the screening is still called into question – and will be addressed by evaluating principles pertaining to the screening process to ensure that the identified disorder can indeed be addressed in an accountable manner.

### **2.3.2. Process-related principles of infant hearing screening**

Whilst disorder-related principles are fundamental to the identification of the need for and effect of screening, the principles pertaining to the screening process are concerned with the accountability of the practice and process of screening. Thus far evidence of the need for IHS has been provided and the discussion in the following paragraphs will focus on the accountability of IHS as healthcare and societal practice from a screening-process perspective. The three principles related to the process of screening accuracy, efficiency and costs, are explored in the following section.

#### **2.3.2.1. Accuracy of infant hearing screening methods**

The accuracy of screening methods is measured in how precise they are able to differentiate between normal-hearing and individuals with hearing loss. It

therefore involves two categories of accuracy, namely – how precise can the screening method identify normal-hearing persons, and how precise can the screening method identify hearing-impaired individuals. These two categories of accuracy measures are referred to as specificity and sensitivity (Davis et al., 2001:3). Sensitivity refers to the ability of the screening method to correctly identify the target disorder, whilst specificity refers to the ability of the screening method to correctly identify individuals without the target disorder (Jacobson & Jacobson, 1987:134). If a group of normal-hearing infants all pass a hearing screening, the specificity is 100% and if a group of infants with hearing loss all fail a screening test, the sensitivity is 100%. In practice there is always a trade-off between specificity and sensitivity, with higher sensitivity usually achieved at the expense of lower specificity and *vice versa* (Lutman, 2000:369). A screening procedure that frequently passes infants who are impaired or too often misclassifies normal-hearing infants as abnormal, renders the screening test invalid and economically unfeasible (Jacobson & Jacobson, 1987:133).

Due to the inherent differences in biomedical investigation, it is highly unlikely that any screening test can separate all individuals with and without the disorder (Northern & Downs, 2002:264). At present the hearing screening procedures of choice are automated auditory brainstem response (AABR) and oto-acoustic emission (OAE) devices (Stach & Santilli, 1998:249-250; Mason & Herrmann, 1998:221; Lutman, 2000:371-373; Watkin, 2003:168-169; JCIH, 2000:14). These procedures are preferred because of their accuracy, time-efficiency and non-invasiveness (Hahn et al., 1999:86-89; Watkin, 2003:168-169; JCIH, 2000:14; Meier et al., 2004:927).

A large multi-centre study, sponsored by the National Institutes of Health, was conducted to evaluate the accuracy of AABR, transient-evoked (TE) OAE and distortion product (DP) OAE screening test measures (Norton et al., 2000a:348-355). The study involved a cohort of 7 179 infants who were also followed up by visual reinforcement audiometry at 8 to 12 months corrected age. The study confirmed that all three methods were accurate screening tools, robust with

respect to infant state, test environment and infant medical status (Norton et al., 2000b:508-509).

Kennedy et al. (1991:1126) evaluated 370 infants (271 from the NICU) with TEOAE, ABR and AABR at 1 month, followed by behaviourally confirmed hearing at a mean age of 8 months. The results indicated that TEOAE identified the same three infants with sensori-neural hearing loss as the ABR and AABR. The specificity of TEOAE screening for bilateral and unilateral hearing loss in the Whipps Cross screening programme was >97.5% and is representative of many TEOAE screens established in the USA (Watkin 2003:168). The Whipps Cross screening programme that has been conducted since 1992, with 47 790 infants enrolled over the last decade, proved the TEOAE screening sensitivity to be 94% as established through longitudinal follow-up evaluations (Watkin, 2003:168).

Mehl and Thomson (2002:5) reported specificity for AABR testing as part of the Colorado screening programme to be 98.5%, with a positive predictive value for having a hearing loss when referred for diagnostic testing of 19%. In a cohort of 41 796 newborns screened in Colorado, as reported by Mehl and Thomson (1998:4), no evidence of a single false-negative test result was discovered and the sensitivity of newborn screening was estimated at or near 100%. Since the inception of newborn hearing screening in Colorado, the cumulative false-positive rate was ~6%, but advances in technology has allowed for a false-positive rate of 2% in more recent years (Mehl & Thomson, 1998:4; Mehl & Thomson, 2002:5). In another study, Hermann et al. (1995:11) reported a 96% sensitivity and 98% specificity rate for AABR testing as measured against conventional ABR evaluations. The Rhode Island Hearing Assessment Project screened 1 850 infants prior to discharge with TEOAE and ABR, and re-screened those referring either test at 3 to 6 weeks. An analysis of the two-stage screening protocol based on heads revealed a sensitivity of 100% and a specificity of 95% (White et al., 1994:215).

The sensitivity and specificity of current OAE and AABR screening methods have proved to produce low false-positive rates of 2-3%, with some reports of

less than 1% (Lutman, 2000:376; Spivak et al., 2000:100; Iwasaki, 2004:1099; Lutman & Grandori, 1999:95, Prieve & Stevens, 2000:87), and false-negative rates of between 6-15% as determined by studies with follow-up procedures for the entire cohort (Vohr et al., 1998:355; Kennedy et al., 1998:1963; Watkin, 1996:F16). According to Lutman (2000:367), both OAE and AABR techniques can achieve specificity in excess of 95%, and Colorado and Rhode Island UNHS programmes suggest screening protocols can achieve sensitivity approximating 100%.

*The literature reviewed provides convincing evidence that the accuracy of these procedures is sufficient to justify IHS as a healthcare practice for all newborns and infants. The evidence has been so compelling that both the JCIH (2000:14) and American Academy of Pediatrics (1999:528) have recommend the use of either OAE or AABR screening devices, or both, in the implementation of UNHS programmes.*

### **2.3.2.2. Efficiency of early identification programmes**

The efficiency of early identification programmes will be presented according to three outcome measures (White, 2002:1). Firstly the coverage and referral rates obtained in UNHS programmes; secondly, the effects of screening on parents; and lastly, the effectiveness of the follow-up system. These outcome measures will be discussed in the following paragraphs.

- **Coverage and referral rates**

Once a target population is identified for screening, an important measure of the efficiency is the number of individuals who actually receive the screen (coverage). A second important measure is to ascertain how many individuals are referred for diagnostic testing based on the screen result (referral rate).

In a summary of 120 AABR and OAE UNHS programmes in the USA, the average reported coverage was 95.5% (White et al., 1997:227). It is widely

accepted that most of the hospital-based screens achieve an acceptable coverage of >95% (Watkin, 2003:168). An average coverage of 95% is reasonable, but variability has also been reported. A recent Japanese UNHS study conducted in two hospitals over a two-year period reported coverage of 99.8% of infants (Iwasaki et al., 2004:1100). It must be noted, however, that healthy newborns were only discharged 7 days after birth, allowing adequate time for screening all infants (Iwasaki et al., 2004:1100). The Wessex trial in the UK reported a coverage of 87%, but attributed this decreased coverage to several factors such as difficulties obtaining informed consent and an initial run-in period for screening where coverage was low (Kennedy et al., 1998:1963). Programmes that follow efficient protocols are able to obtain an almost complete coverage and on average the rates are sufficient to justify their implementation.

The referral rates for different screening technologies do differ, though not significantly. The multi-centre study of the National Institute for Deafness and Other Communication Disorders (NIDCD) that was conducted to evaluate the accuracy of AABR, TEOAE and DPOAE screening test measures confirmed that all three methods were efficient screening tools, with no significant variation in performance between the different screening methods that demonstrated pass rates ranging from 82% to 86% (Norton et al., 2000b:508-509). The screening test criterion affects the referral rate; for example, a more stringent pass criterion will increase the referral rate. The NIDCD study used a stringent pass criterion of 30 dB for AABR and similarly stringent criteria for OAE protocols that decrease pass rates. When these results are considered together as a screening protocol using AABR and an OAE technique, the pass rate increases to between 97% and 98% (Norton et al., 2000c:532). The multi-centre study in New York State confirmed that a two-technology protocol significantly lowered fail rates with Prieve and Stevens (2000:87), reporting a 0.9% refer rate for diagnostic testing. In an analysis of three UNHS protocols the referral rates at discharge were 3.21%, 4.67% and 6.49% for AABR, two-step (TEOAE and AABR for TEOAE referrals) and TEOAE protocols respectively (Vohr et al., 2001a:242). Consideration of these referral rates according to the benchmark of 4% specified

by the JCIH (2000:15), indicates adequate or near adequate referral rates across the different protocols.

Invariably different referral rates are reported, but according to a recent report the typical referral rates for NHS protocols in the USA vary between 2-6%, depending on which type of protocol is used (White, 2003:84). A one-stage inpatient OAE and AABR screening protocol is the most efficient, with a typical referral rate of 2%, whilst a one-stage AABR inpatient protocol typically presents with a 4% referral rate. When a two-stage OAE protocol is followed with the first screen being inpatient and the referred patients being screened as outpatients, it typically produces a 6% referral rate (White 2003:84). Careful protocol development and selection can provide referral rates that are sufficient to ensure an efficient screening process.

*The coverage and referral rates are within or near the recommended rates and demonstrate the efficiency with which NHS programmes are conducted. This efficiency contributes to the justification of IHS as an important and attainable healthcare priority.*

- **Effects on parents**

Although parental anxiety is an important cost that can potentially interfere with maternal infant attachment and cause abnormal parenting behaviour and communication, the potential for it to have such an effect is fortunately small and manageable (Watkin, 2003:170). In a study of parents of severely deaf children, 96% indicated that they would have wanted neonatal identification. Only a small portion indicated that they would have preferred to have waited because of the anxieties caused (Watkin et al., 1995:259). Clemens et al. (2000:5) in a study of 5 010 infants report that 90% of the mothers indicated UNHS to be a “good” idea, while Hergils and Hergils (2000:321) indicate that 95% of the parents in a study in Sweden had a positive attitude towards NHS.

Yoshinaga-Itano (2003:204) reports that neonatal identification of hearing loss through UNHS programmes does not result in greater parental stress than later-identification of hearing loss when the intervention programme contains a comprehensive counselling content. In a study of 184 parents of children with hearing loss, the parents of early-identified children were not more likely to present with stress than parents of late-identified children (Yoshinaga-Itano, 2003:204). Colorado data indicates that 10% of parents of infants referred for follow-up after NHS report negative emotions (Yoshinaga-Itano & Gravel, 2001:63). The reported stress of parents who pass the hearing screening does not prove to be significantly different from the stress reported by parents of children who have been referred for diagnostic testing. (Yoshinaga-Itano & Gravel, 2001:63). In a study investigating 288 mothers whose babies had received a neonatal screen, less than 1% were made very anxious by the test (Watkin et al., 1998:27). Vohr et al. (2001b:18) reported that 88-89% of mothers indicated none or very mild worry at the time of neonatal screen. The Wessex trial study also reported that families of infants who underwent neonatal screening were less anxious than those of unscreened infants (Kennedy et al., 1998:1963). Barringer and Mauk (1997:19) reported on parental attitudes in respect of 169 infants, indicating that 98% of these parents would give permission to have their infants' hearing screened and 88% believed that anxiety caused by their baby not passing the hearing screening would be outweighed by the benefits of early detection if hearing loss was to be found. To date there has been no evidence that newborn hearing screening causes parental harm (Yoshinaga-Itano, 2004:462).

The reports are uniform in their conclusions that parental anxiety due to screening programmes is negligible and does not differ significantly from that of parents whose infant did not receive screening. In addition to this, parents of children with hearing loss demonstrate emotional availability similar to parents of children with normal hearing (Yoshinaga-Itano, 2003:205). Preliminary data also indicates that resolution of grief by families with early-identified children occurs faster than for families with later-identified children, as long as their children develop strong language and communication skills (Yoshinaga-Itano, 2003:205).

In general, parents report that UNHS programmes have improved their awareness of the importance of hearing, language and speech development and as a result of this exposure they can pay more attention to their child's communication skills (Yoshinaga-Itano & Gravel, 2001:63).

*In the light of the negligible costs of NHS programmes in terms of parental anxiety and the possible benefits of faster resolution of grief revealed from the literature reviewed, the importance of conducting NHS as standard neonatal procedure is accentuated. This supports other compelling evidence for IHS as an efficient healthcare practice.*

- **Follow-up**

According to the US Preventative Services Task Force (USPSTF) (2001:96) between 13 and 31% of infants referred for further diagnostic testing in existing UNHS programmes do not return for follow-up. Data from the Colorado NHS project (1992 to 1999), which screened 148 240 newborns and identified 291 infants with congenital hearing loss, indicates a 76% documented follow-up rate for referred infants (Mehl & Thomson, 2002:1). This is a significant increase from a follow-up rate of 48% during the first five years of screening. Nine of the participating hospitals were able to achieve a follow-up rate of 95% or more for infants failing the initial screening tests (Mehl & Thomson, 2002:1). When only the 2002 Colorado data is considered, a follow-up rate of 85% is reported (Yoshinaga-Itano, 2004:463). The New York State multi-centre statewide screening project showed a similar follow-up rate of 72%, with increasingly better results for successive years of programme operation (Prieve et al., 2000:104). Follow-up return rates from the Rhode Island and Hawaii UNHS programmes indicated better follow-up rates of 85% and 82% respectively (Vohr et al., 1998:353; Johnson et al., 1997:354), while the more recent report on the Hawaii UNHS programme reflected an 87% follow-up return rate (Prince et al., 2003:1202). Although reports indicate high follow-up return rates for established programmes, room for improvement still remains.



Most operational programmes identify difficulties in the tracking and follow-up of infants referred for diagnostic evaluation as the biggest challenge pertaining to early identification. It is therefore not surprising that programmes with the highest prevalence rate are also those that are most successful at tracking and following infants through to conclusive diagnosis (White, 2003:85). Gravel et al. (2000:132) and Finitzo, Albright, and O’Neal (1998:1459) specify the rate of return for follow-up (leading to confirmation of hearing loss) to be one of the primary indices of both the efficiency and effectiveness of screening programmes. Although work still needs to be done, the follow-up rates have improved considerably to acceptable percentages in most UNHS programmes in the USA. New programmes elsewhere may expect initial difficulties in attaining high follow-up return rates.

*The results indicate that acceptably high follow-up return rates for NHS programmes can be attained, but may take time to realise and require continued tracking efforts. Thus, although the efficiency of NHS programmes may be compromised by poor follow-up return rates, attaining acceptable rates is a real possibility that need not detract from screening protocol efficiency.*

### **2.3.2.3. Costs of infant hearing screening**

A number of different studies have reported on the costs of NHS. Costs differ due to variability in the factors that impact on the screening cost, such as capital costs, operating expenses, screening technique, follow-up costs, the number of babies, and assumptions regarding the prevalence of hearing loss (Gorga & Neely, 2003:103). A comparative study that investigated the costs of screening by using three different protocols demonstrated similar results across protocols. According to Vohr et al. (2001a:242), estimates of costs were \$28.69, \$32.81 and \$33.05 for TEOAE, AABR and two-step protocols respectively. Mehl and Thomson (1998:4) estimated the true cost for each infant screened to be \$25, which includes labour cost, disposable supplies and amortised capital equipment. The cost of screening per infant ranged from \$18.30 when performed by supervised volunteers, to \$25.60 when performed by a paid technician, and to

\$33.30 when performed by an audiologist. Maxon et al. (1995:271) estimated costs per infant screened to be \$26.05. A volunteer-based UNHS programme reported similar costs of \$27.41 per infant screened (Messner et al., 2001:123). Thus, initial screening costs have been demonstrated by recent studies to be cost-effective (Baroch, 2003:424).

Kezirian et al. (2001:363) compared OAE and AABR screening protocol costs and subsequently estimated costs per screen to vary between \$13 and \$25. The most cost-effective screening was performed with OAE screening with an estimated total cost of \$5 100 per infant identified with congenital hearing loss. Estimated costs for the AABR reached \$25, with a total cost of \$9 500 per infant identified with hearing loss (Kezirian et al., 2001:363). The principle finding was that an OAE/OAE protocol demonstrates the lowest cost and is the most cost-effective by a large margin (Kezirian et al., 2001:364). The Colorado UNHS statewide programme reports a cost of approximately \$9 600 for identifying congenital hearing loss and \$12 600 for identifying bilateral hearing loss (Yoshinaga-Itano & Gravel, 2001:64).

Even though the cost of screening individual infants for other birth defects may be lower, the prevalence of hearing loss is much higher. This leads to cost comparisons indicating that costs for identifying hypothyroidism is similar to the cost for identifying hearing loss (at \$10 000), and higher for cases of hemoglobinopathy (\$23 000) and phenylketonuria (\$40 000) (Mehl & Thomson, 1998:5). Johnson et al. (1993:114) report similar cost comparisons. The above statistics provide an important justification of NHS as an accepted screening practice alongside previously existing programmes.

The case for early identification is also supported by long-term cost benefits for families and society. For every child who will not need special educational services, there will be an annual savings of more than \$10 000 and for each child who will require a less intensive educational programme, annual savings may amount to \$5 000 (Yoshinaga-Itano & Gravel, 2001:64). According to Johnson et al. (1993:115), the annual cost for an infant with hearing loss in a regular

classroom will be \$3 383 compared to \$35 780 in residential programmes. Yoshinaga-Itano and Gravel (2001:64) report similar figures and state an annual cost difference of between \$25 000 and \$35 000 for education in the local educational agency and a residential school for the deaf respectively. It is also probable that the higher the educational outcomes for children with significant hearing loss, the more likely that they will become adults employed to their full potential and contributing to society (Yoshinaga-Itano & Gravel, 2001:64).

*The evaluation of initial IHS costs has revealed that IHS can be justified on the grounds of long-term economic benefit for families and society, as well as on the grounds of a significant improvement in quality of life for individuals and families.*

The six principles discussed clearly demonstrate that the validity of IHS as a valid healthcare practice is no longer a question in debate. The current issues in the developed world have moved beyond the question of validity and now rather concern best practice (Hall, 2000a:396).

## **2.4. INFANT HEARING SCREENING PRACTICE IN THE DEVELOPED WORLD**

During the past 15 years, the entire developed world and especially the USA and UK have seen a dramatic growth in newborn hearing screening, diagnosis and intervention programmes (White et al., 2003:79). Reports of UNHS programmes have also come from all over the developed world including diverse countries like Taiwan, Belgium, the Netherlands, Singapore and Israel (Lin et al., 2002:209; Pratt et al., 2004:28; Stappaerts & Van Kerschaver, 2004:9; Hanneke de Ridder-Sluite et al., 2004:9; Low et al., 2004:29). The majority of reports, however, came from the USA and UK (Mencher et al., 2001:4-5). This growth is the culmination of more than a hundred years of striving to identify hearing loss in the infant to allow early access to auditory and language stimulation (Mencher et al., 2001:3-4). Over these years the notion of early auditory deprivation and the

desire among clinicians to intervene as early as possible have been confirmed by decades of research, which provides the foundation of current IHS practice.

UNHS has become a powerful professional and technological movement with widespread influence within the USA (Hall, 2000b:113). Early Hearing Detection and Intervention (EHDI) programmes were clearly established as part of the public health system by the end of 2001 with all US states having identified a state EHDI coordinator (White, 2003:81). It was recently reported that 42 states and the District of Columbia have EHDI laws or voluntary compliance programmes (Gracey, 2003:309). Of these states, 37 have legislation pertaining to UNHS, with the first state, namely Hawaii, having obtained legislation as far back as in 1990 (White, 2003:81). More than 70% of all newborns in all US states are screened for hearing loss before their discharge from hospital (White, 2003:87). It is clear that in the USA NHS has become the *de facto* medical/legal standard of care (White, 2003:85).

The Department of Health in the UK also commissioned a national NHS programme in 2001 following a systematic review of the role of neonatal hearing screening in the identification of hearing impaired and deaf children in 1997 (Davis et al., 1997:1-177; Davis & Hind, 2003:194). Recommendations were provided for implementing a national UNHS programme (Bamford & Davis, 1998:3) and the initial phase involves 23 sites. These sites are linked to a systematic evaluation that will provide feedback for the development of NHS in all areas of England and other regions of the UK by April 2005 (Davis & Hind, 2003:195). The implementation of UNHS programmes has subsequently commenced nationwide in the UK.

UNHS programmes are also in the process of being implemented in Australia on a national basis at the recommendation of the Australian Consensus Statement on Universal Neonatal Hearing Screening produced by the Australian National Hearing Screening Committee (ANHSC) (ANHSC, 2001:2). These recommendations have been in response to the international move toward UNHS in developed countries such as the USA, UK, Canada and Europe (Wake,

2002:172). Pilot studies have already been conducted and are providing guidelines and recommendations for the future of UNHS in Australia (Bailey et al., 2002:184). The momentum of UNHS programmes is rapidly swaying developed countries such as Australia to follow the example of countries like the USA and UK. It is clear that widespread support for UNHS programmes is a growing reality.

To summarise, numerous authoritative and well-respected bodies with an interest in early detection of hearing loss have supported the implementation of widespread UNHS (Hall, 2000b:113; White 2003:86). In 1993 a National Institute of Health Consensus Development Panel recommended universal screening for hearing loss prior to 3 months of age in order to allow for the identification of and intervention for infants with hearing loss by 6 months of age (NIH, 1993:1-24). The American Academy of Pediatrics produced a statement endorsing the implementation of UNHS in 1999 (AAP, 1999:527). Building upon the recommendations by the NIH consensus statement and the American Academy of Pediatrics statement, the Joint Committee on Infant Hearing 2000 position statement was developed and approved by the American Academy of Audiology; the American Academy of Otolaryngology - Head and Neck Surgery; the American Academy of Pediatrics; the American Speech-Language-Hearing Association; the Council on Education of the Deaf; and Directors of Speech and Hearing Programmes in State Health and Welfare Agencies. The position statement endorses early detection of and intervention for infants with hearing loss through integrated, interdisciplinary state and national systems of UNHS, evaluation and family-centred intervention (JCIH, 2000:9-10). This multi-disciplinary consensus regarding NHS demonstrates the recognition of infant hearing loss as an important healthcare priority that requires early intervention services through early identification.

The Center for Disease Control and Prevention in the USA also supports UNHS through the EHDI programmes by assisting states in implementing screening and intervention programmes and conducting research on EHDI programmes (USPSTF, 2001:97). The Maternal and Child Health Bureau of the Health

Resources and Services Administration (HRSA) supports UNHS and has provided funding to assist states in developing such programmes. It has also produced a publication promoting the early identification of hearing loss (USPSTF, 2001:97).

A European consensus statement supporting UNHS was produced at a consensus conference on neonatal screening held in Milan in 1998 (Lutman & Grandori, 1999:95-96). The British National Coordinating Centre for Health Technology Assessment also supports UNHS, which has led to the implementation of UNHS services by the Department of Health (Davis et al., 1997:87; Davis & Hind, 2003:194). It is therefore clear that numerous international groups and committees have recommended the implementation of UNHS on the grounds of the research evidence available.

To date there is only one group, the USPSTF (Thompson et al., 2001:2008) that has considered the evidence related to UNHS and has not unequivocally endorsed it. Their conclusions have been widely misunderstood and whilst they conclude that there is not yet clear evidence regarding whether NHS truly does result in better language outcomes, they clearly state that UNHS is feasible to implement, results in earlier identification of hearing loss and can be done with equipment that is accurate, practical to use and economical (White, 2003:86). In a recent report, Yoshinaga-Itano (2004:451-465) provides an excellent address to the conclusions of the USPSTF. The author highlights several inaccurate and unsupported statements made by the USPSTF and states that all studies investigating outcomes demonstrated the same result, a robust and repeatable impact of early identification and initiation of intervention on developmental outcomes. Yoshinaga-Itano subsequently (2004:463) concludes that “[a]lthough the USPSTF believes that statistical analysis and experimental group statistical control are not sufficient, the effects were so significant that statistical analysis was unnecessary to demonstrate the impact”. The benefits of UNHS toward earlier identification and early intervention, which lead to improved outcomes, are therefore undisputable.

*Evaluation of the current status of IHS in the developed world reveals that UNHS has become the standard of care for newborns and that services are becoming a widespread and encompassing reality. Attaining this sought-after goal, however, requires a comprehensive system of service provision measured against clearly specified benchmarks and standards.*

#### **2.4.1. Benchmarks and standards for hearing screening**

Early intervention for hearing loss has become an increasingly essential aspect of audiological service delivery. The development and refinement of screening and diagnostic equipment has enabled the extension of audiological scope of practice to include newborns as a significant population for receiving services. This shift in audiological practice has led to the need for establishing standards and guidelines so as to provide effective and accountable services.

The visionary ideal of Marion Downs during the 1960s to introduce widespread newborn hearing screening led to the formation of a national surveillance committee on newborn screening – The Joint Committee on Infant Hearing (JCIH) (Northern & Downs, 2002:267). The establishment of this committee was the single greatest factor that influenced the course of newborn screening in the USA, as it represented the American Academy of Pediatrics, the American Academy of Otolaryngology, the American Academy of Audiology, and the American Speech-Language-Hearing Association (Downs, 2000:291; Mehl & Thomson, 1998:4). Since its first meeting in 1969 it has gathered several times to monitor scientific investigations and to provide guidelines and standards for audiological service delivery to the population of newborns and young infants (Downs, 2000:291). The succession of statements from 1970 right through to the new millennium has provided a review of the progression of expertise and attitudes on newborn screening (Downs, 2000:291).

The recommendations by the JCIH have been the driving force behind the enthusiasm and commitment toward the early identification of infants with hearing loss in the USA and elsewhere in the world. These recommendations

have indeed steered NHS from a targeted to a universal screening approach over the past four decades.

#### **2.4.1.1. From targeted to universal newborn hearing screening**

During the 1950s and 1960s the Hardy Group in the USA focused on the development of a list of etiological factors for sensori-neural hearing loss that eventually became known as the High-Risk Register (HRR) for Hearing Loss (Mencher et al., 2000:4). In 1973 the JCIH recommended that mass newborn behavioural screening be continued in favour of testing only those infants determined to be at-risk according to five identified risk criteria on the HRR (Mahoney & Eichwald, 1987:156). The JCIH revised this statement in a 1982 statement when it updated the recommendations and added two more criteria to the original five high-risk indicators (JCIH, 1982:1017). After that a number of developments led to the JCIH producing a 1994 position statement in which it changed its goal of targeted high-risk screening and endorsed “the goal of universal detection of infants with hearing loss as early as possible. All infants with hearing loss should be identified by three months of age, and receive intervention by six months of age” (JCIH, 1994:6).

The two main reasons for the evolution of recommended NHS practice from targeted to universal were advances in technology and poor yield of infants with hearing loss by high-risk screening. The discovery of the ABR in 1971 (Jewett & Williston, 1971:681) and OAE in 1978 (Kemp, 1978:17) paved the way for quasi-automatic electrophysiological NHS devices becoming available near the end of the 1980s and early 1990s (Hall, 2000b:112; Mencher et al., 2001:5). Pilot projects and continued improvements in technology demonstrated these techniques to be a fast and accurate means of screening newborns (Vohr et al., 1998:343; Hall, 2000b:112; Northern & Downs 2002:268; Roizen, 1998:237). These new screening devices made UNHS a feasible possibility for the very first time.



The second reason for the development of UNHS as the standard of care above Targeted NHS is the fact that only a limited number of infants with hearing loss actually present with high-risk indicators. Targeted NHS is based on the principle that screening a small number of infants will produce a large number of infants with hearing loss. This type of screening however existed in the USA for decades and failed to identify a large cohort of children in the first year of life (Yoshinaga-Itano, 2004:462). In a large study of 283 298 newborns by Mahoney and Eichwald (1987:161), approximately 9% of newborns presented with at least one risk indicator for hearing loss. Mason et al. (1997:91) reported a similar value of 10%. A number of different studies have reported that this at-risk population only accounts for approximately 50% of infants with congenital hearing loss (Chu et al., 2003:584; Davis & Wood, 1992:77; Watkin et al., 1991:1130; Mauk et al., 1991:312). Furthermore, the children identified in their first year of life through targeted NHS have a significantly higher incidence of secondary abilities (~66%) than the children identified through UNHS in well-baby nurseries (~30%). This means that the children presenting only with hearing loss, who have the highest potential for success, are most likely to be missed (Yoshinaga-Itano, 2004:462).

These two reasons are convincing factors that explain the replacement of targeted NHS with UNHS as the standard of care in developed countries. The most recent JCIH position statement (JCIH, 2000:10) reflects the realisation of UNHS as the standard of care and emphasises not only the process of screening, but also the system of providing comprehensive intervention services to infants – of which screening is only the initial component. Effective and efficient systems of service provision are essential to ensure successful NHS programmes.

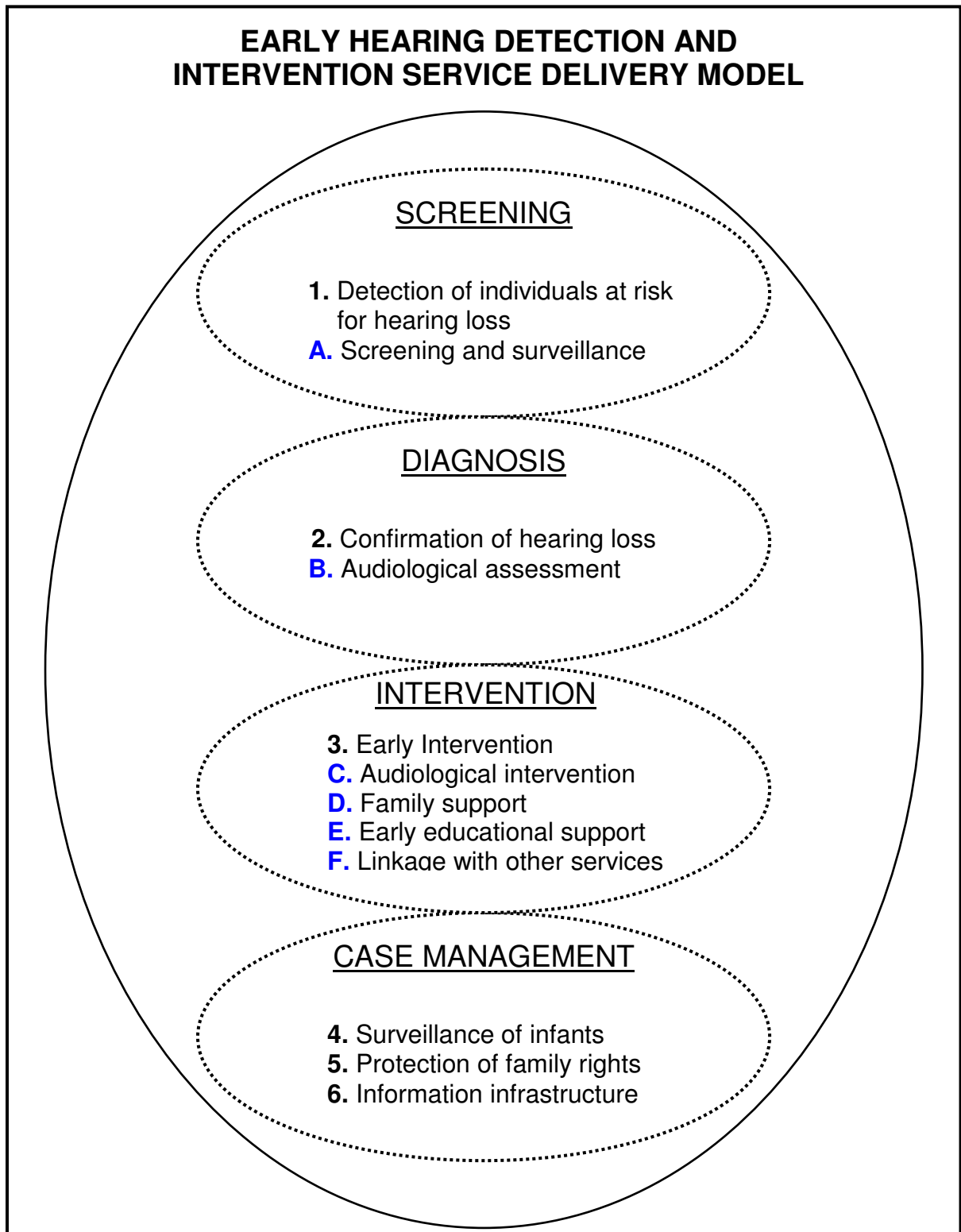
#### **2.4.1.2. Early hearing detection and intervention systems**

The Year 2000 position statement of the Joint Committee on Infant Hearing (JCIH, 2000) is a landmark for all professionals concerned with hearing loss in young infants (Downs, 2000:292). The position statement highlights six important guidelines for hearing detection and intervention programmes that fit into the

model of early intervention service delivery. Figure 2.3 illustrates the JCIH (2000) guidelines and areas to be included in programme design as suggested by Bamford (2000:359) and fitted into the basic model of early intervention service delivery.

Early intervention for children with hearing loss not only emphasises the early identification of hearing loss, but also entails the fitting of sound-enhancing devices like hearing aids or cochlear implants, the implementation of support and counselling services to caregivers, as well as the provision of aural rehabilitative services (Northern & Downs, 2002:150). The purpose of EHDI programmes is the identification, management and support of children with these hearing losses, as well as their families (Bamford, 2000:359). The programmes must therefore cover “screening and surveillance, audiologic assessment, audiologic intervention, family support, developmental assessment and monitoring, early educational support, and linkage with other health, medical, educational, and social services” (Bamford, 2000:359). According to English (1995:117), “audiologists who serve infants and toddlers with hearing loss and their families should consider themselves early interventionists and, therefore, part of an early intervention team”.

These services, however, are primarily dependant on the detection of hearing loss, followed by an accurate diagnosis of the type, degree and configuration of hearing loss for both ears (Gorga, 1999:29). In other words – successful determination of hearing ability is the basis of all early intervention programmes for children with hearing loss.



**FIGURE 2.3 Early hearing detection and intervention model**

*Basic 4-component service delivery model for early intervention. Guidelines for EHD/ I programmes specified by JCIH (2000) are listed under each section from 1 to 6. Areas to be included as specified by Bamford (2000:359) for each component are listed from A to F.*

The first step in the initiation of the early intervention process is identification and screening. This involves the process of locating infants who might be eligible for early intervention (Widerstorm et al., 1997:216). If an infant is identified as at-risk, he/she is referred for an in-depth assessment to professionals in the area or areas failed. The assessment component is a diagnostic facility that establishes whether the presence of developmental delay or disability is present and that decides whether a subject is eligible for services or programmes (Fair & Louw, 1999:15; Widerstorm et al., 1997:218). As mentioned earlier, all early intervention services involve an initial detection of hearing loss, after which the type, degree and configuration of hearing loss for both ears have to be diagnosed accurately (Gorga, 1999:29). This diagnostic assessment information serves as basis for deciding whether early intervention is necessary and should be followed by the planning of appropriate services (Rossetti, 1996:79). The final step is the case management, which involves the continuous surveillance of infants and toddlers, protection of infants' and families' rights and the establishment and maintenance of an infrastructure for managing data. The early intervention process is a structured progression of step-wise procedures with the ultimate aim of assisting the high-risk infant to develop his/her full potential by facilitating age-appropriate developmental skills by means of a family-centred approach.

The development and implementation of high quality services to respond to the numerous possible combinations of child and family needs is a major challenge which, for the most part, has been poorly met (Bamford, 2000:359). It is for this reason that the JCIH Year 2000 position statement has been a landmark for establishing standards and quality indicators for the development and implementation of EHDI services (Downs, 2000:292). The position statement should be used as a guiding document for all stakeholders in an EHDI programme.

#### **2.4.1.3. JCIH Year 2000 position statement**

The JCIH Year 2000 position statement is a "masterful statement concerning the status and future direction of infant hearing screening" (Northern & Downs, 2002:269). The multi-disciplinary committee endorses the "early detection of, and intervention for infants with hearing loss (EHDI) through integrated, interdisciplinary state and national systems of universal newborn hearing screening, evaluation, and family-centered intervention" (JCIH, 2000:10). The aim of endorsing these services is to ensure the maximum linguistic and communicative competence and literacy development for children who are deaf or hard of hearing (JCIH, 2000:10). The committee provided eight principles as the foundation for effective EHDI systems with benchmarks and quality indicators specified for these principles. The benchmarks are quantifiable goals or targets that can be used to monitor and evaluate an EHDI programme and that serve to point toward the next needed steps in achieving and maintaining a quality programme. The quality indicators reflect a result in relation to a specific benchmark and should be monitored using well-established practices of statistical process to control and determine the programme consistency and stability (JCIH, 2000:11-12). These principles and their components, as well as the specified benchmarks and quality indicators for each, are summarised in Table 2.5.

**TABLE 2.5. Summary of the JCIH Year 2000 Position Statement**

PRINCIPLES (1-8)	COMPONENTS	BENCHMARKS	QUALITY INDICATORS
<p style="text-align: center;"><b>1</b> <b>HEARING SCREENING</b></p>	<p><b>1. PERSONNEL</b> <i>Teams of professionals involved in establishing UNHS component of EHDI programme</i></p> <p><b>2. PROGRAMME PROTOCOL DEVELOPMENT</b> <i>Comprehensive review needed of hospital infrastructure before implementation of screening. Development must consider technology, screening protocols, availability of screening personnel, acoustically appropriate environments, follow-up referral criteria, information management, and quality control</i></p> <p><b>3. SCREENING TECHNOLOGIES</b> Objective physiologic measures must be used. Currently OAE and ABR screening procedures</p> <p><b>4. SCREENING PROTOCOLS</b> A variety of UNHS screening protocols have been successfully implemented</p>	<p>1. Minimum of 95% of infants &lt; 1 month, screened within 6 months of programme initiation</p> <p>2. Referral rate less than 4% within 1 year of programme initiation</p> <p>3. Document efforts to obtain follow-up on a minimum of 95% of infants who do not pass the hearing screening. Ideally a return-for-follow-up of 70% of infants or more</p>	<p>1. Percentage of infants screened during the birth admission</p> <p>2. Percentage of infants screened before 1 month of age</p> <p>3. Percentage of infants who do not pass the birth admission screen</p> <p>4. Percentage of infants who do not pass the birth admission screening who return for follow-up services</p> <p>5. Percentage of infants who do not pass the birth admission/outpatient screen(s) who are referred for audiological and medical evaluation</p> <p>6. Percentage of families who refuse hearing screening on birth admission</p>
<p style="text-align: center;"><b>2</b> <b>CONFIRMATION OF HEARING LOSS IN INFANTS REFERRED FROM UNHS</b></p>	<p><b>1. AUDIOLOGIC EVALUATION</b> <i>Purpose is to assess the integrity of the auditory system, to estimate hearing sensitivity (ear-specific estimates of type, degree, and configuration of hearing loss), and to identify all intervention options. Requires test-battery to cross-check both physiologic and behavioural measures.</i></p> <p><b>2. MEDICAL EVALUATION</b> <i>Every infant with confirmed hearing loss and/or middle ear dysfunction should be referred for otologic and other medical evaluation. Purpose is to determine the etiology, identify related physical conditions and provide recommendation for medical treatment and other services. Pediatrician or primary care physician, Otolaryngologist and other medical specialists may be included</i></p>	<p>1. Comprehensive services coordinated between infant's medical home, family, and related professionals</p> <p>2. Infants referred from UNHS begin audiology and medical evaluations before 3 months of age or 3 months after discharge for NICU infants</p> <p>3. Infants with evidence of hearing loss on audiology assessment receive otologic evaluation</p> <p>4. Families and professionals perceive the medical and audiology evaluation process as positive and supportive</p> <p>5. Families receive referral to coordinating agencies, appropriate intervention programmes, parent/consumer and professional organizations, and child-find coordinators if necessary</p>	<p>1. Percentage of infants and families whose care is coordinated between the medical home and related professionals</p> <p>2. Percentages of infants whose audiology and medical evaluations are obtained before 3 months of age</p> <p>3. Percentage of infants with confirmed hearing loss referred for otologic evaluation services</p> <p>4. Percentage of families who accept audiology and medical evaluation services</p> <p>5. Percentage of families of infants with confirmed hearing loss that have a signed IFSP by the time the infant reaches 6 months of age</p>

TABLE 2.5. Continued

PRINCIPLES (1-8)	COMPONENTS	BENCHMARKS	QUALITY INDICATORS
<p style="text-align: center;">3 EARLY INTERVENTION</p>	<p>1. <b>EARLY INTERVENTION PROGRAMME DEVELOPMENT</b> <i>Services designed to meet individualized needs of infant and family which addresses acquisition of communicative competence, social skills, emotional well-being, and positive self-esteem.</i></p> <p>2. <b>AUDIOLOGIC HABILITATION</b> <i>Selection and fitting of some form of personal amplification or sensory device in a timely fashion</i></p> <p>3. <b>MEDICAL AND SURGICAL INTERVENTION</b> <i>Process whereby a physician provides medical diagnosis and direction for medical and/or surgical treatment options for hearing loss and/or related medical disorder(s) associated with hearing loss</i></p> <p>4. <b>COMMUNICATION ASSESSMENT AND INTERVENTION</b> Assessment of oral, manual, an/or visual mechanisms as well as cognitive abilities followed by intervention addressing these aspects with a particular focus on supporting families in developing communication abilities of their infants and toddlers who are hard of hearing or deaf</p>	<p>1. Infants with hearing loss are enrolled in a family-centred EI programme before 6 months of age</p> <p>2. Infants with hearing loss are enrolled in a family-centred EI programme with professional personnel who are knowledgeable about the communication needs of infants with hearing loss</p> <p>3. Infants with hearing loss and no medical contraindication before use of amplification when appropriate and agreed on by the family within 1 month of confirmation of the hearing loss</p> <p>4. Infants with amplification receive ongoing audiologic monitoring at intervals not exceeding 3 months</p> <p>5. Infants enrolled in EI achieve language development in the family's chosen communication mode that is commensurate with the infant's developmental level that is similar to that of hearing peers of comparable developmental age</p> <p>6. Families participate in and express satisfaction with self-advocacy</p>	<p>1. % of infants with hearing loss who are enrolled in a family-centred EI programme before 6 months of age</p> <p>2. % of infants with hearing loss who are enrolled in an EI programme with professionals who are knowledgeable about over-all child development as well as the communication needs and intervention options for infants with hearing loss</p> <p>3. % of infants in EI who receive language evaluations at 6 month intervals</p> <p>4. % of infants and toddlers whose language levels, whether spoken or signed, are commensurate with those of their hearing peers</p> <p>5. % of infants and families who achieve the outcomes identified on their IFSP</p> <p>6. % of infants with hearing loss and no medical contraindication who begin use of amplification when agreed on by the family within 1 months of confirmation of the loss</p> <p>7. % of infants with amplification who receive ongoing audiological monitoring at intervals not to exceed 3 months</p> <p>8. No. of follow-up visits for amplification monitoring and adjustment within the 1<sup>st</sup> year following amplification</p> <p>9. % of families who refuse EI services</p> <p>10. % of families who participate in and express satisfaction with self-advocacy</p>

**TABLE 2.5. Continued**

PRINCIPLES (1-8)	COMPONENTS	BENCHMARKS	QUALITY INDICATORS
<p style="text-align: center;"><b>4</b></p> <p style="text-align: center;"><b>CONTINUED SURVEILLANCE OF INFANTS AND TODDLERS</b></p>	<p><b>1. RISK INDICATORS FOR NEONATES (BIRTH THROUGH AGE 28 DAYS)</b> <i>List of 5 risk indicators for use in neonates where universal hearing screening is not yet available</i></p> <p><b>2. RISK INDICATORS FOR NEONATES OR INFANTS (29 DAYS THROUGH 2 YEARS)</b> <i>These indicators place an infant at risk for progressive or delayed-onset sensorineural hearing loss. Any infant who passed the birth screen but demonstrate one of these risk indicators should receive audiologic monitoring every 6 months until age 3 years</i></p>	<p>None specified</p>	<p>None specified</p>
<p style="text-align: center;"><b>5 - 6</b></p> <p style="text-align: center;"><b>PROTECTION OF INFANTS' AND FAMILIES' RIGHTS</b></p>	<p>Each agency or institution involved in the EHDI process shares the responsibility for protecting infant and family rights. These rights include access to UNHS, information in the family's native language, choice, and confidentiality. The information should cover the prevalence and effects of hearing loss, the potential benefits and risks of screening and evaluation procedures, and the prognosis with and without early identification and intervention. Families have the same right to accept and decline hearing screening or any follow-up care for their newborn. The results of the screening are to be communicated verbally and in writing to families by health care professionals knowledgeable about hearing loss and the appropriate interpretation of results.</p>	<p>None specified</p>	<p>None specified</p>
<p style="text-align: center;"><b>7 - 8</b></p> <p style="text-align: center;"><b>INFORMATION INFRASTRUCTURE</b></p>	<p>Recommends development of uniform state registries and national information databases incorporating standardized methodology, reporting, and system evaluation. Information management should be used to improve services to infants and their families; to assess the quality of screening, evaluation, and intervention; and to facilitate collection of data on demographics of neonatal and infant hearing loss.</p>	<p>None specified</p>	<p>None Specified</p>



Benchmarks and quality indicators are specified only for the first three principles – screening, diagnosis and intervention – which are also the most prominent, and to date, the most studied aspects of EHDI service delivery. Benchmarks and quality indicators were not specified for principles 4 to 8, probably because these principles are not defined as clearly as the first three and also due to a dearth of research into these aspects. Currently there is also no mechanism to enforce application of these standards and no formal measurement of their use in the USA (Mencher & DeVoe, 2001:19). According to the position statement, “to achieve accountability, individual community and state, health and educational programmes should assume responsibility for coordinated, ongoing measurement and improvement of EHDI process outcomes” (JCIH, 2000:10). Thus the improvement of EHDI services is an ongoing process that requires the support and feedback from all role-players in the EHDI system.

#### **2.4.2. Current infant hearing screening issues**

A century of reported research on identifying hearing loss in the newborn has culminated in the ability to identify and diagnose hearing loss for this population. This has been reflected in the recommendations throughout the last decade by several international organisations to diagnose hearing loss by the age of 3 months and initiate intervention before 6 months of age (NIH, 1993:1-24; JCIH 2000:9-29; Grandori, 1998:1219; AAP, 1999:527-530). The fact, however, that it is now possible to identify and diagnose hearing loss at birth does not mean that all the issues have been addressed sufficiently.

The following discussion will highlight some current issues of NHS programmes in the developed world. Although healthcare models in the United Kingdom, United States, Canada and most of the countries in Western Europe differ, a measure of services in one of these countries does offer an insight into comparable services in the rest of the developed world (Mencher et al., 2001:9). The majority of issues identified and to be discussed are based on literature findings from the USA and UK.

The most important issue concerns the *target disorder* to screen for. In the United Kingdom, based on current evidence of outcome benefit for early identification, the target disorder to be screened for is a child with 40 dB HL or greater permanent bilateral hearing loss (0.5 - 4 kHz) (Bamford, 2000:360). The JCIH in turn defines the targeted hearing loss for UNHS programmes as permanent bilateral or unilateral, sensory or conductive hearing loss, averaging 30 to 40 dB or more in the frequency region important for speech recognition (approximately 500 through 4000Hz) (JCIH, 2000:11). These differences in specified target disorders raise a number of additional questions that must be addressed:

- The question of *unilateral versus bilateral hearing loss* detection becomes a compromise between the effectiveness of the treatment and the costs involved. Although research indicates that unilateral hearing loss affects developmental and emotional outcomes in children (Bess et al., 1998:339), limited resources inevitably place a larger emphasis on identifying bilateral hearing loss above the more expensive identification of unilateral hearing loss (Lutman, 2000:368). It therefore becomes a matter of selecting a target disorder within the context of available resources. The UK has selected to screen for bilateral hearing loss while the USA has opted for unilateral and bilateral hearing loss identification. It is clear that deciding upon an appropriate option depends on the context and available resources.
- A more complicated question regards the *types of hearing loss* to be screened for and has important implications for the choice of screening device and protocols. The JCIH (2000:11) specifies screening for sensory and conductive hearing losses. Sensory hearing losses can be identified with OAE and ABR devices but no mention is made of neural hearing losses such as Auditory Neuropathy (AN). The latter can be identified only by using a neural-based test such as an ABR (Berlin, 1999:309; Sinninger, 2002:197). Although it is difficult to determine how common AN is, a recent study reported from a large cohort of clinical findings indicates that the incidence of AN was 1 in 433 infants with risk factors for hearing loss (Rance et al.,

1999:238). Sinninger's (2002:197) summary of reports proposes an incidence of 10.3 per 100 paediatric patients with hearing loss. The prevalence of the disorder therefore seems to be higher than previously expected (1 in 10) and if a priority is placed on identifying these children, recommendations may need to be revised and screening protocols need to be adjusted to include an ABR or some form of auditory evoked potential.

- Transient *Middle-Ear Effusion* (MEE) and other middle-ear factors further complicate the issue of the target disorder to screen for. Infants with mild transient conductive hearing loss refer hearing screenings, which results in higher false positive rates and leads to added expenses and increased chances of anxiety for parents (Mencher & DeVoe, 2001:17; Thornton et al., 1993:322). Even though significant efforts have been made to reduce the number of false-positives by protocols (Prieve & Stevens, 2000:85; Spivak et al., 2000:92; Gravel et al., 2000:131), the question of transient MEE is not addressed. Clear statistical information is needed regarding the number of false-positives due to transient MEE and the implications for diagnostic agencies, funding resources, and the children and their families (Mencher & DeVoe, 2001:17). MEE is not uncommon among infants, and newborns from the NICU are especially prone to the condition (Engel et al., 2001:142). Studies indicate that OAEs are severely diminished and even obliterated by MEE, whilst ABR screening is less affected by it (Yeo et al., 2002:798; Koivunen et al., 2000:214; El-Refaie et al., 1996:7; Taylor & Brooks 2000:54). Unfortunately it is difficult to diagnose transient MEE in the newborn and young infant after referral on a screening test, as conventional immittance evaluations of middle-ear functioning are unreliable for infants younger than 7 months of age (Holte et al., 1991:1; Hunter & Margolis, 1992:33; McKinley et al., 1997:218).

The JCIH (2000:23) identifies the need for rapid screening methods to differentiate between conductive and other hearing losses and suggests that middle-ear reflectance measures may in future contribute to determining whether middle-ear dysfunction contributes to the screen outcome. Recent

reports have demonstrated promising results for the use of high frequency tympanometry using a 1000Hz probe tone to assist in detecting middle-ear dysfunction in neonates (Kei et al., 2003:27; Margolis et al., 2003:383; Purdy & Williams 2000:22; Meyer et al., 1997:194). A reliable test that is able to distinguish between sensori-neural hearing loss and middle-ear pathology for neonates and young infants is important for a) identifying screening fails caused by transient middle-ear conditions; b) determining the need for medical management of middle-ear pathology; and c) determining the need and timing of follow-up procedures such as an ABR evaluation with and without sedation (Margolis et al., 2003:384). Continued research in this area is required to ensure that a reliable procedure is established for referring infants with middle-ear dysfunction or MEE.

- Another issue concerns the identification of *acquired, late-onset, and progressive hearing losses* as early as possible. These hearing losses will not be identified by newborn hearing screening and can be the result of (a) an acquired loss later in life after a traumatic event such as infection, ototoxic therapy, or chemo therapy, (b) a loss of insufficient severity to be detected by a screening procedure at birth but which progresses as the child grows, (c) a genuine late-onset loss that develops without any obvious causative factor (Fortnum, 2003:155). The true prevalence of such disorders is still elusive. Initial reports, based on cohorts mostly from the 1970s and 1980s in Europe, indicate that 14.5% to 27.9% of hearing-impaired children exhibit these types of hearing losses. The large range probably reflects differences in definition (Fortnum, 2003:157). Reports also indicate a higher prevalence of such disorders among NICU-discharged infants (Kawashiro et al., 1996:35). These delayed-onset hearing losses require protocols that will ensure early identification despite having passed a newborn hearing screen. The JCIH has specified a list of risk factors for delayed-onset hearing loss to monitor infants with those risk factors for possible delayed-onset hearing loss (JCIH, 2000:20-21). As UNHS programmes continue to develop, it will become possible to determine the proportion of hearing losses in infants that are truly congenital and those that occur postnatally (JCIH, 2000:23). This will allow

for accurate and comprehensive infant hearing screening programmes that identify congenital and delayed-onset or progressive hearing losses efficiently.

Substantial progress has been made in addressing many of the initial issues involved in the implementation of UNHS programmes in the USA (White 2003:83). A number of current issues identified by White (2003:87) however need to be addressed, and they are summarised in Table 2.6.

**TABLE 2.6 Current EHDl issues in the USA (White 2003:79-88)**

ISSUE	DESCRIPTION
<ul style="list-style-type: none"> <li>• <b>Number of paediatric audiologists</b></li> </ul>	<p>A nationwide shortage of paediatric audiologists has been identified as the most serious challenge in implementing successful EHDl programmes. Only 56% of infants referred from UNHS screening programmes actually received a diagnostic evaluation before the prescribed age criterion of 3 months, most probably due to this shortage of paediatric audiologists (White, 2003:84).</p>
<ul style="list-style-type: none"> <li>• <b>Tracking and data management</b></li> </ul>	<p>Making sure that infants referred from screening programmes receive appropriate and timely intervention remains a significant challenge (White 2003:85).</p>
<ul style="list-style-type: none"> <li>• <b>Programme evaluation and quality assurance</b></li> </ul>	<p>The need for implementing quality assurance evaluations is left wanting. There is little evidence that most state EHDl programmes have yet had time or resources to implement such systematic evaluation and quality assurance programmes (White, 2003:85).</p>
<ul style="list-style-type: none"> <li>• <b>Availability of early intervention programmes</b></li> </ul>	<p>State EHDl coordinators report that appropriate educational intervention programmes for infants and toddlers with hearing loss are not as widely available as they should be. Most programmes were developed before hospital-based NHS programmes became widespread (White, 2003:84).</p>
<ul style="list-style-type: none"> <li>• <b>Linkage with medical home providers</b></li> </ul>	<p>State EHDl coordinators report that the name of the primary care physician who will care for the infant with hearing loss for the first 3 months is known only by approximately 75% of newborns discharged from the hospital. In many cases these physicians are not well-informed about issues related to early identification of hearing loss (White, 2003:85).</p>

Unlike during the early 1990s there is now a firm research and experiential basis for addressing all of the issues listed in Table 2.6. However, White (2003:87) remarks that “it will continue to require the commitment and resources of state health officials, hospital administrators, healthcare providers (particularly physicians and audiologists), and parents”.

## 2.5. CONCLUSION

“Universal infant hearing screening is a noble goal, and the world is well down the pathway toward achieving it” (Mencher et al., 2001:10). The last 10 years witnessed UNHS becoming the *de facto* medical/legal standard of care in a developed country such as the USA, with other countries following suit (White, 2003:85; Davis & Hind, 2003:193). The ground swell of research reports, the technological advances enabling easier and more cost-effective identification, and the growing evidence in support of significant benefits of early intervention for hearing-impaired infants have asserted NHS as an increasingly important aspect of neonatal care (Roizen, 1998:237; Vohr et al., 2000a:295; White, 2003:87). The practice of NHS has established itself as a screening priority against the criteria specified for the justification of widespread screening programmes and has become an important component of preventative public healthcare (Vohr et al., 2000a:295).

To ensure that accountable services are part of an EHDI programme, important guidelines have been developed to weigh NHS practice against quality standards and performance benchmarks (JCIH, 2000:9-29; AAP, 1999:527-530). These standards and benchmarks are continually assessed to include more comprehensive recommendations that extend beyond screening and diagnosis to audiological service delivery (Culpepper, 2004:162). The trends noted in recommended procedures for infant assessment and amplification in the USA are compared to those developed in Canada, the UK and Australia in order to compile encompassing guidelines for all aspects of audiological service delivery (Culpepper, 2004:162).

It is clear that the course of IHS, spanning across the major part of the last century, has paved its way into developed countries around the world (Downs, 2000:292-293). The principles that justify IHS as a valid healthcare and societal practice in developed countries, as well as the current status of these programmes, provide an important framework for the critical consideration of IHS in developing contexts. This matter will be addressed in Chapter 3.

## **2.6. SUMMARY**

Chapter 2 provided the basic philosophy and principles pertaining to widespread IHS and assessed the current status of NHS in the developed world. Principles were selected from the literature and divided into a discussion of disorder-related and screening-process related principles. The practice of IHS was justified by evaluating it against these principles, which underlie the rationale for widespread screening. The discussion was followed up by an assessment of the current status of IHS in the developed world. Screening options, EHDl systems and the JCIH Year 2000 position statement were discussed and the current issues of NHS practice evaluated. The chapter was concluded with final remarks to focus the reader's attention on the framework of current IHS practice provided during the discussion of Chapter 2. The latter serves as background to Chapter 3.