The background of the cover features three dice with a heart on each of their visible faces. The dice are rendered in a light, semi-transparent style with a soft orange glow around them, set against a light green background.

Report of the
**Universal Neonatal
Hearing Screening
Working Group**

Programme of Action for Children

Foreword

The failure to detect hearing problems in babies and children can have a profound negative effect on their subsequent development and well being. The early detection and treatment of hearing loss has been shown to be of enormous benefit, and can often mean that a child is not disadvantaged in terms of developing speech and language.

This report examines the case for developing a national hearing screening service for babies born in Ireland, and was commissioned by the Health Board CEOs, arising out of a previous report, Best Health for Children which considered wider issues in relation to child health. This service would enable the average time between detection of hearing loss and starting treatment to be cut by months and in some cases years, at a crucial time in the development of hearing and speech.

The techniques described in this report are already operating in many countries with great success.

However implementing any new screening programme is a major undertaking, the success of which will be dependent on the quality of the programme. This report identifies the many issues, which would need to be addressed to enable a Universal Neonatal Hearing Screening Programme. These range from testing issues, to staff training, to equipment, and follow up services.

The report makes a compelling case for the introduction of a programme, which will have massive benefits for children with severe hearing loss.

I would like to thank the working group for completing a comprehensive review of this complex topic. I would particularly like to thank Dr. Heidi Pelly, Dr. Tessa Grealley and Ms. Catherine Curry for their chairing of the working group and sub-groups, and Ms. Regina Walsh former Project Officer, and Ms. Jean Kilroe for their work in producing the many drafts of the report.

The report makes a major contribution to an area where the potential benefits for improving the lives of children, are very significant indeed.

Sean Denyer
Director
Programme of Action for Children
December 2004

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Glossary

<p>Acquired hearing impairment post-natally or of late-onset or of a progressive nature which on the basis of case history was not considered to be present and detectable using appropriate tests at or very soon after birth.</p> <p>Audiological Physician a doctor who has consultant status and has completed specialised training in audiology, neurology and developmental paediatrics and is accredited by the Royal College of Physicians.</p> <p>Audiological Scientist is proficient in all procedures. They also interpret and report the results of these tests. Audiological Scientists will have a substantial amount of theoretical knowledge about acoustics and balance. This knowledge enables the scientist to solve technical problems and, when necessary, to develop logical alternatives. Experienced Audiological scientists generally carry out the non-routine aspects of any service, especially where a high degree of competence and responsibility is necessary. They are usually based in hospital and/or community.</p> <p>Audiologist a professional who tests and evaluates individuals with hearing loss or balance problems. Physicians refer patients to audiologists when the hearing or balance problem requires evaluation.</p> <p>Auditory Neuropathy (also known as Auditory Dys-Synchrony) is identified by the presence of OAE in the presence of an abnormal or absent auditory brainstem response.</p> <p>Auditory Brainstem Response [ABR] is an objective neurophysiological test that usually reveals hearing levels at high frequencies, is similar to electroencephalogram [EEG]. This test requires expert interpretation and beyond the neonatal period in most instances sedation is necessary.</p> <p>Automated ABR recordings of the ABR performed with a highly automated and fixed procedure for data collection for the purpose of screening for hearing loss. The presence of a response (pass) or absence (refer) at the screening intensity level is determined primarily by a machine scoring algorithm. Recorded waveforms maybe available to enable visual interpretation of the data.</p> <p>Average hearing level The average of the thresholds (in dB HL) measured in the better hearing ear at 0.5, 1, 2 and 4 kHz, or whatever combination is available.</p>	<p>Conductive Hearing Loss [CHL] is due to a problem in the middle ear and/ or outer ear. This is commonly a temporary problem as in Otitis Media with Effusion [OME]. Glue Ear or Secretory Otitis Media are older terms for the same condition, where indicated it responds well to grommet insertion.</p> <p>Confirmation of permanent hearing impairment date when the first measurement of raised thresholds by an age-appropriate audiological test made, with the reliability of the results being high.</p> <p>Congenital hearing impairment hearing impairment considered by examination of the case history to be present and detectable using appropriate tests at or very soon after birth.</p> <p>Distraction test a sound field behavioural test of hearing that depends on the developmental maturity of the infant to turn and locate to the source of quiet sounds. It requires two trained staff members, some distraction toys and a quiet environment to administer. Ideally performed at 7 – 9 months but with increasing difficulty [and thereby requiring greater skill] it may be employed up to the age of 18 months.</p> <p>Fitting of hearing aid The date when the child is first fitted with a hearing-aid, not the date on which moulds are taken.</p> <p>Key worker the role includes co-ordinating services, identifying ways to provide a seamless and efficient service, and acting as facilitator and link person for the family. The NDCS suggests that the key worker should be a Teacher of the Deaf or a Family Support worker.</p> <p>Incidence Number of new instances of a specific condition occurring during a certain period in a specified population.</p> <p>Intervention activity initiated by a professional intended to deal with a problem affecting health or development.</p> <p>Moderate hearing impairment average hearing level 40-69 dB HL.</p> <p>Neonatal first four weeks of life.</p> <p>OAE oto acoustic emissions acoustic responses produced in the inner ear by the outer hair cells of the cochlea in response to sound.</p>
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Glossary Continued

Permanent Childhood Hearing Impairment [PCHI] is a term coined to encompass sensorineural hearing loss, mostly congenital and the more rare permanent conductive hearing loss mostly found in association with cranio-facial abnormalities where surgical interventions are less likely to be successful.

Prevalence The total number of instances of a specified condition in a given population at a specific time.

Profound hearing impairment average hearing level >95 dB HL

Sensorineural Hearing Loss [SNHL] is caused by a defect in the cochlea or sensory organ in the inner ear or in the auditory nerve or its central connections. This is a permanent condition. It may be unilateral or bilateral. The estimated birth prevalence of congenital sensorineural hearing loss [SNHL] or mixed hearing impairment is 1.16 per 1,000.

Severe hearing impairment average hearing level 70-94 dB HL

Sensitivity The effectiveness of a screen in identifying cases. Test sensitivity is the percentage of cases failing a single test opportunity; screen sensitivity is the percentage of cases tested referred by a screen; programme sensitivity is the percentage of cases referred by a screening programme taking into account the coverage of the target population.

Specificity The ability of a programme to screen out individuals who are not cases (e.g. in a screening programme, the percentage of unaffected individuals who pass the screen.)

Abbreviations

AABR	automated Auditory Brainstem Response	NDCS	National Deaf Children's Society
AN	Auditory Neuropathy also known as Auditory Dys-Synchrony	NICU/ SCBU	Neonatal Intensive Care Unit or Special Care Baby Unit
ARC	Auditory Response Cradle	NIH	National Institutes of Health (USA)
BHFC	Best Health for Children	NRB	National Rehabilitation Board
DB HL	Decibel, log- scale measure of hearing level using pure tone average or an estimate of dB HL made using alternative scales	OAE	Otoacoustic Emission
DPOAE	Distortion Product Otoacoustic Emission	OME	Otitis Media with Effusion (glue Ear)
HVDT	Health Visitor Distraction Test	PCHI	Permanent Childhood Hearing Impairment
IDT	Infant Distraction Test	PHL	Permanent Hearing Loss
JCIH	Joint Committee on Infant Hearing	TEOAE	Transient Evoked Otoacoustic Emission
MRC	Medical Research Council	ToD	Teacher of the Deaf
NCHAM	National Center for Hearing Assessment and Management (USA)	UNHS	Universal Neonatal Hearing Screening

Executive Summary

More than 80 children are born in the Republic of Ireland each year with Sensorineural Hearing Loss (SNHL). The average age of identification using the current “distraction test” screening programme is approx 30 months; this exceeds internationally recognised targets of 4-6 months for confirmation of hearing loss in infants. It is recognised that the opportunity to benefit from early identification is lost with such late referrals and can only be achieved through neonatal screening of all infants in the early weeks of life.

Permanent Childhood Hearing Impairment (PCHI) may disrupt the process of communication and normal language acquisition, leading to poor language, communication and literacy skills. This has long term consequences for a child in terms of educational achievement, mental health and quality of life. Neonatal screening can identify PCHI early, leading to early intervention.

Universal Neonatal Hearing Screening (UNHS) involves screening all neonates ideally when the newborn infant is 48 hours or older. Testing may take place in either the hospital or community setting. The majority of programmes are hospital based as the ‘captive population’ facilitates easy access to infants, ensuring high coverage. Early discharges may have an impact on this method of service delivery. Across the world support for the introduction of UNHS has grown over the last decade and international guidelines suggest that the referral rate from screening programmes should not exceed 4%.

The protocol for carrying out UNHS differs depending on whether a newborn baby has been well or has been admitted to the Neonatal Intensive Care Unit (NICU). For well babies Otoacoustic Emission (OAE) is a screening test which is a rapid, cost-effective means of testing all babies with normal auditory systems provided it is carried out ideally after 48 hours of age. If an infant passes on the first screen the screening process is complete. The baby will continue to undergo routine child health surveillance. This first screen must be completed by 3 weeks of age. The second screen is to be completed by 6 weeks of age and if an infant passes on this second attempt the screening process is complete. If an infant fails this test, s/he is referred to the appropriate tertiary level service for detailed audiological assessment.

Approximately 7% of all new born infants require neonatal intensive care for longer than 48 hours. Auditory neuropathy (AN), also known as Auditory Dys-Synchrony, is a condition in which the patient displays auditory characteristics consistent with normal outer hair cell function and abnormal neural function at the level of the vestibulo-cochlear nerve. The incidence of AN is 1 in 480 in NICU babies compared to less than 3 per 100,000 in the general population. The international trend is towards the use of automated Auditory Brain Stem Response (aABR) to test NICU babies and this test should be done prior to discharge.

In screening programmes technologies using automated response detection are preferred over those that require operator interpretation and decision making. Due to the speed of technology development the Working Group decided not to recommend specific types of equipment but rather to set out a checklist of guidelines for commissioning of equipment and recommend that central purchasing be put in place in order to ensure quality and to effect economies of scale.

It is recognised that as with all screening processes, a certain percentage of infants will fail the screening process. These babies will need to be referred to a Tertiary Audiology Centre for full evaluation and assessment.

A UNHS programme which screens all infants in a one or two stage screening test will involve a diverse range of staff throughout that period. In order to manage the programme, a national Programme Co-ordinator is essential who would most likely be a professional trained in audiology. Screeners with appropriate training from a variety of backgrounds can screen newborn babies. Provision should be made for Irish academic centres for audiology training and statutory registration of Audiology professionals similar to other professions.

Once identification of significant permanent hearing loss has been made, there must be seamless provision of care. To ensure this the following issues must be addressed, delays on the provision of hearing aid moulds; shortage of Speech and Language Therapists and speech and language therapy services for infants; appropriately experienced and qualified teachers and year round service provision by teachers of the deaf.

The first UNHS screening programmes in most countries were generally carried out in hospitals pre-discharge for parental convenience and to maximise uptake of screening. However in light of the trend towards early discharge and home births, community based testing needs to be considered in conjunction with a hospital based screening programme. Screening in the home or at local health centres are options which should be considered in order to provide a family friendly service. There will be a number of challenges to the implementation of UNHS including the follow up of migratory groups, early discharges, home births and babies that have never been screened or require re-screening.

Informing parents of the screening process allows them to make an informed decision regarding consent to, or refusal of the hearing screen. The consent form may be stored in the baby's hospital records or child health records held in the community. Parents with special information needs must receive appropriate health promotion materials and translation facilities must be provided. All health service professionals who are likely to come in contact with the family should be fully informed regarding UNHS.

An Information Management System (IMS) must be put in place to track the infant through screening, from audiological assessment through to early intervention. Prior to the selection of a suitable IMS consideration should be given to: ensuring all existing child health databases are compatible and integrated with the new system; the location of screening service; the point of allocation of unique identifier; an agreed pathway for referral and inputting of data.

In order to ensure the development of a high quality UNHS service adequate resourcing is essential.

Chapter 1

Background

1.1 Best Health for Children Report

The report “*Best Health for Children-Developing a Partnership with Parents*¹” commissioned by the Chief Executive Officers of all the Health Boards in the Republic of Ireland was published in 1999. It made many recommendations regarding changes in delivery of the child health services in the Republic of Ireland.

Amongst the detailed recommendations around screening for hearing defects it was concluded that *serious consideration should be given to the introduction of universal neonatal screening on a pilot basis.*

The Best Health for Children (BHFC) programme (now Programme of Action for Children) was established in 1999 and is responsible for the implementation of the report.

Between 1998 and 2003 considerable changes occurred in the structure of hearing services and their delivery across the country: although not directly linked to the issue of universal neonatal hearing screening (UNHS), the restructuring has had an impact on the follow-on services for children referred as a result of hearing screening. Services formerly organised centrally under the National Rehabilitation Board (NRB) became regionally based under the remit of individual Health Boards as described in Appendix 1.

1.2 Universal Neonatal Hearing Screening Working Group

The Conjoint group of Chief Executive Officers of the 10 Health Boards commissioned BHFC, to consider issues pertaining to the introduction of UNHS on a national basis. In order to further this, a working group, comprising of key personnel, reflecting geographical and professional representation was established in 2001. This Working Group included representation from existing UNHS pilot programmes.

1.3 Terms of Reference

To plan the introduction of a quality assured national UNHS programme by:

- a) Reviewing experience in other countries where similar programmes have already been established.
- b) Reviewing practice and experience in units in the Republic currently running such programmes.
- c) Identifying models of “Best Practice”.
- d) Identifying resources required to support the programme;
 - Staff & Training
 - Equipment
 - Access to Ear Nose and Throat (E.N.T.) and hearing aid fitting services
 - Access to counselling and support in the community.

¹ Denyer, et al. 1999

Chapter 2 Introduction

2.1 Hearing Impairment

There are two main types of hearing impairment in childhood²;

1. Sensorineural Hearing Loss (SNHL) caused by a lesion in the cochlea or the auditory nerve and its central connections. It may be unilateral or bilateral.
2. Conductive Hearing Loss related to abnormalities of the ear canal or middle ear.

Permanent Childhood Hearing Impairment (PCHI)³ may disrupt the process of communication and normal language acquisition, leading to poor language, communication and literacy skills. This has long term consequences for a child in terms of educational achievement, mental health and quality of life⁴.

It is estimated that approximately 84⁵ children are born in the Republic of Ireland with a permanent hearing impairment each year. The estimated birth prevalence of congenital SNHL or mixed hearing impairment is 1.16 per 1,000. 1.3 per 1,000 children have this degree of hearing loss and require a hearing aid; the difference is accounted for by acquired and conductive hearing loss⁶.

For the purposes of this report we are concerned with SNHL which is usually possible to detect in the first few weeks of life. The National Deaf Children's Society (NDCS)⁷ has set the following targets for UK children with SNHL:

- Hearing loss to be confirmed by 4-6 months.
- hearing aid fitting for all true cases must take place within 4 weeks of confirmation.

The NRB study of children born in the South Eastern Health Board between 1986 and 1990 found an average age of identification of hearing loss of 30 months. 90% of eligible children i.e. aged at least 7 months were screened. The median date for first hearing aid fitting was 19.5 months for profound HL, 23 months for severe HL and 49 months for moderate HL as shown in Table 1.

Table 1 Performance indicators of the Audiology Screening Programmes⁸

NRB Study 1986-90	Profound HL [n=18]		Severe HL [n=8]		Moderate HL [n=42]	
Median Age of first suspicion	7 months		10.5 months		11.5 months	
Date of first appointment in months	NRB 12.5-13 months	ENT 11-14.5 months	NRB 12-13.5 months	ENT 15-16.5 months	NRB 27-29 months	ENT 22-25.5 months
Median date of first Hearing Aid fitting	19.5 months		23 months		49 months	

² Hall, D. & Elliman, D. 2003

³ PCHI is a term coined to encompass SNHL, mostly congenital and permanent conductive hearing loss mostly found in association with cranio-facial abnormalities where surgical interventions are less likely to be successful.

⁴ Yoshinaga- Itano, C and Gravel, J.S. 2001; Davis et al. 1997; Denyer et al. 1999; Hall, D. & Elliman, D. 2003; NHMRC, 2002; PHAA 2000

⁵ Figures are based on UK prevalence rates and Republic of Ireland birth rates.

⁶ cited in Davis et al. 1997

⁷ The National Deaf Children's Society 2000

⁸ Department of Public Health South Eastern Health Board, 2000

2.2 Historical Overview of Screening for Permanent Childhood Hearing Impairment (PCHI)

The earliest hearing screening programmes targeted children of school going age. In the 1940s it was demonstrated that it was possible to test children's hearing at 9 months using the "distraction test."

However a number of factors have led to the development of neonatal hearing screening;

- In the 1970s the effectiveness of the distraction test and its ability to identify PCHI early was questioned.
- Knowledge of the importance of the early months for a child's communication development led to the belief that infants were being identified too late by the distraction test.
- This discussion gave rise to the development of behavioural testing devices such as the Auditory Response Cradle (ARC) to screen neonates (i.e. infants in the first weeks of life).
- Epidemiological findings which highlighted at-risk groups led to arguments in favour of targeted neonatal screening of the at-risk population in Neonatal Intensive Care Units (NICUs). Existing equipment was unsuitable for screening these neonates.
- Suitable automated equipment for screening neonates was developed- Otoacoustic emissions (OAE) and Auditory Brainstem Response (ABR).

2.3 Current Screening Practice for PCHI in Ireland

The Manchester /Health Visitor Distraction Test (HVDT) was first introduced to Ireland in the 1950s. It cannot be performed on babies under the age of 6-7 months⁹ and requires two trained personnel with knowledge of child development. The validity of the tests is in doubt when carried out on children over 10 months of age, however the 7-10 month timescale is not always achieved owing to staff shortages. Children who do not pass the test are generally re-tested one month later; if they fail the test, they are referred for the diagnostic and assessment stage to Health Board audiology services (formerly provided by NRB). The Davis report in 1997 highlighted the inadequacy of the HVDT screening tool¹⁰.

2.4 Objective of Neonatal Hearing Screening

The ultimate goal of neonatal hearing screening is to reduce the age of diagnosis of hearing loss to 3 months and to undertake/commence amplification, fitting and enrolment in early intervention programmes by 6 months of age¹¹. This is because the negative effects of hearing impairment can be reduced through effective intervention and management including hearing aid fitting, habilitative interventions, language and family support. At one year of age, if appropriate, cochlear implantation should be available to the deafest infants.

Neonatal screening can identify PCHI early, leading to early intervention. Thus early detection and management of PCHI lessens the impact of the condition on the child's social, emotional, intellectual and linguistic development¹².

Screening programmes for neonatal hearing screening may be **targeted or universal**.

⁹ Hall, D & Elliman, D. 2003; Denyer et al. 1999; Pitt et al. 1999; Bamford et al. 1998

¹⁰ Davis et al 1997; Denyer et al. 1999

¹¹ NIH Consensus Statement Online 1993; American Academy of Paediatrics 1999; Pitt et al.1999; NHMRC 2002; CHSR 2003; Denyer et al. 1999; Abbasi 1997

¹² Yoshinaga- Itano, C and Gravel, J.S. 2001; Davis et al. 1997; Denyer et al. 1999; Hall, D. & Elliman, D. 2003; NHMRC, 2002; PHAA 2000.

Targeted screening programmes screen babies in higher risk groups for PCHI who meet agreed criteria which include;

- infants who require NICU for longer than 48 hours
- birthweight less than 1.5kg
- Apgar score of 0-4 at 1 minute or 0-6 at 5 minutes after birth
- mechanical ventilation lasting 5 days or longer
- perinatal infection
- very high levels of jaundice
- chromosomal abnormalities
- syndromes known to include hearing loss (e.g. Usher's , Wardenburg's)
- family history of hearing loss PCHI/SNHL
- cranio-facial abnormalities
- congenital infections (toxoplasmosis; bacterial meningitis, syphilis, rubella, cytomegalovirus; herpes virus)
- hyperbilirubinaemia requiring exchange transfusion
- severe birth asphyxia
- child who receives certain drugs e.g. aminoglycosides/ototoxic medications
- consanguinity i.e. marriage between close relatives.

A policy of restricting screening to high risk groups results in 30- 50% of infants with hearing loss being missed¹³.

2.5 Universal Neonatal Hearing Screening Programmes (UNHS)

UNHS involves screening all neonates ideally when the newborn infant is 48 hours or older. When screening is performed during the first 24 hours after birth, debris or fluid in the external and middle ear may effect OAE resulting in higher referral rates; 48 hours of age or older for SNHL¹⁴. Testing may take place in either the hospital or community setting. The majority of programmes are hospital based as the 'captive population' facilitates easy access to the infants, ensuring high coverage. Early discharges may have an impact on this method of service delivery. Across the world support for the introduction of UNHS has grown over the last decade.

Republic of Ireland

Two stand alone programmes have commenced at Tralee and Castlebar General Hospitals respectively; the Castlebar service has recently extended to include University College Hospital, Galway. A targeted programme commenced at Sligo General Hospital in January 2001 (see appendix 2). These programmes have not been centrally funded and have been established only as a result of enthusiasm and commitment of the personnel involved.

¹³ Davis, A. & Wood, S. 1992; Watkin, PM et al 1991; Davis et al 1997; Watkin 1996; NHMRC, 2002; USPSTF, 2001; Hall, D. & Elliman D 2003; Denyer et al. 1999; Pitt et al. 1999; PHAA, 2000

¹⁴ Sensori- neural deafness, or nerve deafness is a hearing loss in the inner ear. This means that the cochlea may not be working effectively. It leads to loss of loudness as well as lack of clarity.

America

The main endorsements of UNHS in America include

- National Institute of Health (1993)
- Joint Committee on Infant Hearing (1994)¹⁵
- American Academy of Pediatrics (1999)

In 2000 the Joint Committee on Infant Hearing issued programme principles and guidelines to provide proper screening, diagnosis, follow-up and intervention for newborns¹⁶. In the USA over 35 states have mandated UNHS¹⁷. By September 2001, 70% of all newborns in the USA were screened for hearing loss prior to discharge from hospital.

Europe

Standards of best practice were issued from the European Consensus Development Conference on UNHS in 1998 (see appendix 3). In Europe, over 34 regions (regional and national) have established UNHS programmes and it is estimated that 19% of newborns in the EU were being screened in 2002.

U.K.

As a result of the positive evaluation (see table 2), the UK government decided in 2001 to introduce UNHS on a phased basis across the country; to date twenty pilot UNHS programmes have been set up in over 50 hospitals and in some community settings including a pilot programme that commenced in the Royal Victoria Hospital, Belfast in October 2002¹⁸.

Table 2 Comparison of UNHS and Distraction Testing (Davis et al. 1997)¹⁹

Compared by	UNHS	Distraction Testing
Coverage	90%+	80-95% falling to nearer 60% in some urban areas
Yield	1-1.3 per 1000	-
Age of Identification	2 months	12-20 months
Age of Intervention	6 months	32 months
Sensitivity	Has not yet been assessed but may be greater than 90%	18-88%
Specificity	95%	-
Cost	Lower on a cost per child screened basis	Higher on a cost per child screened basis

¹⁵ American Academy of Pediatrics 1995

¹⁶ American Academy of Pediatrics 2000

¹⁷ Commentary from 2nd International Conference on Newborn hearing Screening Diagnosis and Intervention Villa Erba (Como), Italy, May 30- June 1, 2002

¹⁸ Group on the Implementation of Universal Neonatal hearing Screening [On Line], (<http://www.nhsp.info/index.shtml>) accessed 28 Oct. 04)

¹⁹ This was the information provided at the time, since it's publication in 1997 UNHS coverage is better and costs are lower.

Chapter 3 Methodology

A combination of research methods was used to inform this report:

3.1 UNHS Working Group

A Working Group was established to develop and oversee the terms of reference. The Working Group was established in 2001 and met as a plenary group. Two sub-committees comprising consumer, professional and managerial representatives were established to examine various issues required to support the programme.

3.2 Literature Review

An extensive literature review was carried out to inform the Working Group. Because of the rapidly developing field of knowledge and the international character of the material, the literature was gathered through a combination of the following:

- a) materials fed through the committee membership and contacts established with UNHS programmes
- b) information collated from conference materials.

3.3 Site visits

Representatives of the Working Group carried out site visits to the existing programmes in the Republic of Ireland and to the pilot programme at the Royal Victoria Hospital, Belfast. The purpose of these visits was to examine and detail the screening process and to learn from the experience of these programmes.

In addition representatives of the Working Group attended the 2nd International Conference, NHS 2002 which took place in Como, Italy, May 30 - June 1, 2002.

3.4 Contacts

Contacts were also established with other international programmes including;

- NHS Newborn Screening Programme, U.K.
- Kind & Gezin Newborn Screening Programme, Flanders region of Belgium.
- Professor Ferdinando Grandori, Project Leader, EU Project AHEAD II, Quality of Life Programme, Milan, Italy.

3.5 Workshop

A Workshop was held in September 2002 to facilitate a consultation process with stakeholders. The target audience included consumers, policy makers, senior health service managers and relevant health care professionals. Feedback from this workshop was used to inform this report.

Chapter 4

Review of literature and principles

We can conclude that, although the evidence on early identification is limited and complex, there is a definite indication that, in terms of language and communication outcomes, earlier identification is beneficial²⁰. Effective UNHS will not replace the need for vigilance and for continued surveillance to detect hearing impairment in children who have not received neonatal screening or who develop PHL at a later age²¹.

- Any newborn screening programme must encompass the principles set out in the UN Convention on the Rights of the child²².
- All conditions included in a Newborn Screening Programme should fulfil in part or in full the internationally established criteria for screening²³ (see appendix 4).
- It is easier to establish the cause of PCHI if it is diagnosed early. In particular, intrauterine infections become increasingly difficult or impossible to diagnose after the first few months of life.
- It is easier to achieve high coverage for screening and early detection services for babies in the first year of life than any time subsequently until school entry.
- The first six months have been suggested as a sensitive or critical period for learning and intervention. Early diagnosis of PCHI prior to six months of age affords the child the opportunity to achieve significantly higher levels of receptive and expressive language skills and speech intelligibility than children identified at a later age²⁴.
- Children identified earlier did better on measures of language (signed or spoken) and social emotional development than later identified peers regardless of their gender, ethnicity, socio economic status, communication modality, degree of hearing loss or presence of multiple disabilities²⁵.
- Young children who have a hearing loss and are enrolled early in an effective early intervention programme are 2.6 times more likely to have language within the normal range in the first five years of life than a child who does not have this advantage²⁶.
- The earlier a child with hearing loss is identified, the greater the opportunity for normal language to develop²⁷

²⁰ Yoshinaga-Itano, D. et al 2001; Markides A, 1986; Yoshinaga- Itano, C. et al. 1998; Denyer, 1999; Hall, D. & Elliman, D. 2003; NHMRC, 2002; PHAA, 2000; Yoshinaga- Itano, C. et al. 1996; Downs, M.P. 1994; Yoshinaga- Itano, C. et al.2000; Moeller, 2000; Eilers, R.E. Oller, D.K. 1994; Ramkalawan, T.W., & Davis, A.C. 1992; Evans, R. & Robinshaw, H. 1999

²¹ Hall, D. & Elliman, D. 2003; Denyer et al. 1999; PHAA, 2000

²² British Association for Community Child Health 1994

²³ Oxford Handbook of Public Health Practice 2001

²⁴ Markides A, 1986; Yoshinaga- Itano, C. et al. 1998; Denyer, 1999; Hall, D. & Elliman, D. 2003; NHMRC, 2002; PHAA, 2000; Yoshinaga- Itano, C. et al. 1996; Downs, M.P. 1994; Yoshinaga- Itano, C. et al.2000; Moeller, 2000; Eilers, R.E. Oller, D.K. 1994; Ramkalawan, T.W., & Davis, A.C. 1992; Evans, R. & Robinshaw, H. 1999

²⁵ Yoshinaga-Itano, C. et al. 2000

²⁶ Yoshinaga-Itano, C. et al. 2000

²⁷ Prendergast et al. 2002

- Better language development has a significant relationship with improved social- emotional development of the child, parental skills and emotional well being.
- UNHS has high test sensitivity and reasonably high programme sensitivity, with high specificity²⁸. Coverage for UNHS can be as high as 90%. UNHS could identify children with a hearing impairment at a younger age, in addition intervention and habilitation for the majority of those screened using UNHS is routinely taken within 6 months of birth²⁹.
- HVDT at 6-9 months fails to detect a significant number of hearing problems sufficiently early. Coverage for the traditional distraction testing was lower between 80-95%, falling to nearer 60% in some urban areas, with relatively low yield. The median age of identification via the HVDT varies from 12 to 20 months³⁰.
- UNHS has a lower running cost and much lower cost per child detected than HVDT³¹.
- UNHS will fail to identify progressive congenital or acquired hearing loss, therefore at 7 months, a targeted HVDT is recommended to identify children deemed to be ‘at risk’³².
- The main argument against neonatal hearing screening is its consequences for parent- child relationships, family dynamics, infant acceptance, child management and parental anxiety³³. However a number of studies have shown that parents want screening and welcome early diagnosis of disabling conditions and have a low opinion of services if they fail to identify serious long- term problems in their children despite the possible stress and anxiety this may cause at the time³⁴.

Summary

More than 80 children are born in the Republic of Ireland each year with SNHL. The average age of identification using the current “distraction test” screening programme is approx 30 months; this exceeds internationally recognised targets of 4-6 months for confirmation of hearing loss in infants. It is recognised that the opportunity to benefit from early identification is lost with such late referrals and can only be achieved through neonatal screening of all infants in the early weeks of life.

²⁸ Davis et al. 1997

²⁹ Abbasi, K. 1997; Denyer et al, 1999; Davis et al; 1997; PHAA, 2000; NHMRC, 2002; CHSR, 2003

³⁰ Davis et al. 1997

³¹ Davis et al. 1997

³² Hall, D. & Elliman, D. 2003; Denyer et al, 1999; NHMRC, 2002

³³ Kuyper, P. 1981.

³⁴ Hergils, L. and Hergils, A. 2000; Uilenberg, N et al. 2002; Watkin, P. et al 1998; Van der Ploeg, C. et al. 2002.

Chapter 5 Critical pathway

International guidelines suggest that the referral rate from screening programmes should not exceed 4%. To achieve this standard, most international programmes recommend a two stage protocol. (Workshop, Kildare. September 2002)

The protocol developed will be determined by local factors which include;

- Well baby versus NICU baby
- Hospital discharge policy
- Parents ability to return for outpatient screening
- Type of equipment available
- Level of training

The critical pathway (see page 25) sets out a child's journey which differs depending on whether (s)he is a well baby or one admitted to a Neonatal Intensive Care Unit (NICU).

5.1 Well Baby Screening Protocol

The majority of babies are well babies, most of whom are, at present, born in a hospital setting. Screening protocols for well babies may be one stage or two stage.

- One Stage- Babies are screened once. Failure to pass the test leads to referral for further assessment (usually to a tertiary centre).
- Two stage- If an infant fails the first test, a retest is performed using the same or different test techniques prior to referral to a tertiary centre.

Table 3 Advantages and Disadvantages of 1 and 2 Stage Screening Protocols

	Advantages	Disadvantages
One stage	Shortens parental contact with screening	Leads to higher referral rates
Two stage	Reduces referral rates significantly; Lower referral rates decreases medical costs, increases paediatric support and increases the return for follow-up.	Parental stress may ensue if a baby does not pass the initial screening test

OAE is a rapid, cost-effective means of testing all babies with normal auditory systems provided it is carried out after 48 hours³⁵. It is therefore suitable for use in testing all well babies. This has implications for service planning given the Irish context of early discharge policies, where babies are being discharged from some maternity units as young as 6 hours of age. Continuous technological advancements lead to changes and improvement in equipment, rather than state the most appropriate equipment at this stage the Working Group endorses the use of Guidelines for Equipment Commissioning (See appendix 5).

³⁵ debris in the ear canal is thought to cause diagnostic problems in the first 48 hours

5.2 NICU Baby Protocol

Approximately 7% of all new born infants require neonatal intensive care for longer than 48 hours. Sick, irritable babies are more difficult to test and discharge patterns are more erratic making testing more problematic in the NICU³⁶. The time taken to test a NICU baby is significantly longer³⁷.

Auditory neuropathy (AN) is a condition in which the patient displays auditory characteristics consistent with normal outer hair cell function and abnormal neural function at the level of the vestibulo-cochlear nerve³⁸. The incidence of AN is less than 3 per 100,000 in the general population as compared to 1 in 480 in NICU babies. Infants with AN may appear to have a normal response on OAE. Thus OAE technology may be inappropriate in this situation, and the international trend is towards the use of aABR to test NICU babies³⁹. This test should be carried out prior to discharge.

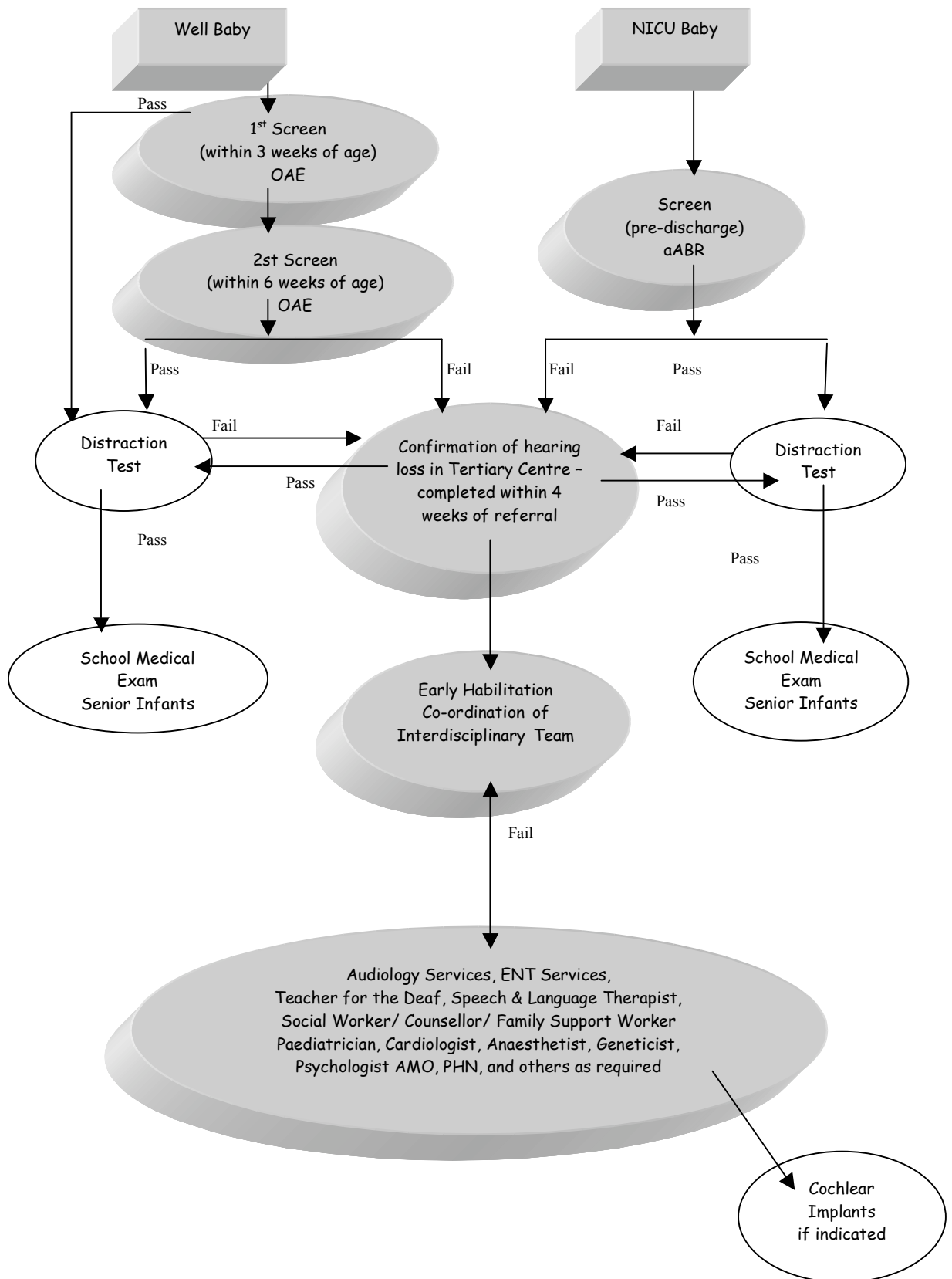
³⁶ Prieve B, et al. 2000

³⁷ Spivak L. 2000

³⁸ Hood, L.J. 1998

³⁹ Mehl, A.L., 2002

5.3 Critical pathway



5.4 Step by Step through the UNHS Critical Pathway to Specialist Services

Pre- Screening

- Parental information distributed
- Informed consent obtained from parents

Well Baby Screening Protocol

- OAE is used for screening well babies.
- If an infant passes on the first screen the screening process is complete. The baby will continue to undergo routine child health surveillance. **This first screen is to be completed by 3 weeks of age. The second screen is to be completed by 6 weeks of age.**
- If an infant passes on this second attempt the screening process is complete. The baby will continue to undergo routine child health surveillance. If an infant fails this test, s/he is referred to the appropriate tertiary level service for detailed audiological assessment.

NICU Screening Protocol

- aABR is used for NICU screening.
- If an infant passes on the screen the process is complete. The baby will continue to undergo routine child health surveillance. If an infant fails, referral to the appropriate tertiary level centre is initiated to allow for detailed audiological assessment.

Pre-requisite for Screening Protocol

- Appropriately trained and qualified screening staff perform the test.
- Appropriate screening facilities are required.
- Results are recorded in the appropriate child health and Patient Held Records.
- A unique identifier is given to the infant.
- Each programme must clearly define “pass” or “fail” criteria.

Diagnosis

- Following the more detailed audiological assessment the baby will be diagnosed as having a hearing impairment or not. Infants diagnosed with a significant hearing impairment will be referred for habilitation. **Confirmation of diagnosis is to be completed within 4 weeks from date of referral to Tertiary Centre.** This may be delayed where multiple pathologies exists.
- **Confirmation of hearing loss and whether or not the child needs aiding should be made by no later than 4-6 months of age.** Genetic diagnosis may take longer.
- Full assessment of hearing impairment requires a combination of audiological, surgical and medical consultations.
- A multi-disciplinary professional team is necessary for full evaluation of the infant.
- Appropriate assessment and diagnostic facilities and equipment are required.

Habilitation

- Babies found to have a hearing impairment continue through to early habilitation.
- Provided by a multi-disciplinary professional team.
- Appropriate hearing aid fitting facilities are required.
- **Fitting of hearing aid (if appropriate) within 4 weeks of confirmation.**
- Key worker interfaces between the family and professionals.
- Appropriate peer and family support provided.
- **Access to cochlear implant assessment (if appropriate) by 1 year of age.**

Tertiary Audiology Centre

- It is recognised that as with all screening processes, a certain percentage of infants will fail the screening process. These babies will need to be referred to a Tertiary Audiology Centre for full evaluation and assessment from referrals, which will be one of the services provided by a Tertiary Audiology Centre.
- A service agreement must be in place between each network or regional neonatal screening service and a specific Tertiary Audiology Centre.
- Linked in a suitable hospital in order that skilled staff can be available for safe sedation and anaesthesia
- Access to the following facilities to support UNHS;⁴⁰
 - i) Personnel - on referral to the Centre access may be required to any one of the following e.g Consultants in Audiological Medicine, ENT consultants, Audiologists and Audiological Scientists, Anaesthetists, Geneticists, Otorhinolaryngologists, Paediatricians, Teachers of the Deaf, Speech and Language Therapists, Family Support Workers, Psychologists and Social Workers.
 - ii) Impression-taking for earmoulds.
 - iii) Provision of hearing aids.
 - iv) A quiet area will be needed for children who do not require general anaesthetic or sedation i.e. children undergoing ABR when naturally asleep.
 - v) Administrative support with links to national IT system.

A multidisciplinary approach is required to provide a seamless and efficient early hearing detection and habilitation service.

⁴⁰ Ms. Laura Viani, Consultant E.N.T. Surgeon. The National Cochlear Implant Programme, Beaumont Hospital.

Chapter 6

UNHS - Models of Screening Practice

Models of Neonatal Hearing screening programmes vary across countries and within countries. Best practice is determined by the following factors;

1. Is the setting for screening in the hospital or within the community?
2. Is unilateral or bilateral testing the norm?
3. Is written consent required and what level of information is required?
4. What particular challenges are involved in establishing a screening programme in the target area?

6.1 Setting

Hospital / Community Based Screening Programme

The first UNHS screening programmes in most countries were generally carried out in hospitals, pre-discharge for parental convenience and to maximise uptake with small numbers of available staff. However in light of the trend towards early discharge and home births or inconvenience for parents, community based testing needs to be considered in conjunction with a hospital based screening programme. Community screening programmes have been the preferred option in some countries⁴¹ i.e. Flanders region of Belgium and Holland, (see appendix 6). Programmes covering both hospital and community have a better outcome but may require more staff time.

Hospital Community Liaison. Irrespective of the location of screening, liaison is required between hospital and community sectors. Information regarding the infants must be passed from the hospital to the community in a consistent, timely and effective manner. Existing newborn screening programmes in the Republic of Ireland provide this information by phone or fax as there are few electronic data transfer systems between maternity hospitals and communities.

6.2 Unilateral or Bilateral Hearing Screening

PCHI may be identified using either unilateral or bilateral testing protocol. Unilateral testing is sufficient to meet the American Academy of Pediatrics (1999) guidelines for screening which states that the methodology used should detect at a minimum, all infants with significant unilateral hearing impairment⁴². However, unilateral testing is not sufficient to assess the full hearing capacity of a child, as screening one ear only, may result in undiagnosed unilateral hearing loss.

Hearing screening in the neonatal period cannot identify acquired or progressive hearing loss occurring subsequently. Surveillance methods are required to identify those cases, which may be 10-20% of all permanent childhood hearing impairment. A child who has passed e.g. a unilateral hearing test may later develop a conductive problem in the 'good' ear impacting on communication skills, educational attainment and quality of life of that child. In a small number of cases, a false negative result will arise. Using bilateral testing, unilateral hearing loss would be identified and followed up appropriately.

⁴¹ Van Kerschaver E. & Stappaerts L. 2000; Stappaerts, L. and Van Kerschaver, E., 2002

⁴² American Academy of Paediatrics 1999

6.3 Consent

Obtaining consent before provision of care is a fundamental part of good practice. In general, parental consent is required before children undergo medical or surgical procedures⁴³. The UK pilot programme is seeking consent to screen the baby and to use the data for national audit⁴⁴.

Informing parents of the screening process allows them to make an informed decision regarding consent to, or refusal of the hearing screen. Consent may be written or verbal. Written consent is not required as informed consent will suffice from a risk management perspective⁴⁵. On the other hand written consent is preferred as it provides a record of the parent's decision. The consent form may be stored in the baby's hospital records or child health records held in the community. The Mid Western Health Board has completed a pilot project which evaluates the use of Personal Health Records. Once this is rolled out nationally, these records would provide the ideal location for the completed consent forms.

Informed consent requires parents to have knowledge regarding;

- Benefits and the risks of the proposed screen
- What the screen will involve
- The implications of not having the screen
- Alternative test if available
- The practical effects on their lives of having, or not having, the screen.

6.4 Challenges to a Screening Programme

There are a number of challenges common to screening programmes in either setting including;

- Follow up of **migratory groups**, including Travellers, Refugee and Asylum seekers or infants born in cross-border areas.
- **Early Discharge** from maternity services is now common practice from 6 hours of age. When screening is performed during the first 24 hours after birth, debris or fluid in the external and middle ear may affect OAE, resulting in referral rates of 5 to 20%⁴⁶. Hence the ideal time to perform early newborn hearing screening is when the newborn infant is 48 hours or older. This means that infants discharged early are not screened prior to discharge. Families will be required to attend for screening in the hospital or in the community, thus increasing the possibility of loss to follow up.
- A trend towards **home births** will require special provision to ensure that a hospital based programme will not exclude these babies. Thus a protocol needs to be developed to ensure that this group of infants is screened.

⁴³ http://www.oasis.gov.ie/health/childrens_health/child_health_services.html (accessed 3 November 2004)

⁴⁴ Presentation Informed Consent NHSP Phase 3 Local Co-ordinators Training 25th- 26th June
<http://www.nhsp.info/meets2003.shtm> (accessed 3 November 2004)

⁴⁵ Cowan, J. 2002

⁴⁶ American Academy of Paediatrics. 1999

- Babies require **follow up** if they
 - a) have never been screened or
 - b) require re-screening

The benchmark set out for UNHS programmes is that more than 70% of babies who have failed initial screening should return for follow up⁴⁷. International data suggests that anywhere from 20% to 70% of early discharged and 1st screen failures are not appearing for test/ retest. The fact that successful return rates can be achieved by larger hospitals and by programmes with excellent databases allowing for ease of tracking, emphasises the importance of integration between the maternity hospital and ongoing follow up services. An evaluation of the UNHS programme in Tralee identified the provision of information and Public Health Nurses involvement as being essential components of follow up⁴⁸. A programme will not be successful if it doesn't have a management system to ensure that all the high-risk groups are followed up.

Convenience of screening location is an issue for many parents, as owing to transport difficulties, child minding responsibilities or lack of time, attendance at hospital based screening clinics can be problematic. Screening in the home or at local health centres are options which should be considered in order to provide a family friendly service.

Parents with special information needs include;

- **Deaf parents** who are parents to approximately 10% of Irish deaf children. Information should be provided in e.g. Irish Sign Language.
- **Adults with low levels of literacy**- who make up one in four Irish adults between the ages of 16 and 66 years⁴⁹. It is estimated that up to 80% of Traveller adults have literacy problems⁵⁰. A recent report recommended the use of simple language and layperson's words in order to make written health information more accessible to parents⁵¹.
- **Travellers** are a minority ethnic group with different perceptions of health, disease and care needs⁵². The involvement of Travellers in developing health promotion information has been identified, as the most effective method for ensuring that the information produced is clear, simple and easily understood. Visual Health Promotion campaigns that Travellers can self identify with have had proven success in communicating health information to Traveller parents.
- **Ethnic Minorities and refugees**- In 2000, it was estimated that non-EU births accounted for 6% at the National maternity hospital, 15% at the Rotunda and 16% at the Coombe Women's Hospital respectively. Although this figure undoubtedly includes non- EU nationals who are not seeking asylum, management at the hospitals are of the opinion that the majority are from the asylum seeking population. The main countries of origin are in Eastern Europe and Africa⁵³. Not surprisingly communication difficulties arise. Health promotion material for ethnic minorities needs to be culturally sensitive and appropriate⁵⁴. A recent report⁵⁵, developed in consultation with refugee and asylum seeking women, identified the lack of culturally sensitive translation facilities as the dominant health issue.

⁴⁷ White, K., and Maxon., <http://www.infanthearing.org/impguide/index.html>

⁴⁸ Syed Tahir, A. 2002

⁴⁹ Morgan M., et al. 1997

⁵⁰ Primary Health Care Project for Travellers 1996

⁵¹ McCarthy A. & Lynch J. 2002

⁵² www.pavepoint.ie/pav_about_a.html (accessed 3 November 2004)

⁵³ O' Neill F, Browne C, et al. 2001

⁵⁴ Irish refugee Council. (2001)

⁵⁵ ICCL (2000)

Chapter 7 Screening Equipment

The techniques used in UNHS are derived and adapted from general audiological techniques. In screening programmes, screening technologies using automated response detection are preferred over those that require operator interpretation and decision making⁵⁶. Such technologies reduce the effects of screener bias and errors on test outcome, and ensure test consistency across all infants, test conditions, and screening personnel. Automated screening technology machines determine;

- when conditions are right for testing
- whether the infant has passed the test (pass/refer)

Those in common use include;

1. Auditory Brainstem Response (ABR)
2. Transient Evoked Otoacoustic Emissions (TEOAE)
3. Distortion Product Otoacoustic Emissions (DPOAE)

Equipment using a combination of techniques are now being tested in centres internationally (see appendix 7).

Automated ABR screening technology machines are fully automated. The pass/ refer decision for OAE instruments has also been automated. However, probe fitting still requires operator skills to decide when conditions are right for testing. If screening is to take place in a variety of settings, equipment appropriate to each setting must be considered. (e.g. a portable machine for use in noisy environments is required for community based screening; secure storage facilities need to be made available.)

The features of the 3 types of screening equipment are described in Appendix 7 and compared in Table 4.

Table 4 Comparison of Screening Techniques⁵⁷

	aABR	TEOAE	DPOAE
Portable	Limited portability ⁵⁸	Yes	Yes
Time taken to screen*	15-40 minutes	10-30 minutes	10-30 minutes ⁵⁹
Use in Noisy Setting +	No screens in noisy settings, but noise may slow data collection.	Yes Once there is a good probe fit. In noisy ⁶⁰ conditions or with a noisy baby, data collection is slower	Yes Once there is a good probe fit. In noisy conditions or with a noisy baby, data collection is slower
Well Baby or NICU Screening	NICU-detects AN ⁶¹	Well baby	Well baby
What degree of hearing loss is likely to be detected	35dbHL (misses mild sensory loss)	As low as 25 dB HL	Early findings with this procedure suggested that a significant hearing loss (50 DB) would have to be present. Recently TEOAE and DPOAE reveal essentially similar findings
Is hearing frequency specific information provided	No	Yes	Yes

⁵⁶ American Academy of Pediatrics 2000

⁵⁷ Adapted from NCHAM, 2004 (<http://www.infanthearing.org/resources/equipment/equipmenttable.html>)

⁵⁸ Correspondance with B. Lennon, Regional Manner NAD – Algo3i is extremely portable

⁵⁹ Correspondance with P. Heffernan - 10-12 mins to screen

⁶⁰ Manufacturers state that their equipment can be used at the bedside in noisy settings.

⁶¹ Auditory Neuropathy is identified by the presence of OAE in the presence of an abnormal or absent auditory brainstem response.

What is being measured?	Provides information about the auditory pathway up to the brainstem	Provides information only up to and including the cochlea. Hence, infants with central auditory processing problems would not be discovered	Provides information only up to and including the cochlea. Hence, infants with central auditory processing problems would not be discovered
Referral rate screening is designed to identify a small group of at-risk infants who will require further diagnostic testing	1-10% (average 4%)	4-15% (average 8%). Two stage testing- referral of 1%	3-12% (average 7%). Two stage testing- referral of ½% to 1%
Children with hearing loss that will pass the screen? (False Negatives) Measure of the tests sensitivity	Very mild loss (25-30 dB HL) High frequency loss	Infants with AN may pass.	Infants with AN may pass.
Specificity	90-70%	80-86%	80-86%
Cost 2002 in Euro Not including VAT	13,934-20,902	13,034-20,949	7,869-13,443

**“Screening time” is best computed by taking the total number of hours worked by screening technicians and dividing that time by the number of babies screened during that period. A quality programme would take account of getting the baby ready for screening, talking to the parents if necessary, setting up the equipment, conducting the screening, recording information about the baby so that results can be retrieved later, etc.*

+ All procedures require infant to be quiet.

Because of the speed of technology development and the length of time that it is likely to take until all resources needed to support a quality UNHS programme are in place in the Republic of Ireland, the **Working Group decided not to recommend specific types of equipment but rather to set out a checklist of guidelines for commissioning of equipment as outlined in Appendix 5.** A weighting will need to be applied to each issue based on its importance to the screening process. It is envisaged that individual project teams will develop option appraisals. **However, the location of screening testing, category of infant being tested (i.e. Well or NICU baby) and expertise of screener will ultimately determine choice of testing equipment to be used.**

Chapter 8 Staff and Training

A UNHS programme which screens all infants in a one or two stage screening test, refers at least 4% of them for full audiological assessment and follows up more than 0.1% of all children throughout childhood in hearing habilitation programmes which will involve a diverse range of staff throughout that period:

- **Programme coordination staff**
- **Screeners**
- **Audiology professionals**
- **Other professionals involved in the management of children with hearing loss**

8.1 Programme coordination staff

The Programme Co-ordinator should be a named individual who manages the service and whose responsibility it is to ensure:

- Testing is performed to the required standard
- Local protocols are defined and adhered to so that national standards are met
- Screening staff performance is monitored and audited in terms of test technique, patient/parent interaction, interpretation and recording of results
- An annual audit of the service is undertaken and any improvements identified from the audit are implemented
- Screening staff attend training updates at the specified times
- Adequate service provision is available for follow up of screen referrals including liaison with other programme co-ordinators.

In order to manage the above, the Programme Co-ordinator is most likely to be a trained professional in audiology e.g. an Audiological Scientist, Community Paediatrician or a Medical Consultant trained in audiological medicine. Good project management skills are important to ensure delivery of a high quality service which is integrated, responsive and accountable. In smaller units the audiology professional could hold both the clinical and programme co-ordinator roles. The Programme Co-ordinator should participate in continuing professional development programmes to keep up to date with developments in paediatric audiology, screening and child health promotion.

If the Programme Co-ordinator does not have a background in audiology, then a health care professional with additional training in audiology should take responsibility for the quality assurance aspect of the service.

It is envisaged that a Child Health Co-ordinator as recommended by "*Best Health for Children*", could aid the Programme Co-ordinator by adopting some of the administrative responsibilities of the role.

8.2 Screeners are responsible for carrying out the screening test. The U.K. UNHS Working Group on Training Requirements sets out the responsibilities, skills and experience, and knowledge required for a screener (see appendix 8)⁶². Depending on the test being used and the background of the screener, the screener may be responsible for;

- performing screening test
- reviewing test results
- reporting results to parents in a family friendly manner
- recording and reporting results to the appropriate parties
- ensuring follow up is arranged where necessary
- liaising with other health care professionals.

⁶² UNHS Working Group on Training Requirements, 1999

Technological advances mean that screening equipment now provides a simple pass/ refer result. Screeners with appropriate training from a variety of backgrounds can screen newborn infants using the techniques of OAE and ABR. In Colorado, 80% of all newborn screening is performed by volunteers, technicians or nurses rather than audiologists⁶³ although most screening programmes begin through the involvement of audiology professionals in the screening process. Spivak (2000) states that performing screening tests is neither the best nor most cost- effective use of audiologist's time and suggests that the most effective screeners are those who are well trained, screen a large number of babies on a consistent basis, and have a genuine commitment to the goals of the program⁶⁴. In order to ensure efficient screening, screeners must also have a certain through put to maintain their skills⁶⁵. Johnson et al observed that best screening outcomes were obtained when screeners worked a minimum of 20 hours per week⁶⁶.

8.3 Audiology professionals play a vital role in both screening and assessment stages of UNHS programmes in the following ways:

- Initiation of screening programmes
- Training and accreditation of screeners
- Quality control of screening
- Interpretation of borderline test results
- Audiological management of infants referred from the UNHS programme
- Hearing aid fitting
- Follow-up.

8.4 Other professionals involved in the diagnosis, follow up and support of children with PCHI may be required to access any one of the following Consultants in Audiological Medicine⁶⁷, ENT consultants; Audiologists and Audiological Scientists, Anaesthetists, Geneticists, Otorhinolaryngologists, Paediatricians, Teachers of the deaf, Speech and language therapists, Family support workers, Psychologists and Social workers.

8.5 Training and ongoing accreditation processes for staff⁶⁸

- Audiology professionals

There are no existing academic centres for audiology training in Ireland. All personnel seeking training must go to the United Kingdom. There is an urgent need to establish a training course for Audiology professionals in the Republic of Ireland : a proposal has been made by the Irish Society of Audiologists to the Department of Health regarding an undergraduate degree for General Audiologists and a graduate audiological science programme for Audiological Specialists or Scientists similar to the newly introduced UK training structure. This document also proposed automatic registration for existing qualified and experienced professionals and continuing professional development programmes for both of these professions to maintain registration. This course should be established in a college with a Speech and Language Therapy Faculty as both of these professions have similarities and could be allied in certain subjects of their undergraduate training.

⁶³ Yoshinaga-Itano, C. et al. 1998

⁶⁴ Spivak, L. 2000

⁶⁵ White, K., and Maxon., A. <http://www.infanthearing.org/impguide/index.html> (accessed 26 Nov. 04)

⁶⁶ Johnson JL et al. 1993

⁶⁷ Consultants in Audiological medicine exist in the UK, there are no such specialists in the Irish Medical System at present.

⁶⁸ An accreditation body defines training requirements; assesses submissions for training courses for screeners, awards accreditation to suitable courses and reviews training courses. This is desirable to ensure that a standardised approach will be taken in all screening programmes throughout the country.

- Screeners

“The best people to provide such training are those who are already successfully participating in a newborn hearing screening program”⁶⁹. As a consequence of the extreme shortage of audiology professionals presently employed by the Irish health care services, this training resource may not be available. It may be necessary to look at external alternatives in order to train screeners and maintain quality control.

- Other professionals

Few professionals in Ireland currently have the appropriate training and skills in dealing with families in the first months of a baby’s life to support their role in a UNHS programme. Staff in tertiary centres may need additional training in working with small infants and families. Protocols and awareness training for maternity hospital staff, midwives, community midwives, NICU staff, GPs, ENT services, Paediatricians, Paediatric nurses, PHNs, medical record staff, speech and language therapists, media, education and social services.

8.6 Registration of Professionals of Audiology

The “*Health and Social Care Professionals*” Bill has been prepared to extend registration to include a number of different paramedical/ therapeutic professions: to date there is no requirement for the statutory registration of Audiology professionals and they are not included in this Bill. Provision should be made for statutory registration of Audiology professionals similar to other professions.

- To fulfil the criteria for statutory registration, there needs to be a Professional Body which would validate qualifications, accredit training, monitor standards of professional practice and support continuing professional development.
- The establishment of statutory registration would maintain the standards of competence required for the special assessment in the tertiary level centre.
- Accreditation of suitable courses is desirable to ensure that a standardised approach will be taken in all screening programmes throughout the country.

⁶⁹ White, K., and Maxon., <http://www.infanthearing.org/impguide/index.html> (Accessed 26 Nov. 04)

Chapter 9

Early Intervention and Habilitation

Once identification of significant PCHL has been made, there must be seamless provision of care, requiring:

- Accurate early audiological management to ensure appropriate early hearing aid fitting
- Speech and Language Therapy Intervention
- Appropriate family support and early management involving education services and trained Teachers of the deaf
- Experienced paediatric and paediatric otological assessments.

9.1 Accurate Early Audiologic Management

Audiological Scientists use a range of audiological tests to confirm the existence of a hearing loss, usually provided at a tertiary centre. The vast majority of infants and children with bilateral -moderate to severe hearing loss, benefit from some form of personal amplification or sensory device such as a hearing aid. There are a number of issues in fitting hearing aids in young infants;

Wax Removal. UK guidelines for ear impressions and ear moulds for children have been drawn up under Modernising Children's Hearing Aid Services (MCHAS)⁷⁰. The guidelines state that an otoscopic examination is essential to remove any wax before taking an impression.

Delay on Hearing Aid Mould. A problem that has been identified by Irish audiology professionals is a delay in obtaining ear mould replacements. Moulds for very young infants may require replacement on a 2-4 weekly basis. Moulds are not produced in Ireland and delivery from the UK can take up to several weeks at present. Provision of quality moulds and hearing aid repairs/replacements in a timely fashion is necessary.

9.2 Speech and Language Therapy Intervention

UNHS early intervention programmes require an input from Speech and Language Therapy professionals to cater for communication disorders associated with hearing impairment. There are a number of issues in providing a Speech and Language Therapy service to young infants including;

- Shortage of Speech and Language Therapists as identified by The Bacon Report (2001)⁷¹ has resulted in a vacancy factor of approx 25% in Irish Health Boards. The report recommended an annual increase of 75 training places for Speech and Language Therapists. Although additional courses have been established, students will not graduate until 2006.
- The majority of Speech and Language Therapists are inexperienced in working with hearing impaired infants because very few infants are confirmed as having PCHI in early life. A new curriculum with a focus on early language intervention with hearing impaired infants would be required for Speech and Language Therapists and retraining would also be necessary for many existing therapists.

9.3 Appropriate Family Support and Early Management Involving Education Services and Trained Teachers of the Deaf

In Ireland the National Association for Deaf People (NAD) provides a family support service⁷². The family support team provides counselling, information and advice and advocacy for parents of deaf children. The Family Support Service has established a parental support network. This is a network of trained parent volunteers who will provide peer support to parents of deaf children. Teachers of the deaf are seen as an integral part of the early intervention team working with the family.

⁷⁰ Modernising Children's Hearing Aid Services (MCHAS) <http://www.mchas.man.ac.uk/service/service.htm> (Accessed 26 Nov. 04)

⁷¹ Department of Health and Children, 2001

⁷² National Association for Deaf People; (accessed at <http://www.ioi.ie/~nad/nad-homepage.html> 4 November 2004)

In England, Evans & Robinshaw found teachers of the deaf to be the main providers of pre- school educational support to deaf children and their families⁷³. The visiting teacher service in the Republic of Ireland provides a service to young children with visual and/ or hearing impairment, from the age of two years. Teachers with specialist qualifications visit and teach the young children in their home and offer an advisory service to parents and classroom teachers. Currently there are 31 Visiting Teachers working in the Republic of Ireland catering for 1,355 pupils with hearing impairment with 48 pupils as the average caseload per teacher⁷⁴.

Early education interventions are to be set in the context of The Disability Bill, 2004 and The Education Act, 1998 which endorses the rights of children with disabilities and with other special educational needs. The Report of the Special Education Review Committee⁷⁵ sets out a number of issues that impinge on policy regarding early childhood special education in general including demographic and prevalence issues, education and care issues, along with curriculum issues. In addition to these there are a number of issues specific to providing the visiting teacher service to hearing impaired children identified under a UNHS programme including:

- **Appropriately experienced and qualified teachers.** Currently only 9% of pupils catered for by visiting teachers are pre- school children. Similar issues of curriculum change and retraining would be required for Teachers of the Deaf to prepare them to work with infants.
- **Year Round Service Provision** is not a feature of the existing service because of term-time working arrangements; provision for holiday cover would be needed to avoid a delay in accessing early education support services particularly for infants newly diagnosed as a result of a UNHS programme.

9.4. Experienced Paediatric and Paediatric Otological Assessments

Children diagnosed with a hearing loss must have aetiological investigations in accordance with local protocols based on nationally agreed standards. Aetiological investigations must be carefully overseen by an appropriately medically qualified person to optimise the information and support for families and children⁷⁶.

The purpose of these evaluations is to determine the etiology of hearing loss, to identify related physical conditions, and to provide recommendations for medical treatment as well as referral to other services. Professionals involved in the medical evaluation often include:

- Paediatrician
- Otolaryngologist
- Medical geneticist
- Cardiologist/ophthalmologist

The concept of a “medical home” is mentioned in some UNHS programmes to describe the coordination role undertaken by a professional or group of professionals. They are responsible to oversee the totality of services required by a child who may have a number of other medical problems in addition to hearing loss. In the UK this role is often undertaken by the Consultant in Audiological Medicine or by the Consultant Community Paediatrician; in Ireland it is likely that the Consultant Community Paediatrician, where available or General Consultant Paediatrician will take the lead in this area because of the growing number of appointments in this field.

⁷³ Evans, R and Robinshaw, H. 1999

⁷⁴ Data submitted on behalf of Teachers of the Deaf to UNHS Working Group, 2002

⁷⁵ Department of Education, 1993

⁷⁶ http://www.ndcs.org.uk/docs/Quality_Standards_in_Paediatric_Audiology_Guidelines.pdf (accessed 8 December 2004)

9.5 Genetic Considerations in Deafness

Parents must be informed of genetic screening and counselling services. Such services must be made available when the family and, where relevant the child, chooses to access them. These genetic services must be well informed on all issues relating to deafness⁷⁷. Causes of deafness are numerous, both genetic and environmental and establishing the cause of a child's deafness is considered important by both parents and clinicians⁷⁸. Parents of a deaf child welcome genetic testing for deafness⁷⁹. There is ample published evidence that attempting to offer genetic testing for deafness through non-genetic clinics does not work and results in widespread parent dissatisfaction⁸⁰. For this reason, it is envisaged that deaf children identified through the proposed neonatal screening programme will be referred directly to a genetics department.

9.6 Cochlear Implants

A cochlear implant converts sound into electrical impulses which are transmitted directly to the auditory nerve to stimulate it. In a surgical procedure a cochlear implant is attached to the cochlea. Sound is picked up by a small microphone worn behind the ear, and processed by a device worn on the person. Infants diagnosed with severe to profound SNHL or infants who receive little benefit from hearing aids are considered for cochlear implantation.

Appropriate immunisation is required in view of the higher than expected rate of pneumococcal meningitis that has been observed in children who have had cochlear implantations.

The **age at implantation** is a critical factor in the development of communication skills and the earlier a child is implanted the more successful the implant will be⁸¹. Teams around the world have been successful at implanting children at one year of age and younger, as a result UNHS programmes have set cochlear implantation at one year as a programme target.

Six months has been set in some programmes as the lower limit for cochlear implantation. The main reasons for this lower limit include;

- Time to establish reliable auditory results
- Baby should be sitting up to be able to start effective rehabilitation.
- Higher risk in young children for otitis media, which could threaten the integrity of an implanted device.

⁷⁷ http://www.ndcs.org.uk/docs/Quality_Standards_in_Paediatric_Audiology_Guidelines.pdf (accessed 8 December 2004)

⁷⁸ Brunger et al. 2000; Parker et al. 2000

⁷⁹ Parker et al. 2000; Middleton et al. 2001; Brunger et al. 2001

⁸⁰ Parker et al. 2000

⁸¹ Hammes, D. et al. 2002

Chapter 10 Information Systems

10.1 Systems delivering information to families

10.1.1 Family Friendly Hearing Service

Around 55000 infants are eligible for hearing screening in the Republic of Ireland every year; with a referral rate of at most 4%, as many as 2,200 will be referred for audiological assessment. Every infant screened belongs to a family network which will be affected by the screening and/or assessment process. There is evidence that outcomes for hearing impaired children are significantly dependent upon the extent to which family concerns and anxieties are taken into account, and whether the services involved with the child are family-centred⁸². The importance of this has been acknowledged in England with the development of the concept of a Family Friendly Hearing Service (FFHS). The Working Group endorses the concept of Family Friendly Hearing Service developed by the NDCS for the United Kingdom.

Principles of Family Friendly Hearing Services for Children (1999)⁸³

- Families are all different
- Families and professionals should work in partnership
- Partnership between agencies
- Families have a right to accurate, up to date and comprehensive information
- Families deserve continuity of care
- The attitude of professionals should be characterised by listening
- The family- professional dialogue should be undertaken in appropriate language
- The FFHS should be responsive
- When a family cannot go to the FFHS, the FFHS should go to the family
- Family representatives should be involved in the strategic management of the FFHS
- The physical environment of the services should be family-friendly
- Meeting the needs of the family is more important than adhering to targets and standards

From these principles, four main elements of what families want and what constitutes a family-friendly service can be identified:

- Collaboration
- Responsiveness
- Optimal provision of information
- Continuous evaluation of services

10.1.2 Model of Information Provision in the UK

In England, the NDCS developed an information package around UNHS for families⁸⁴. To provide clear, accessible and ongoing information a number of methods were used including:

- Dialogue between screeners and parents
- Information leaflets to support dialogue
- Video for antenatal classes- dubbed, signed and sub- titled
- NICU leaflets.

Materials used undergo constant evaluation to ensure that the message they carry is both efficient and effective in educating and informing parents of the benefits of UNHS.

⁸² Davis et al. 1997

⁸³ Baguley, D., et al. 1999

⁸⁴ Jones, D. 2002

10.1.3 Information Provision

It is recognised that parent's preference for screening increases when good and sensitive information is provided⁸⁵. Parents must be well informed of the important link between hearing, communication and early childhood development. There is often a difference in the information that parents receive and in the information that they wish to receive:

- The majority of babies identified have mild and moderate losses but information tends to be geared towards severe and profound losses.
- Furthermore, parents want as a priority, contact with other parents and emotional/ financial support. They do not want detailed technical information (type of loss, extent etc) at an early stage, although this becomes more important later.
- A survey of parental views of hearing screening⁸⁶ found that parents' satisfaction could have been increased had the parents been given more information about hearing impairment prior to the screen.
- Most children with moderate losses are identified as a result of parental or professional concerns over speech and language development later in the pre-school period⁸⁷. Parental observations for early diagnosis may continue to be far more effective than professionals or technological advances⁸⁸. A systematic approach to increasing parental awareness can be enhanced by the use of a check list in the Personal Child Health record⁸⁹.
- Critics argue that defining a child as having a disability so young will affect the bonding process thus preventing the development of a normal relationship between the parents and the child.

10.1.4 Timing and Type of Information Provided

It is important to communicate the correct information to parents at a time when they can understand it and when they are likely to benefit from it⁹⁰. Existing international programmes typically provide information at different stages of the screening process as follows:

- Before screening
- For the first screen
- The follow up screen
- The audiological assessment.

The information provided is tailored to the particular stage the parents and the child have reached. The type of information that parents receive includes details regarding⁹¹;

- Whole screening programme
- Organisational responsibility for the programme
- Hearing loss
- Prognosis with and without early diagnosis
- Possible risks or side effects if any
- What the tests mean
- Likelihood of their child being hearing impaired
- Consequences of false positive and false negative results
- Assessment and diagnosis
- Importance of attending follow up appointments
- Structure of services
- Contact name and telephone numbers

⁸⁵ Bamford J, et al. 1998

⁸⁶ Sweetow, R.W. Barrager, D. 1980

⁸⁷ Davis et al 1997

⁸⁸ Polnay, L. 1989

⁸⁹ Hall, D. & Elliman, D. 2003; Denyer, 1999

⁹⁰ White, K., and Maxon., A. <http://www.infanthearing.org/impguide/index.html> (Accessed 26 Nov. 04)

⁹¹ Baguley et al. 2000

10.2 Systems delivering information to staff

All health service professionals who are likely to come in contact with the family should be fully informed regarding UNHS. These include midwives on the maternity ward, Public Health Nurses (PHNs) in the community and the General Practitioner. In Ireland, midwives and PHNs are already highly regarded as information providers to parents.

The Center for the Education of the Infant Deaf in California realised the importance of educating professionals at local level to increase the awareness of UNHS amongst parents⁹². Key stakeholders such as paediatricians, public health nurses, early childhood special education caseworkers, schools district administrators and childcare providers were targeted for information. The result of their efforts was to increase referrals to the service by 65% and increase enrolments by 60%.

10.3 Information Management System

An Information Management System (IMS) tracks the infant through screening, from audiological assessment through to early intervention. In order to facilitate the transfer of data, existing hearing screening programmes recommend that technology used in all sectors involved must be compatible. Programmes are now using management systems specifically tailored to their needs.

10.3.1 Functions of an IMS

- **Ensure coverage-** IMS are involved in calculating the coverage of a screening programme⁹³. Experience from other screening programmes suggests that if a programme is established without an IMS in place to efficiently manage the information from the start, the whole system will in time collapse⁹⁴.
- **Tracking and Follow up-** To trace the movement of babies and highlight babies with no screen results, efficient tracking and follow-up is necessary to ensure babies referred from screening receive appropriate and timely diagnostic, audiological and early intervention services⁹⁵. To be effective tracking must take place at every stage of the programme. This is essential in order to determine the incidence and efficacy of UNHS. A computerised system allows targeting of groups associated with low up take of screening services.
- **Quality Assurance-**IMS aid in the monitoring and auditing of UNHS programmes ensuring the effectiveness and quality of the programme. Information from annual audit reports at regional and national level can be fed back into the system to continuously improve the quality of the service.
- **Recording-** To allow results to be stored and accessible. The type of information to be included in data-sets includes at a minimum; key identifiers, different protocols such as well baby or NICU protocols, other infant details such as gender, health care providers, contact information, high risk factors, screening results, audiological assessment results and follow up information⁹⁶. In the event of litigation, regarding failure to diagnose PCHI, such information can prove to be most useful.

⁹² Ellis, J. 2002

⁹³ Correspondance with Nick Waddell IT Co-ordinator Presentation Information technology. NHS Newborn Hearing Screening Programme Second Phase Sites

⁹⁴ White, K., and Maxon., <http://www.infanthearing.org/impguide/index.html> (accessed 26 Nov. 04)

⁹⁵ Marion Downs National Center for Infant Hearing. http://www.colorado.edu/slhs/mdnc/colo_model.html (accessed 26 Nov. 04)

⁹⁶ Correspondance with Nick Waddell

- **Risk management-** False positive and false negative results occur in all screening programmes. A computerised information management system allows for storage and retrieval of patient records. This is particularly relevant from a risk management perspective where litigation is pending. Medical records personnel will need to be consulted to determine the correct format and procedure for recording the results of the hearing screening in the baby's medical chart.
- **Communication-** an IMS will generate correspondence to parents and professionals regarding follow up appointments and results.

Prior to the selection of a suitable IMS consideration should be given to the following;

- Existing child health databases to ensure compatibility with the new system (Birth Notification System; National Physical and Sensory Disability Database; Child Health Information Systems and Central Audiology Service database)
- Location of screening service (hospital or community)
- Point of allocation of unique identifier
- Locus of responsibility for programme co-ordination
- Agreed pathway for referral
- Inputting of data (screeener or clerical resources available)

The Working Group recognizes the difficulty in dealing with a whole set of existing systems but note that whatever system is chosen must be set within the National Health Information Strategy principles⁹⁷.

In Ireland the development of a computerised IMS for universal screening raises a number of issues including:

- Incompatibility of systems between Health Boards
- Lack of compatibility within Health Board birth notification systems
- Tracking across Health Service Region (county border and cross border births)
- Liaison and Clerical Manpower- there is a need for designated personnel to ensure data is inputted accurately and collected in a timely fashion
- Facilitation for calculation of performance indicators.

Any data collected in an IMS must;

- Comply with minimum data set
- Feed into Audiology Register
- Have a named co-ordinator
- Subject to requirements of the Data Protection Act 1988

⁹⁷ <http://www.dohc.ie/publications/nhis.html> (accessed 7 November 2004)

Chapter 11

Costs of a UNHS Programme

UNHS appears to have lower associated costs than HVDT on a cost per child screened basis⁹⁸. Additionally, the cost per case found would be several orders of magnitude lower with UNHS. Late identification of PCHI costs money long-term in educations and support services.

The costs of the screening programme:

- Set up costs
- Staff training
- Call up procedure
- Counselling
- Tests (and repeat tests)
- Consumables
- Adequate family support service for UNHS
- Provision of adequate back-up units⁹⁹ and replacement equipment
- Provision for upgrade accommodation and facilities for UNHS
- Diagnostic procedures
- Intervention and follow up
- IT
- Total set up and annual revenue/ capital costs in order to deliver the programme for a standard Irish population

Advancing the average age of identification before 24 months, there will be a wide range of disciplines engaged, and there will a year round service required.

- Additional average of 2 years for the 84 children diagnosed each year,
- Overlap for a few (2-3) years

⁹⁸ Davis et al. 1997

⁹⁹ If purchasing combi-units, ensure that a replacement is available at all time in case of breakdown.

11.1 Staffing

Cost model for the financial year 2004/5; figures include on-costs and 7% superannuation.

Personnel		Background	Salary
National Programme coordinator	1WTE (1 day per week)	Community Paediatrician, Audiological Physician, Medical consultant trained in audiological medicine.	€152,604 per WTE
Regional Co-ordinator	1WTE per 10,000 births, min 0.5 wte	Audiologist, PHN, Midwife	€ 41,000 - € 53,000 per WTE
Dedicated Screener (hospital)	1WTE per 1,250 births, min 2.0 wte	-	€ 39,000 – € 48,000 per WTE
NICU screeners (community)	1WTE per 1,250 admissions, min 0.1 wte	-	€ 39,000 – € 48,000 per WTE
Regional Administration	1WTE per 10,000 births min 0.5 wte (hospital) or 1.0 wte (community)	-	€ 39,000 – € 48,000 per WTE

Additional personnel costs to be considered include Speech and Language Therapists and Teachers of the Deaf.

11.2 Equipment

Screening Equipment	TEOAE (Well babies)	AABR (NICU babies)	Costs 2004 ¹⁰⁰
Hospital	1 TEOAE per 1,000 births	1 AABR per 1,800 births	€ 5,000 single unit (TEOAE) € 9,000 single unit (AABR)
Community	1 TEOAE per health centre		€ 5,000 single unit

Working Group decided not to recommend specific types of equipment but rather to set out a checklist of guidelines for commissioning of equipment.

Procurement of Testing Equipment

Central purchasing should be put in place in order to ensure quality and to effect economies of scale.

¹⁰⁰ Costings given as an example of current practice December 2004.

Chapter 12 Recommendations

The objective of Neonatal Hearing Screening is to reduce the age of diagnosis of hearing loss to 3 months and to undertake/commence amplification, fitting and enrolment in early intervention programmes by 6 months of age. At one year of age, if appropriate, cochlear implantation should be available to infants.

For the reasons outlined in this report the Working Group recommend the introduction of UNHS in the Republic of Ireland, as a matter of urgency, according to the format outlined in the Critical Pathway. This will ensure that every child will have access to the following:

- Parents fully informed about screening and have given consent
- UNHS in the first 3 weeks of life for well babies and pre-discharge for NICU babies
- Referral for confirmation and diagnosis for babies who fail
- **Confirmation of hearing loss by 4-6 months**
- Fitting of hearing aid (if appropriate) within 4 weeks of diagnosis
- Engagement with early intervention services within weeks of diagnosis
- Comprehensive assessment for other medical needs
- **Cochlear implant assessment (if appropriate) by 1 year**

To achieve UNHS in the most appropriate way the group have decided to make the following recommendations under the following headings:

1. A Steering Committee

A Steering Committee must be established with representation from all the stakeholders to oversee the implementation of a quality health service probably under the direction of the Health Information and Quality Authority (HIQA). The role of steering committee would include at IT, equipment and support services.

2. The Critical Pathway

The Critical Pathway to Specialist Services must be followed, as shown on Pg. 25. The critical pathway sets out a child's journey which differs depending on whether (s)he is a well baby or one admitted to Neonatal Intensive Care Unit (NICU).

The Key elements of the critical pathway to be followed are:

- 2.1 **Well babies** are screened using OAE. If an infant fails this test on two occasions, s/he is referred to the appropriate tertiary level service for detailed audiological assessment. **NICU screening** is carried out once using aABR. If an infant fails this test, s/he is referred to the appropriate tertiary level service for detailed audiological assessment.
- 2.2 Screening must be performed by **trained and qualified** screening staff.
- 2.3 Confirmation of hearing loss must be completed by 4 weeks from date of referral.
- 2.4 Confirmation of hearing loss should be made by no later than **4-6 months** of age.
- 2.5 Babies found to have a hearing impairment must continue through to **early habilitation**.
- 2.6 Fitting of **hearing aid** (if appropriate) must take place within **4 weeks of confirmation**.
- 2.7 Access to **cochlear implant** assessment (if appropriate) is recommended by 1 year of age.

- 2.8 Children diagnosed with a hearing loss must have **aetiological investigations** in accordance with local protocols based on nationally agreed standards. Aetiological Investigations must be carefully overseen by an appropriately medically qualified person to optimise the information and support for families and children. Professionals who may be involved in the medical evaluation include:
- Paediatrician
 - Otolaryngologist
 - Medical geneticist
 - Cardiologist/ophthalmologist
- The evaluation will include coordination of all other non-audiology interventions appropriate referrals and interventions in other areas and a review of the totality of services required by a child who may have a number of other medical problems in addition to hearing loss.
- 2.9 Deaf children identified through the proposed neonatal screening programme must be referred directly to a genetics department.
- 2.10 Following the detailed audiological assessment and appropriate early hearing aid fitting if indicated, the child should be referred for:
- Speech and Language Therapy Intervention
 - Appropriate family support and early management involving education services and trained Teachers of the deaf
 - Year Round Service Provision; provision for holiday cover is recommended to avoid a delay in accessing early education support services particularly for infants newly diagnosed as a result of a UNHS programme.
- 2.11 **Service agreement** must be in place between each neonatal screening service and a specific Tertiary Audiology Centre which is linked in a suitable hospital.
- 2.12 It is essential that a formal commitment from the **Maternity hospitals** is received.
- 2.13 **Community based testing** must be considered in conjunction with a hospital based screening programme.
- 2.14 For screening in the hospital and the community it is essential that a **dedicated room** is available along with the provision of storage for equipment and personal belongings and administrative supplies
- 2.15 Screening in the home or at local health centres are options which should be considered in order to provide a family friendly service.

Personnel and Training

A UNHS multi-disciplinary professional team is recommended for full evaluation and early habilitation of the infant. A UNHS programme which screens all infants in a one or two stage screening test, will involve a diverse range of staff throughout that period:

- Programme coordination staff
- Audiology professionals
- Screeners
- Other professionals involved in the management of children with hearing loss.

3.1 The National Programme Co-ordinator

It is recommended that a National Programme Co-ordinator should be appointed who should be a named individual with responsibility for managing the service and leading on quality control. The Programme Co-ordinator would be responsible for ensuring:

- 3.1.1 Training, recruitment and equipment procurement occurs according to an agreed timescale and that ongoing arrangements and resources for maintenance of the agreed standards are put in place
- 3.1.2 Negotiating referral pathways from screening programmes to tertiary service and ensuring that appropriate service agreements are defined
- 3.1.3 Identifying the appropriate local configuration for early intervention and medical assessment and ensuring that appropriate referral arrangements are in place
- 3.1.4 Establishing the infrastructure for audit to include information management systems, service agreements which include the provision of information and feedback/review arrangements
- 3.1.5 Ensuring integration of services for a family-friendly approach
- 3.1.6 Producing an annual report for the National Steering Committee/HIQA on the performance of the UNHS Programme in the context of the agreed standards, any improvements identified from the audit are implemented.
- 3.1.7 Screening staff performance is monitored and audited in terms of test technique, patient/parent interaction, interpretation and recording of results. Testing is performed to the required standard.
- 3.1.8 Screening staff attend training updates at the specified times
- 3.1.9 Adequate service provision is available for follow up of screen referrals including liaison with other programme co-ordinators.
- 3.1.10 The Programme Co-ordinator should participate in continuing professional development programmes to keep up to date with developments in paediatric audiology, screening and child health promotion.
- 3.1.11 If the Programme Co-ordinator does not have a background in audiology, then a health care professional with additional training in audiology should take responsibility for the quality assurance aspect of the service.

3.2 Audiology Professionals

- 3.2.1 There is an urgent need to establish a training course for Audiology Professionals in the Republic of Ireland.
- 3.2.2 Substantial investment in a training strategy is required for audiology professionals to include: a higher training institution for audiology training at post graduate level to be established providing an accredited programme for the training of audiologists to provide accredited training and update skills.
- 3.2.3 Provision should be made for statutory registration of Audiology professionals similar to other professions

3.3 Screeners

- 3.3.1 Effective screeners are those who are well trained, screen a large number of babies on a consistent basis, and have a genuine commitment to the goals of the program and work a minimum of 20 hours screening per week. Screeners must also have a certain throughput to maintain their skills.
- 3.3.2 Accreditation for training of screeners is required.
- 3.3.3 It may be necessary to look at external alternatives in order to train screeners and maintain quality control.

3.4 **Other professionals involved in the management of children with hearing loss**

- 3.4.1 Training is recommend training for all professionals to support their role in a UNHS programme in baby handling skills, and adaptive training in early intervention at infant level for existing professionals. This training should be incorporated into the curriculum for undergraduate programmes
- 3.4.2 The current shortage of Speech and Language Therapists must be addressed
- 3.4.3 A new curriculum with a focus on early language intervention with hearing impaired infants is required for Speech and Language Therapists and retraining is also recommended for many existing therapists.
- 3.4.4 A new curriculum and retraining is recommended for Teachers of the Deaf to provide appropriately experienced and qualified teachers, to work with infants.
- 3.4.5 Training in IT is recommended for all personnel in use of the IMS database.

4. **Information Provision**

In order to ensure all key personnel and parents are informed it is essential that the following are available:

- 4.1 **Key worker** to interface between the family and professionals.
- 4.2 Appropriate **peer and family support** and information must be provided.
- 4.3 **Parental information** is distributed and informed consent obtained from parents before provision of care.
- 4.4 Culturally appropriate health promotion materials and translation facilities must be provided for parents with **special information needs** including deaf parents; adults with low levels of literacy; travellers; ethnic minorities and refugees.
- 4.5 Standardised appropriate **health promotion** materials must be developed for the following groups: parents, professionals, teachers, and/or directed to websites.
- 4.6 The Working Group endorses the concept of **Family Friendly Hearing Service** developed by the NDCS for the United Kingdom.
- 4.7 **Parents** must be well informed of the important link between hearing communication and early childhood development.
- 4.8 Information for parents must be provided before screening, for the first screen, the follow up screen and aetiological assessment. This should provide clear, accessible and ongoing information allowing dialogue between screeners and parents and should include:
 - information leaflets
 - video for antenatal classes- dubbed, signed and sub- titles
 - NICU leaflets.
- 4.9 All **health service professionals** who are likely to come in contact with the family should be fully informed regarding UNHS.
- 4.10 **Hospital and community** sector liaison is paramount. Information regarding infants must be passed from the hospital to the community in a consistent, timely and effective manner.

5. **Information Management System**

IMS must be developed which will allow integration of the following databases to the audiology service: Birth Notification System; National Sensory and Disability Database; Child Health Information Systems and Personal Health Records all of which will be compatible and integrated with the new system.

- 5.1 Prior to the selection of a suitable Information Management System consideration should be given to the following;
 - The location of screening service (hospital or community)
 - The point of allocation of unique identifier
 - The locus of responsibility for programme co-ordination
 - An agreed pathway for referral
 - The inputting of data (screener or clerical resources available)
 - A database for call and recall
 - The follow-up of non-attenders/defaulters
 - Coverage and uptake performance indicators; address sensitivity and specificity of the programme; proportion of hearing loss screened and post screen detected
 - Audit

- The production of epidemiological information on hearing loss (allowing for planning for future resource allocation)
 - The comparison of costs and effectiveness of different patterns of screening
 - Records for litigation purposes
- 5.2 In order to facilitate the transfer of data, existing hearing screening programmes it is recommended that technology used in all sectors involved in UNHS must be compatible.
- 5.3 Efficient tracking and follow-up is necessary to ensure babies referred from screening receive appropriate and timely diagnostic, audiological and early intervention services. To be effective tracking must take place at every stage of the programme. A computerised tracking system is recommended. A programme will not be successful unless it has a management system to ensure that all the high-risk groups are followed up.
- 5.4 Whatever system is chosen must be set within the NHIS principles.
- 5.5 Tracking and follow up is recommended, to include:
- All high risk groups
 - Migratory groups
 - Patients discharged early from maternity services
 - Protocol needs to be developed to ensure that babies born at home are screened
 - Babies who have never been screened or requiring re-screening.
- 5.6 Information from annual audit reports at regional and national level must be fed back into the system to continuously improve the quality of the service.
- 5.7 The type of recorded information to be included in data-sets includes at a minimum; key identifiers, different protocols such as well baby or NICU protocols, other infant details such as gender, health care providers, contact information, high risk factors, screening results, audiological assessment results and follow up information.
- 5.8 Data Collection any data collected in an IMS must;
- Comply with minimum data set
 - Feed into Audiology Register
 - Have a named co-ordinator
 - Subject to requirements of the Data Protection Act 1988
- 5.9 Medical records personnel must be consulted to determine the correct format and procedure for recording the results of the hearing screening in the baby's medical chart.
- 5.10 Results should be recorded in the appropriate child health and Patient Held Records.
- 5.11 Quality Control Measures must be put in place to allow the development of performance indicators against which the programme is audited including:
- quantitative indicators from the information management system examining uptake, timeliness , costs etc;
 - qualitative indicators from occasional surveys which examine the family's experience of the service.
 - Annual Report to be produced on the performance of the programme.
- 5.12 Recommend a costing assessment for an Information Management System for UNHS.

6. Tertiary Audiology Centre

- 6.1 A Tertiary Audiology Centre undertaking evaluation and assessment of referrals from the screening process must be identified in strategic locations allowing reasonable access from all parts of the country to the following adequately resourced to support UNHS who include any one or more of the following personnel:
- Consultants in Audiological Medicine
 - ENT Consultants
 - Audiologists
 - Audiological Scientists
 - Anaesthetists
 - Geneticists
 - Otorhinolaryngologists
 - Paediatricians
 - Teachers of the Deaf
 - Speech and Language Therapists

- Family Support Workers
 - Psychologists
 - Social Workers
- 6.2 Facilities which must be available at the Tertiary Centre include:
- Impression-taking for earmoulds.
 - Provision of hearing aids.
 - A quiet area will be needed for children who do not require general anaesthetic or sedation i.e. children undergoing ABR when naturally asleep.
 - Link to a suitable hospital to ensure that skilled staff would be available for access to supervised anaesthesia.
 - Administrative support with links to national IT system.
- 6.3 Consideration needs to be given to having Consultants in Audiological medicine who's function would be to cover the role as they exist in the UK, as there are no such specialists in the Irish Medical System at present.
- 6.4 Staff in tertiary centres may need additional training in working with small infants and families.

7. Equipment

- 7.1 Screening technologies using automated response detection are recommended.
- 7.2 The location of screening testing, category of infant being tested and expertise of screener must be considered in determining the choice of testing equipment to be used.
- 7.3 The Working Group decided not to recommend specific types of equipment but rather to set out a checklist of guidelines for commissioning of equipment (see appendix 5).
- 7.4 Provision of quality hearing aid moulds and hearing aid repairs/replacements in a timely fashion is necessary. Earmoulds should be sent with a priority turnaround system to ensure that they come back within a week.

8. Funding

It is essential that the above issues are adequately resourced both for start up and ongoing costings to ensure a high quality UNHS service.

Appendices

- Appendix – 1 Timetable of Organisational Restructuring of National Community Audiology Services
- Appendix – 2 Irish Pilot Sites
- Appendix - 3 European Consensus Statement on Neonatal Hearing Screening
- Appendix – 4 Screening Principles applied to UNHS
- Appendix – 5 Guidelines for Equipment Commissioning
- Appendix - 6 Flemish Community Based Pilot
- Appendix - 7 Equipment
- Appendix – 8 Skills and Experience

Appendix 1

Timetable of Organisational Restructuring of National Community Audiology Services

1998	Decision taken by the Government to implement the recommendations of a report entitled “ Building a Future Together” which specified the reconfiguration of institutional responsibility for people with a disability.
1998-9	An Audiology Working Group chaired by the Department of Health which included representatives from the Health Boards and the NRB recommended that the National Rehabilitation Board (NRB) audiology service should be transferred to the Health Boards and linked to the hospital ENT Departments. It also proposed the reorganisation of clinics on a regional basis.
May 1999	A group composed of representatives from all eight Health Boards subsequently met and decided to implement the restructuring in a two stage process involving initial transfer to the Eastern Regional Health Authority (ERHA) and division of <u>current</u> resources with no immediate local control. Complete devolution to local health boards was to occur at the latest by 31/03/2002.
June 2000	Transfer of audiology service to ERHA; lead responsibility assigned to the Northern Area Health Board who formed a committee to oversee the second stage of transition process under the chairmanship of Mr. J. Cahill (ACEO NAHB) with representation from all Health Boards.
June 2002	Period of preparation by Health Boards for final transfer involving securing/equipping new premises (where original soundproofed facilities had been allocated to FAS or Comhairle), decisions on shared purchasing/repair arrangements, development and implementation of IT links, budget negotiations with NAHB, recruitment of staff to vacancies, staff contract negotiations for existing staff etc.
Feb. 2003	Final transfer of former NRB staff to new regional audiology services.

Appendix 2 - Irish Pilot Sites

There are currently four neonatal hearing screening programmes operating in Ireland, one in Northern Ireland and three programmes in the Republic of Ireland, at Tralee, Castlebar and Sligo. Universal neonatal hearing screening is most common with only Sligo operating a programme of targeted neonatal hearing screening.

Tralee

Newborn hearing screening began in July 2000 at Tralee General Hospital. Tralee has 1450 births per year requiring 8- 10 hours testing time weekly. A trained midwife using DPOAE tests newborns either before discharge from the hospital or alternatively in an outpatient clinic. Parents are informed of results by post. Infants who fail the first screen are re-screened within 6 weeks. The Audiology Department of Tralee General Hospital performs a full audiological evaluation on infants who fail the 2nd test. The results from the first 2,320 newborns screened indicate a 96% screening rate, with 11% failing the first screen and 2.5% failing the second screen. Difficulties with the funding of replacement portable equipment has resulted a change of location of testing to the Audiology Department since 2002; although this takes place on an appointment basis there has been no appreciable reduction in uptake with parents displaying some enthusiasm for the screening programme. Almost 6700 infants had been screened up to October 2004 with a rate of hearing loss identification of 0.8/1000 screened. Initially the programme used bi-lateral testing but has recently adopted uni-lateral testing. The Tralee programme has fostered a partnership approach with the community. While the programme is hospital based there is a concerted effort to involve the community with PHNs and GPs being up-dated on infant's results. Information is given to parents regarding the screening process at the time of booking and after the baby is born.

Mayo General Hospital Castlebar¹⁰¹

Newborn hearing screening began at Mayo General Hospital Castlebar in October 2000 and was extended to University College Hospital Galway in January 2003. Infants are generally screened within 48 hours of birth by a trained audiologist using a two stage screening programme (TEOAE). Screening is conducted twice a week in the maternity ward, patients who are not screened on those days, are asked to return to an out-patients clinic for their first screen. Re-screening is also carried out in the outpatient department either in Galway or Mayo. All diagnostic testing is carried out in University College Hospital Galway.

Up until September 2004, 11,453 babies have been tested (98.5% of total births). Babies who fail the 1st screen (752) are referred for a second test (6.5%) 55 bilateral; 192 unilateral. 706 passed the second screen, 46 were referred for diagnostic testing. Of these 46, 28 failed in both ears, 18 in one ear. To date 44 diagnostic tests have been carried out, 8 of whom have been diagnosed as having a bilateral hearing loss, 2 have a unilateral hearing loss.

The mean age of diagnosis - 3.75months, mean age at hearing aid fitting 7.6months. The equipment used otodynamics echocheck x3, SLE biologic AABR x1, on order Natus Algo 3i x2. The names of those who are not screened who refused to be screened or who do not turn up for review after failing the first test are forwarded to the public health nurse to target for 9/12 distraction test. Verbal information is provided to parents at the time of screening, written consent is not sought and informed verbal consent is viewed as sufficient from a risk management point of view.

¹⁰¹ Correspondence Mr John Lang, Consultant ENT Surgeon

Belfast

A neonatal hearing screening pilot study was established at the Royal Victoria Hospital, Belfast in October 2002. Babies born are screened, using OAE, by a trained audiologist¹⁰², 48 hours after birth, on the maternity ward. Using a two stage screening protocol, those infants who fail are retested prior to discharge with aABR. The babies who fail at this stage are sent to the Paediatric Audiology Department for a diagnostic ABR. Referral rates to paediatric audiology are of the order of 0.3% for well babies. At the diagnostic stage, support services are available to the family and are co-ordinated by a key worker. Similar to Tralee, the Belfast programme has placed great emphasis on communication with community services. Seminars have been held to inform community professionals, and results are provided to the relevant GP, community midwife and health visitor. Information is given to parents regarding the screening process at time of booking and after the baby is born. Written consent to perform the procedure is also sought on the maternity ward. If the child enters hearing services, additional information is available for families.

Sligo

A targeted screening programme was established at Sligo General Hospital in January 2001. An audiologist performs the screening using OAE equipment. Since its implementation, 35 babies have been screened. A Two stage screening protocol has been adopted so that children who fail the first screen are re-screened. On failing the 2nd screen children are referred to the Audiology Department at Sligo General Hospital. The programme aims to extend to universal screening over the next twelve months. Since this programme has begun, one child has been identified with permanent sensori- neural hearing loss. Two main factors are preventing extension of the programme to provision of universal screening, namely; the shortage of Audiological Scientists and the unacceptably lengthy turn around time for ear mould manufacturers.

¹⁰² At the time babies were screened by a trained audiologist however now babies are screened by screeners (Irish Society of Audiology 2004, Presentation Sharon Brown, RVH pilot site coordinator)

Comparison of Hearing Screening Programmes Operating in Ireland

	Tralee	Castlebar	Sligo	Belfast
Date Screening Commenced	July, 2000	January, 2001	January, 2001	Oct, 2002
Location	Hospital Only Discharge 3-4 Days	Hospital Only Discharge 3-4 Days	Hospital Only	Hospital Only Discharge 3-4 Days
Frequency of Screening on Ward	Morning- daily	Morning- twice weekly	-	Morning- daily
Responsibility	Audiology Otolaryngology Paediatrics	E.N.T	Audiology	E.N.T.
Babies screened	6700 (to October 2004)	11,453 (to September 2004)	35	5,500 (to October 2004)
Hearing Problems Detected	6	10	1	11
Uni v's bi-lateral	Unilateral	Unilateral- Bilateral	-	Bi-lateral
Screeener	Midwife	Audiologist	Audiologist	Audiologist
Community Contact	GP PHN SLT Visiting Teacher	None		GP, Community midwife, Health Visitor
Protocol	OAE AABR	OAE OAE ABR OAE+ BSER	OAE	OAE OAE AABR Diagnositc ABR

Appendix 3 - European Consensus Statement on Neonatal Hearing Screening

Item 1 Permanent childhood hearing impairment (PCHI) is a serious public health problem affecting at least one baby in one thousand. Intervention is considered to be most successful if commenced in the first few months of life. Therefore, identification by screening at or shortly after birth has the potential to improve quality of life and opportunities for those affected.

Item 2 Effective programmes of intervention are well established.

Item 3 Methods for identification of PCHI in the neonatal stage are now accepted clinical practice. They are effective and can be expected to identify at least 80% of cases of PCHI whilst incorrectly failing 2-3% of normally hearing babies in well- controlled programmes.

Item 4 Neonatal testing in maternity hospitals is more effective and less expensive than behavioural screening conventionally carried out at 7-9 months.

Item 5 Targeting neonatal testing on only the 6-8% of babies at increased risk of PCHI reduces costs but cannot identify more than 40-50% of cases. Targeted neonatal hearing screening in parallel with 7-9 month behavioural testing is more expensive and less effective than universal neonatal screening.

Item 6 Hearing screening in the neonatal period cannot identify acquired or progressive hearing loss occurring subsequently. Surveillance methods are required to identify those cases, which may be 10-20% of all permanent childhood hearing impairment.

Item 7 Risks associated with neonatal hearing screening include anxiety from false positive results and possible delayed diagnosis from false negative results, but these risks are acceptable in view of the expected benefits.

Item 8 Neonatal hearing screening should be considered to be the first part of a programme of habilitation of hearing impaired children, including facilities for diagnosis and assessment.

Item 9 A system of quality control is an essential component of a neonatal hearing screening programme. Quality control includes training of personnel and audit of performance. The person responsible for quality control should be identified.

Item 10 Although the healthcare systems in Europe differ from country to country in terms of organisation and funding, implementation of neonatal hearing screening programmes should not be delayed. This will give new European citizens greater opportunities and better quality of life into the next millennium.

Appendix 4 - Principles of Screening Applied to UNHS¹⁰³

All conditions included in a Newborn Screening Programme should fulfil in part or in full these internationally established criteria for screening.

- 1 *Is there randomized control trial evidence that earlier intervention works?*
Many studies provide evidence on the performance of neonatal universal screening. However, for methodological reasons, there are no published Randomised Controlled Trials (RCTs) in this field and the published studies that exist are somewhat mixed both in terms of methodology and quality.
- 2 *Were the data identified selected, and combined in an unbiased fashion?*
The evidence from the above trials was selected and combined by Davis et al. (1997) in ‘A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. Health Technology Assessment’.
- 3 *What are the benefits?*
Benefits include;
 - Early diagnosis and intervention improve the outcome in terms of speech and language quality, communication skills and emotional development.
 - It is easier to achieve high coverage for screening and early detection services for babies in the first year of life than any time subsequently until school entry.
 - The first six months have been suggested as a sensitive or critical period for learning.
 - Parents welcome early diagnosis of disabling conditions and have a low opinion of services if they fail to identify serious long- term problems in their children.
 - It is easier to establish the cause of PCHI if it is diagnosed early.
- 4 *What are the harms?*
Risks associated with neonatal hearing screening include anxiety from false positive results and possible delayed diagnosis from false negative results¹⁰⁴.
- 5 *How do benefits and harms compare in different people and with different screening strategies?*
 - Neonatal screening shows high test sensitivity and reasonably high programme sensitivity, with high specificity. HVDT shows poor sensitivity and relatively poor specificity with relatively low yield.
 - Screening programmes for neonatal hearing screening may be universal or targeted. Targeted screening programmes screen babies in higher risk groups for PCHI who meet agreed criteria. However restricting screening to high risk groups results in 30- 50% of infants with hearing loss being missed. Universal hearing screening programmes involves screening all neonates at 48 hours of age or older for SNHL.
- 6 *What is the impact of people’s values and preferences?*
Findings from studies show the general attitude among parents is positive towards neonatal hearing screening. Most parents want their infant to be screened in order to identify PCHI early and avail of early intervention to lessen the impact of the condition on the child’s social, emotional, intellectual and linguistic development. Other parents will refuse screening because they do not wish to know early that their child has PCHI.

Calls for the introduction of UNHS in the Republic of Ireland, have been made by the Faculty of Paediatricians and the Best Health for Children Programme (now Programme of Action for Children).

¹⁰³ Oxford Handbook of Public Health Practice (2001)

¹⁰⁴ European Consensus Statement (1998).

7 *What is the impact of uncertainty?*

Risks associated with neonatal hearing screening (anxiety from false positive results and possible delayed diagnosis from false negative results) are acceptable in view of the expected benefits.

- **False Positive Results**
A number of studies have shown that parents want screening despite the possible stress and anxiety this may cause at the time. A Dutch study¹⁰⁵ found no lasting anxieties in parents after false positive results from a neonatal hearing screening. An American study¹⁰⁶ found that parents' satisfaction could be increased if parents are given more information about hearing impairment prior to the screen.
- **False negative Results**
Research is required to estimate the incidence of false negative results.

8 *What is the cost- effectiveness?*

Universal neonatal screening has a lower running cost and much lower cost per child detected than HVDT.

Principles of good practice:

- Services should balance both the quantity and quality of provision
- Services should be both accessible and child friendly
- Services should promote and protect the rights of children and families and be advocates for their needs
- Services should be well co-ordinated with continuity over time between agencies and services involved
- Services should be evaluated regularly to ensure they are meeting the evolving needs of the child population
- Services should work within the available resources taking account of financial, political and environmental factors
- Different organisations should seek to influence each other in a positive way to produce the best possible overall service.

¹⁰⁵ Van der Ploeg, C. et al. (2002).

¹⁰⁶ Sweetow, R.W. Barrager, D. (1980)

Appendix 5 - Guidelines for Equipment Commissioning

Due to speed of technology development and the length of time that it is likely to take until all resources needed to support a quality UNHS programme are in place in the Republic of Ireland, the Working Group decided not to recommend specific types of equipment rather to set out guidelines for commissioning of equipment. A weighting will need to be applied to each issue based on its importance to the screening process. It is envisaged that individual project teams will develop option appraisals. However, the location of screening testing, category of infant being tested (i.e. Well or NICU baby) and expertise of screener will ultimately determine choice of testing equipment to be used.

- **What population is being screened? i.e. well babies or NICU babies**
- **What technique is to be used?**
 - AABR
 - DPOAE
 - TEOAE
- **Where screening to take place?**
 - Is screening hospital based?
 - Is screening community based?
- **What is the cost of equipment?**
- **What is the cost of supplies? i.e. cost of all consumables necessary**
- **What is the average time taken to screen each baby?**
 - “Screening time” is best computed by taking the total number of hours worked by screening technicians and dividing that time by the number of babies screened during that period. A quality programme would take account of getting the baby ready for screening, talking to the parents if necessary, setting up the equipment, conducting the screening, recording information about the baby so results can be retrieved later, etc.
- **What is the Specificity and Sensitivity? (see glossary)**
- **What is being measured?**
 - What degree of hearing loss is likely to be detected?
 - Is frequency specific information available?
- **What is the scoring criteria to decide if a baby will be referred for test i.e. pass refer?**
- **What are the published referral rates from screening programmes using this technology?**
 - Are they dependent on equipment?
 - Are they set by Quality Assurance?
 - Do they change as test matures?
- **What is the cost per infant screened?**
 - *What is the cost of equipment?*
 - What is the cost of Audiologist?
- **What are the arrangements for maintenance of equipment?**
 - *Back up equipment and supplies readily available. Make arrangements to obtain replacement or loan equipment within a very short time form the sales person, a hospital*
 - Is there technical support?
 - Is there after sales support?

- **Is the equipment user friendly?**
 - Is the equipment portable?
 - Is the equipment robust?
 - Is the equipment easy to use?

- **What is the level of training required to administer test?**
 - Are professional staff required?
 - Can non-professional staff administer test?

- **What is the level of involvement of the screener in the decision making?**

If screening is to take place in a variety of settings, equipment appropriate to each setting must be serviced. (e.g. A portable machine for use in noisy environment is required for community based screening; secure storage facilities need to be made available.)

Appendix 6 - Flemish Community Based Pilot¹⁰⁷

An example of a successful community based screening programme is the Kind & Gezin programme based in Flanders. Kind & Gezin is a Flemish public agency whose purpose is to promote the welfare and health of all children up to the age of three years. In 2000, 91.52% of babies were screened using aABR. Hearing screening is fully integrated into the normal programme of basic preventive care, so that no additional time or additional staff need to be provided for carrying out the hearing screening, and the target group can be easily approached. District nurses perform the screen having contact with virtually all newborn babies via (i) the bedside visit at the maternity ward, (ii) 3 house calls or (iii) consultation in the welfare baby clinic. Babies are tracked using the Kind & Gezin IKAROS databank, which covers all newborn babies.

Every new mother is made aware of hearing screening during the district nurse's visit to the maternity unit, and, during the first home visit, an appointment is made for the test. At about age of four weeks the district nurse carries out the hearing screening. If a possible hearing impairment is detected, a second screening is carried out within 48 hours in the presence of the welfare baby clinic medical officer. If the infant fails the 2nd test, contact is immediately made with the family doctor or paediatrician and immediate referral to a specialised referral centre is initiated. Families link into early home intervention and within 3-5 months the infant will have a fitting for a hearing aid. The UNHS programme in 2000 reported that no false negatives were reported in over 55,000 screens. Using aABR the refer rate was 0.56% after an initial screen. The second screen resulted in a referral rate for assessment on 0.2% (screens excluded NICU babies). 2 babies per 10,000 were false positive referrals.

¹⁰⁷ Stapparets, L. Van Kerschaver, E. 2002. Achieving efficient and effective early hearing detection in Flanders presented at presented at 2nd International Conference on Newborn hearing Screening Diagnosis and Intervention Villa Erba (Como), Italy, May 30- June 1, 2002

Appendix 7 - Equipment

Auditory Brainstem Response (ABR)

An electrophysiological technique that reflects the working of the outer, middle and inner ears and the lower auditory pathway. A soft click is presented to the ear via earphones and electrodes record the response as the sound travels from the ear through the auditory nervous system to the brain. ABR measures the electroencephalographic waves generated in response to these clicks. Electrode impedance, ambient noise level and movement artifacts must be within acceptable limits.

aABR

Automated ABR uses technology similar to conventional ABR. aABR screens the entire hearing pathway from the outer ear through to the brainstem. It is designed to identify infants with hearing problems anywhere along the hearing pathway. In the presence of OAEs, an abnormal ABR suggests Auditory Neuropathy (AN). aABR screening has been shown to be very effective in screening the NICU population where the incidence of AN is high.

Otoacoustic Emissions (OAE)

Otoacoustic emission responses are produced in the inner ear by the outer hair cells of the cochlea. Their presence indicates that the middle ear and the outer ear hair cells are functioning normally. A soft click is presented and a small microphone measures the echo that is returned from the baby's ear. Debris can cause a false positive result in the presence of normal function.

The value of OAE testing for hearing screening is based on the fact that in a very high proportion of congenital hearing impairments, the sensory cells of the inner ear are affected and result in no OAEs being produced. OAE screening has therefore been shown to be very effective in screening the well baby population¹⁰⁸.

Experiments from programmes using OAE techniques indicates that probe fitting is the single most important aspect of the test. Probes need to be fitted deep into the ear canal to collect the most sound and to exclude the most external noise. 4 types of OAEs exist including; spontaneous (SOAE), stimulus-frequency (SFOAE), transient evoked (TEOAE) and distortion product (DPOAE) otoacoustic emissions. Only the last two are used clinically in UNHS.

Transient Otoacoustic Emissions (TEAOE)

The test most commonly used in UNHS and typically uses click stimuli. TEOAE is usually absent when a hearing loss of 30dBHL exists. All major trials and longest running programmes have employed TEOAE and the majority of literature refers to TEOAE. Transient stimuli may be clicks, tone bursts or noise bursts.

Distortion Product Otoacoustic Emissions (DPOAE)

Recent studies have confirmed its usefulness, and it is increasingly used in the U.S.A. TEOAE is still the most common screening procedure used in the U.S.A. Early findings with this procedure suggested that a significant hearing loss (50 DB) would have to be present in order to fail a screen. Recent studies, however have found that in cases of known hearing loss of various degrees, TEOAE and DPOAE reveal essentially similar findings.

¹⁰⁸ Neonatal hearing Screening and Assessment. Transient evoked Oto-Acoustic emission (TEOAE) testing in babies. Recommended Test Protocol
ed Stevens, J Created 26/11/01 Last modified 18/08/02. www.nshp.info/protos.shtml

Appendix 8 - Skills and Experience

Qualifications Required:

- Basic Standard of Education: Leaving Certificate plus additional qualification
- Desirable experience to include any one of the following:
 - Audiology
 - Childcare
 - Nursing
 - Social work
- Computer skills desirable
- Familiarity with Information Technology

After a BSc Course has been established, it should be further developed to allow students to continue to MSc level. A proposal has been made by the Irish Society of Audiologists to the Department of Health regarding an undergraduate degree for General Audiologists and a graduate audiological science programme for Audiological Specialists or Scientists suitable for all “relevant” graduates.

Skills and experience required to perform responsibilities include;

- functioning of the screening programme and the local audiology department and the follow up procedures for a referred screening test
- knowledge of anatomy and physiology of the ear and common congenital abnormalities that can result in hearing problems
- types of hearing loss, their aetiology, treatment and management of such conditions from birth onwards
- acoustics and necessary test conditions for screening
- screening test being used and the equipment and its limitations and interpretation.
- in order to ensure efficient screening, screeners must have a certain through put to maintain their skills,¹⁰⁹ best screening outcomes were obtained when screeners worked a minimum of 20 hours per week¹¹⁰.
- baby handling skills appropriate to the population being tested
- excellent communication skills
- education on the importance of early identification of hearing loss in newborns
- IT skills to operate test equipment and documentation of test results
- organisational skills
- understanding of birth methods and the emotional and physical effects of birth on both mother and baby.

The importance of these non- audiology skills is recognised in a guidance document¹¹¹ produced by the NDCS in addition to basic audiological knowledge regarding the ear, hearing loss, testing conditions, screening test and the functioning of the screening programme.

¹⁰⁹ White, K., and Maxon., A. *Early Identification of Hearing Loss. Implementing Universal Newborn Hearing Screening* [Online], Available: Programs <http://www.infanthearing.org/impguide/index.html>

¹¹⁰ Johnson, JL, Mauk, KM, Taekawa, RP, et al. Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Sem Hear* 1993; 14:105-119.

¹¹¹ Quality Standards in paediatric Audiology. Guidelines for the Early Identification and the Audiological management of Children with hearing Loss Volume IV, 2000

To ensure uniformity in screening practises three distinct types of training will be required:

1 In- service training for audiologists:

Initial audiological staff currently in post will require training in testing of newborns.

2 Training for Non- audiologists

- complete training for screeners consisting of theory and practical training with site visits for supervised screening on babies.
- competency-based and require trainees to demonstrate their proficiency (as in cervical screening).
- understanding of the concepts of the screening programme and the ability to communicate these with ease.
- regular supervision and feedback regarding screening performance.
- accreditation body should agree detail of course syllabus.

3 A refresher course

All qualified screeners would attend a refresher course at intervals not exceeding three years, to retain their right to practise. Standard refresher courses could be developed centrally and administered at screening centres.

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