Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

HSE
National Audiology Review

APRIL 2011

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HSE NATIONAL AUDIOLOGY REVIEW

APRIL 2011

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Foreword – National Director, Integrated Services Directorate, HSE

I would like to offer my sincere thanks to Professor John Bamford and to Mr. Brian Murphy for carrying out this National Review of Audiology Services which I commissioned in 2009.

I would also like to thank the members of the Review Group for their contribution to the process and the report.

This is a valuable and informative report which will provide the blueprint for the planning, development and delivery of HSE audiology services. The proposed changes will improve access to audiology services, especially for children, and will strengthen the links between primary and secondary care.

This Review provides a worthwhile model for the restructuring and planning of an integrated audiology service, and I am certain that it will have a positive impact on both service users and staff.

Laverne McGuinness,
National Director,
Integrated Services Directorate,
Performance and Financial Management
April 2011

Foreword - Chairman

Hearing impairment is a hidden disability. In adults, it can lead to social isolation, family tensions, and employment challenges. In children, if present from birth or early years, it can have a major impact upon communication, literacy, educational achievement and social and psychological development. Yet this need not necessarily be the case. With early identification, authoritative and timely assessment, support and intervention, including appropriate technological support, children and adults who are hard of hearing or deaf can be supported to participate fully with family, peers and society based upon their own informed choices.

Audiology services represent an important part of the support structures that should be available to people with hearing difficulties or deafness; they provide assessment, information and intervention that are necessary for choices to be made and actions decided upon.

The evidence-base for audiology and related disciplines is relatively strong. We know the prevalence of hearing disorders and deafness, and the potential that deafness has to disrupt almost all aspects of daily living. We have well-developed procedures for investigating the type, degree and cause of deafness, and for making timely interventions, whether these are technologically-based (e.g. hearing aids), psychologically-based (e.g. advice and counselling) and/or socio-culturally-based (e.g. access to the Deaf community and sign language); and we know that properly applied these 'interventions' can result in very positive outcomes.

The vision for HSE audiology services is of high quality, safe, effective and efficient services, meeting and responsive to the changing needs of those, from birth onwards, with potential or suspected difficulties with their hearing, auditory function, or balance, or with tinnitus. Services should offer clear and accurate information upon which clients (or carers) can exercise their rights to make informed choices, using techniques, procedures, facilities and equipment that reflect best practice.

It is therefore of the utmost importance that audiology services are adequate and consistent in quality across the country, and thus Ms. Laverne McGuinness, National Director, Integrated Services Directorate requested in June 2009 that a National Review of Audiology Services be carried out. The National Audiology Review Group (NARG) met for the first time in September 2009. This Report, and its recommendations, is the product of the Review.

The Report consists of an Executive Summary including recommendations (Chapter 1); a description of the review process (Chapter 2); the background to hearing and balance disorders (Chapter 3); a description of current audiology services in Ireland (Chapter 4); and the results of a public consultation exercise carried out as part of the review (Chapter 5). Chapters 6, 7 and 8 look forward to what audiology services in Ireland should be offering: explicit care pathways (Chapter 6), universal childhood screening, particularly newborn hearing screening (Chapter 7), and finally, a number of changes encapsulated in a range of strategic recommendations (Chapter 8). Extensive Appendices include a full separate newborn hearing screening report with operational recommendations and extensive written quotes from some parents of deaf children who submitted to the Review. I would encourage readers to take the time to look at these quotes, because they make it abundantly clear that doing nothing is not an option.

The process of the Review has itself already led to positive service changes. Foremost is the decision of HSE in mid-2010 to fund the first phase of a national newborn hearing screening programme. The childhood screening subgroup of the NARG has put in extensive effort to bring this to fruition; the national model of newborn screening is about to start in some maternity hospitals in the South of the country, an encouraging start, but we can only be satisfied when all births are covered. Some new posts have been agreed; short-course training programmes have been carried out in HSE South Region with agreement to cascade to other Regions; and the indicative data from the audit exercises (see Chapter 4) will provide essential baseline information not previously available as modernisation of services takes hold.

It has been an honour to chair the Review, and I have been lucky to have had so many good and committed colleagues around the review table willing and able to work hard to make the process and the consequent Report a potential success. 'Potential' because what matters now is the extent to which the recommendations are accepted and acted upon, by policy makers, managers, and clinicians. These are not the easiest of economic times, yet while some of the recommendations clearly depend upon a step change in resourcing of services, others can be acted upon given only commitment and goodwill. The investment of effort and resources will pay off in the medium to long term, giving better value for money in meeting the needs of hearing impaired and deaf people, and better outcomes for individuals, families and society.

Finally, I would like to thank all those who submitted their views as part of the consultation exercise; all those, including several colleagues abroad, who responded at short notice to requests for information or advice; the administrative and managerial support staff from the HSE who have done so much to support this review process; and the Review team members who over the year of the Review have demonstrated the value of team working.

Professor John Bamford
April 2011

Acknowledgements

A very sincere thanks to all, who contributed to the public consultation exercise, in particular

- to parents and users who submitted written contributions and
- to those who attended the focus groups (adults and children) to share their experience.

This input has kept the client/user very much at the center of our deliberations and considerations and has hugely enriched this report and its recommendations.

To our other HSE Directorate Leads who supported this project, through commitment of their staff with the appropriate expertise to the project work, our thanks for this and for enabling an integrated approach to this work.

Our sincere thanks to the client/user representative on the group, for his time and commitment in striving to ensure that the user's voice was heard at all times.

To the Department of Health and Children, external agencies/organisations and professionals and to our audiology colleagues in the UK for giving of their time and expertise our very sincere thank you.

To our colleagues in Consumer Affairs, our thanks for your support in guiding the work of the focus groups and to the facilitators, for your work in conducting the focus groups.

Our thanks to our colleagues in the National Primary Care Office for their work and support to the project.

To the staff in the Hearing Service North Great Georges Street for hosting and supporting the NARG meetings - our sincere appreciation for both venue and hospitality.

To all who directly or indirectly contributed to the work of the NARG our sincere thanks.

We hope that your work and contribution has served to make this report an appropriate road map for the future of audiology services in this country.

National Audiology Review Group Members
April 2011

Membership of the National Audiology Review Group

Membership of the NARG was agreed in August/September 2009 as follows:

- Prof. John Bamford, Honorary Professor of Audiology, University of Manchester (Chair)
- Mr. Brian Murphy, National Primary Care Services Manager (HSE Executive Lead)
- Mr. Michael Flynn, Service User Representative
- Ms. Eileen O'Neill, General Manager Health Intelligence
- Mr. Martin Cromb, Chief Audiologist, Temple Street Hospital
- Dr. Aine Mc Namara, Consultant in Public Health Medicine, Dublin Mid-Leinster
- Ms. Shirley Keane, Business Planning & Development, Primary Care
- Ms. Aisling Regan, Administrator, Audiology Services, Dublin North East (Secretariat)
- Dr. Siobhan Laoide-Kemp, Teacher for Deaf Children, Department of Education and Skills, and Audiological Scientist
- Ms. Patricia Barr, Audiological Scientist, North West
- Mr. David Clarke, Audiological Scientist, Dublin North East
- Mr. Michael Nevin, Senior Community Audiologist, Waterford[I]
- Ms. Laura Viani, Consultant ENT Surgeon, National Cochlear Implant Service, Beaumount Hospital[II]
- Mr. John Lang, Consultant ENT Surgeon, University Hospitals Galway
- Ms. Jean Hegarty, Chief Audiologist, South Infirmary Victoria Hospital, Cork
- Dr. Evan Murphy, Principal Medical Officer, Dublin
- Ms. Sarah O'Reilly, Audiologist, Dublin Mid Leinster [III]
- Ms. Kate Duggan, Speech and Language Therapy Manager, HSE West
- Ms. Kathleen Malee, Director of Public Health Nursing, HSE West
- Mr. Tom Oxley, Senior Administrative Officer, Meath LHO
- Mr. Laz Mahon, Technical Manager, Hearing Service, Dublin
- Ms. Elaine Farrelly, Chief Audiologist, Dublin North Central
- Mr. Michael Knowles, General Manager, Naas General Hospital

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[I] Mr Nevin resigned after the first two meetings

[II] Ms Viani was able to attend only the first meetings; she remained a member of the Group, and was consulted fully throughout the review process

[III] Ms O'Reilly resigned after the first two meetings

"When (name deleted) was born in 2006 she spent about 1 week in neonatal undergoing tests for suspected genetic disorders….., as she had poor muscle strength. She had also suspected meningitis and had jaundice. Thankfully, all came back negative, she was released home and continued to be seen by a consultant paediatrician for approx one year. At no time was her deafness suspected. Note: during her stay in neo, she had extensive testing including MRI, ECG, EEG, lumber puncture, but no newborn hearing screening. This should be the first step taken as early diagnosis is vital.

We were told after the ABR that she was profoundly deaf (bilaterally) and our world fell apart, as we were not expecting this news (….. she was 17 months old). To make matters worse, we were released home with no supporting/contact information. I remember the next day vividly, sitting in my office wondering who to contact, not having anyone to contact in a very emotional frame of mind. No one should ever be left in this situation, yet unfortunately as we meet parents of newly diagnosed deaf kids the story is only too familiar.

As you can imagine in this difficult time in our lives this situation was extremely upsetting and caused us a great deal of unnecessary stress. To cut a long story short, since then we have been sourcing (name deleted) moulds privately. They cost €95, are replaced every month and are turned around within a week. During this period we have continued to get the approved HSE version, they never fit and can take up to 7 weeks to turn around".

Quote from parent, NARG consultation exercise 2010

CHAPTER 1: EXECUTIVE SUMMARY

1.1 Background

Audiology services comprise a range of clinical, technical and rehabilitative services that include:

- Assessment and management of adults and children with hearing problems, tinnitus (ringing in the ears) and balance disorders
- Assessment of people with middle ear problems for whom surgery offers a potential clinical management.

Ms. Laverne McGuinness, National Director, Integrated Services Directorate requested in June 2009 that a National Review of Audiology Services be carried out. In line with strategic developments in the Health Service Executive (HSE), a key focus of this review is the integration of PCCC, Acute Services and external agencies involved in the provision of audiology services.

The National Audiology Review Group (NARG) was convened in September 2009 and met on 12 occasions, through to October 2010. The Group was tasked with examining the services currently provided to children and adults nationwide, and with formulating a national plan for the service. The overarching objectives of the review were to:

- Assess the needs of the population for audiology services
- Examine the services currently provided to children and adults nationwide
- Review current provision in order to assess the extent to which it is both adequate and consistent
- Make recommendations for a national plan for the service which would address any current inadequacies and inconsistencies, with an implementation 'road map' for the plan.

In order to progress its work, the Group invited submissions from the public and from professionals, and carried out a number of focus groups with service users. An audit of staff, budgets, and resources across all existing audiology services in acute and community sectors was undertaken, and existing systems of care were examined. The learning of the HSE South Review was communicated to the Review group through the Chair. A range of face-to-face meetings with key stakeholders or representative bodies associated with audiology service provision took place. The NARG drew on published international research and on the experiences of services in other countries, particularly the UK. Links with key leaders in England and Wales were established, a leading audiology service in Wales was visited, and a comprehensive Needs Assessment Report from Scotland[1] provided key information and guidance.

This work undertaken by the Review Group constitutes the most extensive examination to date of audiology services in Ireland[IV]. It is clear that there are many committed and dedicated professionals working to deliver good quality audiology services under challenging circumstances, and they are to be praised for their efforts. Nevertheless, it is also clear that there are serious shortcomings in the services delivered to children, their parents, and to adults with hearing impairments. To address these shortcomings, to better meet the needs in the population, and to achieve better value for money, the National Audiology Review Group (NARG) has made a number of recommendations in this Report; chief amongst these are:

[IV] Ireland in this Report refers to the Republic of Ireland and is used in this context throughout the Report

- The implementation of a national newborn hearing screening programme
- Improvements in hearing aid and earmould services
- A restructuring of services and staffing to provide better integrated teams, with enhanced communication between professionals and with patients
- The appointment of a national clinical lead for audiology and four regional clinical leads to lead the modernisation programme, and to implement new care pathways and improved clinical governance
- An urgent workforce review to confirm the extent of the required uplift of numbers of audiology professionals
- Establishment of within-country training for audiology professionals, with professional registration

1.2 Population Needs

1.2.1 Hearing Impairments

Hearing deficits not identified or addressed in a timely manner impact directly on communication ability, constrain development in children, lead to limitations in everyday activities and restrict personal and social participation. They have demonstrable effects on health-related quality of life. In the case of children, these effects may be devastating for the child and family.

Permanent bilateral hearing impairment of a moderate or greater degree is present from birth in 1 to 1.2 per 1000. This prevalence increases during the early years with late-onset and acquired moderate or greater childhood hearing impairment to about 2 to 2.5 per 1000. Additionally, about 0.4-0.6 per 1000 are born with a unilateral hearing loss of a moderate or greater degree. If (so-called) 'mild' hearing impairments are included the total prevalence at school entry (unilateral and bilateral, mild to profound) is thought to be of the order of 3 to 4 per 1000; thus some 3,000-4,500 preschool and school age children in Ireland will have a permanent hearing impairment, with potential consequences for communication, literacy, social and emotional development, and later employability. In addition, lack of appropriate and timely intervention, as international evidence suggests, increases the likelihood of undue parental distress, increases later costs in health[2,3] education and social care.

Temporary childhood hearing impairment due to 'glue ear' is widespread, with an 80% period prevalence between birth and seven years of age; 3% of 2-4 year-olds have a hearing loss due to glue ear for more than 50% of the time and this group would benefit from surgical intervention. The self-limiting condition is the commonest reason for GP visits in childhood, and sorting out those for whom surgical intervention is warranted from those for whom it is not represents a major burden on audiology and ENT services.

Permanent acquired hearing loss of a significant degree affects some 8% of the adult population. In the over-70 age group this rises to some 50%. Thus, about a quarter of a million adults in Ireland will have a permanent hearing impairment, due mainly to ageing and/or noise exposure, which affects their quality of life, communication, social activity and participation to varying degrees.

There is strong evidence that timely diagnosis and intervention for children and adults with permanent and temporary hearing impairment results in improved outcomes at a relatively low health care cost.

1.2.2 Balance Disorders

Although most people experiencing dizziness and/or imbalance do not present to their GP, such symptoms are the commonest reason for visits to a doctor by patients aged over 75 years. Although age is a major predictor of imbalance, the working age population also experiences a wide range of disorders, which may lead to referral to a specialised balance unit, where one exists.

Neuhauser et al[4] found that the lifetime prevalence of vestibular vertigo, which specifically needs a specialised balance service, was estimated at 7.8%, the prevalence in any one year was 5.2%, and the incidence was 1.5% new cases per annum. The condition causes significant distress and disability.

1.2.3 Tinnitus

Audiologists and ENT Departments receive referrals for patients whose major complaint is tinnitus, which may 'stand alone' as a symptom or which is often associated with hearing impairment. It may also be associated with other medical conditions which require medical, surgical or clinical management such as acoustic neuroma. An MRC study[5] of ENT symptoms in the UK showed that 36% of adults had tinnitus at the time of the study and that prevalence increased with age. Tinnitus lasted for more than 5 minutes in 13.2% and was there most of the time in 4% of the study population.

The accurate assessment of the nature of the tinnitus is important to ensure that underlying conditions are identified, and appropriate treatment to help the individual manage their tinnitus is initiated. Treatment may include cognitive approaches to therapy, advice on management, and/or noise-making devices which counteract the internal noise of the tinnitus.

1.3 The adequacy of existing services

It is important to record that we have been impressed by the dedication and hard work of many existing staff, often working under difficult conditions. In some areas or locations there are good examples of multidisciplinary teams working together for the benefit of patients. One parent commented:

"…when we attend appointments there we meet a whole team and it is much easier for us to make decisions regarding our son's needs. We meet everyone from surgeon to audiologist to visiting teacher to speech therapist under one appointment and the service is very efficient with no time lost. This is easier on our son and on us as his parents".

On the other hand, there are serious shortcomings in many audiology services in Ireland. At its most bleak (see extracts from parental submissions in Appendix A), the perception is that audiology services are not to the required standard, with access issues, poor information, inadequate staffing levels, poor infrastructure, and waiting times that have reached unacceptable levels. The work of the National Audiology Review Group during 2009-2010, including an extensive public consultation, and its findings confirms the view that many audiology services in Ireland are substandard.

The current service inadequacies represent poor value for taxpayer's money. Despite an estimated annual investment in services by HSE of some €11.3 million (excluding voluntary organisation funding):

- Median age of diagnosis of congenital permanent childhood hearing loss is very late: data from one Region show the median age of intervention for permanent congenital hearing loss to be 24 months for children with severe and profound hearing loss and 60 months for children with moderate hearing loss.
- Access to good authoritative audiological assessment and intervention is patchy at best, and nonexistent in some areas
- Children requiring cochlear implants have to wait longer than is optimal for surgery
- Children's earmould services are often slow, inadequate or even nonexistent in some areas
- Waiting times for adults requiring audiological assessment or hearing aids are unacceptably long
- Modern digital signal processing hearing aids are not yet universal for HSE's clients
- Services user comments about the services are highly critical of a range of issues concerning services or the lack thereof.

Thus, key outcomes such as developmentally-appropriate communication and language skills at school entry for children with permanent hearing impairment in Ireland will be poor. This gives rise to consequent higher special education costs, higher social welfare costs, mental health challenges, and lower employability[2].

The reasons for this state of affairs are many, and include:

- Lack of understanding by planners and policy-makers of the population needs
- Historical carry over from a non unified health system
- Lack of investment in facilities and staff
- Structural anomalies in service organisation
- Lack of national clinical leadership and structured clinical governance
- Lack of training and regulation of workforce
- Lack of an evaluative and improvement culture
- Structural inefficiencies.

1.4 The vision for future services

The Review Group's vision for audiology services delivered by HSE in Ireland is of high quality, safe, effective and efficient services, meeting and responsive to the changing needs of those of any age, from birth onwards, with potential or suspected difficulties with their hearing, auditory function, or balance, or with tinnitus. The services should be accessed without undue or unnecessary delay, and as far as possible be geographically convenient. They should offer clear and accurate information upon which clients (or carers) can exercise their rights to make informed choices and should result in a high level of client (or carer) satisfaction. The services should be staffed by a well-trained, dedicated, caring and competent workforce with a good governance and accountability framework, providing excellent clinical leadership at both national and regional levels, and committed to an evidence-based and evaluative service. They should work cooperatively, efficiently and collaboratively with closely allied disciplines as a multidisciplinary team, especially Ear Nose & Throat departments, Speech and Language Therapy, and with other Government Departments and Agencies. They should use techniques, procedures, facilities and equipment that reflect best practice.

1.5 Realising the vision: recommendations and implementation

A fundamental step-change is required in order to fulfil the vision, and this will require a very substantial commitment from clinicians, policy-makers and patient representatives of a kind and degree not seen before in this clinical area. The potential health, societal, and cost gains are very significant and this review presents an unprecedented opportunity to address many of the shortfalls of the current services. Some of the changes required and recommended can be achieved through reconfiguration and without additional resources.

However, the cost-neutral changes alone will not deliver the required services. Additional resources are required to augment the changes referred to above and to provide the leadership, workforce and infrastructure necessary for a modernised audiology service in Ireland. The total additional investment would be likely to amount to a doubling of the existing indicative annual investment of €11 million (excluding voluntary organisation funding).

It is the view of the Review Group that better use of existing resources coupled with necessary additional funding and full service integration to support the recommendations of this review would represent a highly justifiable long term investment, giving far better value for money in providing the best possible care, with improved health and social outcomes for clients.

We have developed an unavoidably complex and interrelated set of recommendations that will require careful and integrated project management for their implementation, should HSE accept the need for modernisation of audiology services. A simple linear 'road map' for implementation is not realistic; rather, connected progress can and should be made on several fronts simultaneously, constrained in part (but by no means wholly) by resource availability. Therefore, as a starting point, **we recommend** that HSE appoints a National Lead[V] with full accountability for the modernisation of audiology services in Ireland based on the phased implementation of our prioritised recommendations.

The following substantive recommendations are organised into four areas:

- Patient focus
- Workforce, structure and governance
- Clinical services
- Infrastructure and support.

Each recommendation, or inter-related set of recommendations, is prioritised by one, two or three stars in order to provide a differential basis (other than availability of resources) for implementation. They are presented in summary form here; for more detailed background to, and discussion of each recommendation, see Chapter 8. We have concentrated our deliberations and recommendations on hearing impairment; our recommendations will, however, provide service structures and a workforce also able to address the needs of those with tinnitus and balance disorders.

[V] In advance of the national clinical lead appointment (see below, section 1.5.2) a time-limited non-clinical project manager with suitable experience of change management of public sector clinical services would be useful in driving this project forward, until the national clinical lead is appointed.

1.5.1 Patient Focus

***__We recommend__ that services provide full and comprehensive information to patients/carers in a variety of accessible formats, including information on services provided by the voluntary and private sectors.

**__We recommend__ that all patients, adult and children, who have a permanent hearing loss, or tinnitus, or balance disorder, and who are being treated by audiology services, should have an Individual Management Plan to provide an organised framework for planning, provision and evaluation of their care.

**__We recommend__ the introduction of the concept of a 'link worker' for the parents/carers of children with permanent hearing impairment.

*__We recommend__ that audiology services facilitate the creation of user-led support and information networks for parents of children with permanent hearing impairment, for adult hearing aid wearers, and where appropriate for other groups (e.g. those with Meniere's disease, tinnitus, or balance disorders).

**__We recommend__ that the patient charter "You and Your Health Service" be promoted from an audiological services perspective.

**__We recommend__ that Children's Hearing Services Working Groups (CHSWGs) be set up in each Region/area. The CHSWG model in the UK would serve as a useful model. CHSWGs should have multidisciplinary and multiagency membership, and include significant representation from parents of children with hearing impairment. The CHSWG role should be to monitor service performance, to encourage and support innovation and improvement, and to involve users in planning, provision and operational changes to services.

***__We recommend__ that audiology departments introduce flexible working hours for the benefit of users of the service in particular working patients and/or school age children.

1.5.2 Workforce, Structure and Governance

***__We recommend__ that community and acute audiology services in each of the four HSE Regions should be merged and reorganised into a single managerial and clinical structure with identified high quality clinical leadership. The clinical leadership to the integrated all-age Regional Department of Audiology should be provided from a fulltime consultant-equivalent audiology post occupied by a suitably qualified and skilled person whose primary speciality is audiology[VI]. The Regional Audiology Clinical Lead should report for operational matters to the Regional Director Operation (or appropriate delegate), and should be the budget-holder for the audiology services in that Region.

This reform is in line with the HSE's Transformation Programme, and would help to ensure effective critical mass of staff and expertise, good clinical governance, efficient skill mix, efficient use of facilities and equipment, and opportunities for staff support, peer review and continuing professional development. Additionally, it would reduce current duplication and service complexity detrimental to the patient journey. The integrated and autonomous department of audiology should have a main base location with adequate accommodation and equipment

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[VI] Consultant-equivalent should not be taken to imply consultant in medical or surgical specialities.

commensurate with good quality evidence-based audiology practice, taking into account that audiology services for adults and children are effective only when functioning links with child health, speech and language therapy, ENT surgery, other medical specialties and allied health professionals are in place. Justifiable outreach arrangements and/or satellite sub-departments should be made as and where appropriate.

***We recommend** a root and branch restructuring of audiology careers in Ireland into a unified career structure and pay scale spanning audiological assistants (non-graduate), audiologists (graduate qualifications) and senior and consultant audiologists (postgraduate qualifications), with training opportunities for those willing and able enough to progress from lower bands to higher bands, and with direct entry routes possible with additional appropriate conversion programmes. Suggested draft Scopes of Practice (SoPs) for these three broad levels are given in Appendix B; these would introduce more flexible working practices with regard to audiologists providing care to both children and adults without unnecessary demarcations. We recommend the usual procedures in such situations of the 'grandparenting' of existing staff to appropriate grades based upon competencies and tasks being practiced (rather than qualifications), with the usual protection for individuals' terms and conditions of employment.

***We recommend** that the title 'audiologist' become a protected title, registered under the Health and Social Care Professionals Council, with graduate level (BSc in Audiology) as the point of entry as a registered practitioner, and with the title ('audiologist') covering both graduate level and postgraduate level (i.e. MSc or above) practitioners.
In this context, we support the proposal from the Irish Society of Hearing Aid Audiologists, who provide hearing aids and associated care for adults in the private sector, for registration of Hearing Aid Audiologists based upon the two year training programme. This should link in with the registration and training of audiologists such that there is reciprocity and an integrated career structure with 'stepping on and stepping off' training opportunities.

***We recommend** that HSE carry out an urgent workforce planning exercise of audiology clinical staff in order to confirm numbers for the necessary workforce uplift. Based upon data from services in the UK, and taking into account different entitlement in Ireland, we have estimated that current staff numbers should be more than doubled in order to meet the need, but with a different, more effective, skill mix than is found at present. Estimated staffing requirements include:

- The introduction of an additional 23.5 assistant audiologists
- An increase of 21.1 WTE graduate level audiology staff,
- An increase of 38.9 WTE postgraduate-level audiology staff

This uplift should be undertaken within the proposed integrated audiology departments in the four HSE Regions, with the prior appointment, in 2011, of four Regional Clinical Audiology Leads and one National Clinical Lead to drive this forward. The first task of these 'consultant' level leads would be to oversee the implementation of integrated audiology services and to prepare fully justified cases for the numbers and deployment of additional staff and equipment needs in their Region. Conditional upon the validation of these staffing numbers, would come the recruitment of the estimated 21.1 graduate-level audiologists, alongside the estimated 23.5 assistant audiologists, in 2012, followed by the remaining 33.9 postgraduate audiologists (i.e. 38.9 less the five clinical audiology leads) in 2013.

*****We recommend** that a suitable Higher Education institution be commissioned by HSE to develop integrated training programmes (based on the proposed Scopes of Practice) for BSc and MSc level training in audiology, and for non-graduate audiology assistants, with stepping on and stepping off points that allow those able and willing to progress according to their personal needs and the needs of the service.

However, in order to address the immediate workforce needs,
*****We recommend:**

- That HSE negotiate a formal arrangement with a suitable University/Universities in the UK to provide MSc-level training in audiology for five suitable graduate recruits per year for six years starting academic year 2011/12. Since the clinical competence required to practice independently is outwith the one-year MSc in Audiology in the UK, arrangements would have to be made for the MSc Audiology graduates to secure competencies under a system of clinical education to be developed in Ireland using centres of excellence, drawing upon best practice elsewhere, and assured for quality. Development and coordination of such practical training and assessment of competency should be the responsibility of the new national and regional clinical audiology leads in collaboration with the ISA/IAA (Irish Society of Audiology/Irish Academy of Audiology).
- That HSE ensure that any students currently being sponsored are recruited into the service as soon as possible as part of the workforce uplift.
- That a coherent forward-looking national recruitment drive be developed to recruit the required graduate audiologists from the UK BSc Audiology programmes in 2012.
- That a training programme to train 23 assistant audiologists during the year 2012 be developed in a suitable venue or network of venues during 2011.
- That each Region be allocated dedicated once off CPD funding of €10,000, to be managed by the Regional Clinical Leads in collaboration with the National Clinical Lead, in order to address immediate needs for skills uplifts for existing staff, particularly in paediatric audiology and the requirements around newborn hearing screening.

1.5.3 Clinical services

*****We recommend** that a universal national programme of newborn hearing screening be introduced as a priority, such that all babies have their hearing screened shortly after birth[VII]. Once UNHS (universal newborn hearing screening) has been implemented, **we recommend** that the 8-month Infant Distraction Test screen be discontinued.

*** **We recommend** that within the constraints of the Visiting Teacher (VT) service, which is managed through the Department of Education and Skills, that very early pre-school support for parents of children with permanent hearing impairment identified via newborn hearing screening is recognised as a major priority and that continuous availability of the service is ensured. The current VT service (delivered by 29 WTE Teachers of the deaf) supporting deaf children up to 18 years of age and their families is overstretched and is not all year round; thus an increase in staff resources is urgently required to support the newborn hearing screening initiative. The significant potential for outcome benefit that follows the implementation of newborn hearing screening is not achieved without appropriate follow up and intervention. Thus newborn screening has implications for paediatric audiology (requiring high quality family-centred diagnostic assessments and fitting and management of hearing aids), and for the number and training of

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[VII] See Chapter 7 of this Report, and the full childhood screening report in the Appendix, for more detailed operational recommendations for the newborn hearing screen.

Visiting Teachers for deaf children. There is good evidence that newborn screening with good quality intervention brings consequent significant educational and social care cost savings.

***We recommend** the designation of one audiology department as a national specialist centre for those infants and children with suspected Auditory Neuropathy Spectrum Disorder (ANSD).

We recommend that school entry hearing screening should continue to be implemented nationally as a back-stop for indentifying late onset or mild permanent childhood hearing impairment (PCHI) not identified through the newborn screen or through responsive services, and any other hearing disorders at this important point in a child's education and development. A national group should be tasked to draw up guidance on protocols and training, and initiate mechanisms for performance monitoring of the screen.

***We recommend** that each Region should, as matter of urgency, validate their existing audiology waiting lists in order to establish the extent of ongoing need, and to prioritise patients according to level of urgency. Services should put measures in place to reduce waiting lists. As part of this exercise, there should be a common waiting list and referrals should be placed on that list by reference to the agreed criteria which cannot include the fact that the referral is arising as a consequence of the patient's attendance at a private ENT clinic (HSE National Contracts Office. Personal communication, 2010). We have been advised by clinicians that the numbers of patients from private ENT consultations are likely to have a significant effect on waiting times for non-private patients; this could lead, for example, to further delays in the diagnosis of permanent childhood hearing impairment.

***We recommend** that audiology services should immediately put into practice the outline Care Pathways (CPs) in this report. To support the CPs, by the end of 2011 all services should be using the Good Practice Guidelines (GPGs) listed in Appendix C of this Report. **We recommend** that the HSE convene, with appropriate representation, a national audiology standards group with responsibility for updating and monitoring the use of these and subsequent evidence-based GPGs.

***We recommend**

- An increase in the overall budget for hearing aids and earmoulds to match 2009 expenditure
- The necessary additional financial accommodations to support the fitting of modern good quality Digital Signal Processing (DSP) hearing aids
- A review of the budget to ensure its allocation nationally is based on principles of equity and need.

***We recommend** that all hearing aids issued by HSE services to children and adults should be modern good quality Digital Signal Processing (DSP) hearing aids, fitted and verified by published procedures; manufacturers' click-and-fit rules should not be used.

***We recommend** that HSE services cease issuing In-the-Ear aids and phase out their use.

***We recommend** that the Department of Health and Children and Department of Education and Skills collaboratively develop a robust and comprehensive candidacy strategy for personal FM systems, to include pre-school provision. **We recommend** that the two Departments review the system for procurement, provision, repair and maintenance of personal and soundfield FM systems, to ensure the needs of children are fully and effectively met in the most efficient way.

*****We recommend** that clinical leads for services ensure that paediatric audiology staff are fully trained to take impressions from babies, infants and children, and that the time from impression-taking to fit of the new earmoulds is no more than five working days.

*****We recommend** that the administrative and postal systems supporting the national repair service's activities be reviewed and improved to remove unnecessary delays.

*****We recommend** that all audiology departments should have a walk-in service for repairs staffed by assistant or graduate audiologists.

*****We recommend** that future hearing aid contracts with manufacturers include a repair guarantee and decontamination clause (repaired aids returned to stock 'as new') in order to provide another repair route option. This option could and should be used for those for whom any downtime would represent a severe challenge to daily living (e.g. severely or profoundly deaf clients; deaf-blind clients, children).

****We recommend** continued ring-fenced financial support for the cochlear implant programme but at levels which allow for simultaneous bilateral implantation for children. We support the proposal to locate the national paediatric cochlear implant service within the new children's hospital. **We recommend** that in order to take better advantage of the interactions and synergies between the clinical decisions, processes, and equipment, and to provide parents and children with a more seamless service, the paediatric cochlear implant team be integrated with the paediatric audiology service at the national paediatric hospital.

****We recommend** ring-fenced financial support for a new national Bone Anchored Hearing Aid (BAHA) service, based upon data on predicted national numbers of 25-35 per year, and located in three ENT departments (e.g. Dublin, Cork and Galway), where expertise can be concentrated. **We recommend** in addition that BAHA devices and repairs be subject to national procurement to ensure value for money.

***We recommend** that in the context of audiology and hearing-related services HSE reviews all Service Level Agreements (SLAs) currently in place to ensure

- That there exists for each agency receiving funding one SLA with a supporting accountability framework
- That allocation of monies satisfies the priorities set out
- That the SLA is scripted and standardised to support quality, transparency and accountability
- That robust and regular performance monitoring occurs
- That all SLAs supporting audiology and hearing-related services are reviewed in the context of the whole audiology service to ensure best value for money in the context of finite resources.

****We recommend** that, in order to ensure ongoing continuity of care, for those who have a permanent hearing impairment requiring hearing aids during childhood, the HSE makes a policy decision with the Department of Health and Children with a view to providing hearing aids for life.

1.5.4 Infrastructure and support services

***We recommend** that a single unified audiology Patient Management System (PMS) be introduced to cover the activity of each Region's audiology department, with the necessary support training. The effective use of these systems will require additional IT support from the HSE. **We recommend** that HSE develop a national strategy to introduce a PMS throughout the proposed integrated HSE audiology services.

***We recommend** that an equipment audit be carried out for integrated audiology services in each Region by a specially-appointed HSE group led by the new national audiology clinical lead. This should be undertaken in collaboration with each of the four newly-appointed regional clinical leads as a first and necessary planning step in the effective functioning of the modernised services. An audit of facilities should similarly be undertaken to assess current strengths and additional requirements.

***We recommend** that a national procurement approach be adopted to take advantage of efficiencies, service consistency and economies of scale for:

- Postaural DSP hearing aids (separately for children's and adult's needs)
- DSP hearing aid fitting systems
- Audiological assessment equipment (e.g. equipment for ABR, OAE, tympanometers)
- An efficient and effective earmould manufacturing service
- Audiology Patient Management Systems and other IT requirements for the service.

To support national procurement, **we recommend** the establishment of a national advisory group whose brief would include audiological and related equipment including hearing aids. The responsibilities of this group would also include working with procurement and supply services, advising on specifications for these national contracts, and overseeing and advising on evaluation exercises run by the national technical support service.

***We recommend** that plans be developed for the National Technical Service to provide:
- A national calibration service for all audiological equipment
- A repair service for BAHAs, subject to negotiation with manufacturers (as part of the procurement process)
- A technical evaluation service for potential contract aids and audiological equipment during procurement processes.

The recommendations are summarised for clarification and overview in Table 1.1.

Table 1.1 Recommendation headings by priority (1, 2, 3 star). All recommendations are high priority, but the stars suggest levels of urgency that allow some differentiation.

*** Star Rating	** Star Rating	* Star Rating
8.2 Patient Focus	**8.2 Patient Focus**	**8.2 Patient Focus**
This table refers to recommendations in Chapter 8		
8.2.1 Patient Information***	8.2.2 Individual Management Plans (IMPs)**	8.2.4 Patient/Family Networks or Groups*
8.2.7 Flexible Access***	8.2.3 Link Workers for Children/Families**	
	8.2.5 Patient Charter**	
	8.2.6 Children's Hearing Services Working Groups (CHSWGs)**	
8.3 Workforce, Service Structure and Governance	**8.3 Workforce, Service Structure and Governance**	**8.3 Workforce, Service Structure and Governance**
8.3.1 Integrated Audiology Departments: Community and Acute Services ***		
8.3.2 Integrated Audiology Departments: 'Audiologists', 'Audiological Scientists' and a Unified Grading and Pay Structure ***		
8.3.3 Registration***		
8.3.4 Workforce Numbers, Training and Recruitment***		
8.4 Clinical Services	**8.4 Clinical Services**	**8.4 Clinical Services**
8.4.1 Universal Newborn Hearing Screening (UNHS) ***	8.4.2 Other Childhood Hearing Screens **	8.4.7 External Services and Service Level Agreements (SLAs)*
8.4.3 Validation and clearance of Current Waiting Lists ***	8.4.6 Cochlear Implants (CI) and Bone-Anchored Hearing Aids (BAHA) **	
8.4.4 Care Pathways and Good Practice Guidelines ***	8.4.8 Children's continuing entitlement to services into adulthood **	
8.4.5 Hearing Aids, FM Systems and Earmoulds ***		
8.5 Infrastructure and Support Services	**8.5 Infrastructure and Support Services**	**8.5 Infrastructure and Support Services**
8.5.1 Information Systems ***		8.5.4 National Hearing Aid Repair Service *
8.5.2 Equipment and Facilities ***		
8.5.3 Procurement and Supply ***		

CHAPTER 2: INTRODUCTION AND METHODS

2.1 The National Audiology Review and Terms of Reference

Ms. Laverne McGuinness, National Director, Integrated Services Directorate requested in June 2009 that a National Review of Audiology Services be carried out. In line with strategic developments in the Health Service Executive (HSE), a key focus of this review is the integration between PCCC, Acute Services and external agencies involved in the provision of audiology services.

A National Audiology Review Group (NARG) was convened in September 2009. The NARG was tasked with examining the services currently provided to children and adults nationwide, and with formulating a national plan for the service. The overarching objectives of the review are to:

- Assess the needs of the population for audiology services
- Examine the services currently provided to children and adults nationwide
- Review current provision in order to assess the extent to which it is both adequate and consistent
- Make recommendations for a national plan for the service which would address current inadequacies and inconsistencies, with an implementation 'road map' for the plan

The work of the NARG was to include the following tasks:

- Determine best practice with regard to assessment, referral and treatment
- Develop integrated care pathways to ensure integrated care
- Chart a "roadmap" to improve access and equity including integration across community and acute services
- Recommend standards of clinical governance and accountability
- Assess current training systems
- Consider future service requirements with an emphasis on scope of practice and workforce planning
- Make recommendations on service development proposals in line with resources available and required
- Take account of any learning from the recent audiology review in the HSE South[VIII].

2.2 Timetable

The NARG met for the first time in September 2009 and thereafter on a monthly basis until October 2010.

2.3 Methods and Work Plan

The NARG employed a number of strategies for undertaking its work, including;

- Inviting submissions from the public
- Inviting submissions from professional and voluntary groups
- Organising a number of focus groups with parents of deaf children and adult service users in different parts of the country

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[VIII] The learning of the HSE South Review was communicated to the Review group through the Chair.

- Undertaking a detailed audit of staff, budgets, and resources across all existing audiology services in acute and community sectors
- Reviewing existing service delivery and care pathways (where they exist) in Ireland
- Undertaking a range of face-to-face meetings with key stakeholders or representative bodies associated with audiology service provision
- Initiating discussions with procurement colleagues in HSE
- Reviewing existing good practice guidance and care pathways from the UK and internationally
- Consulting with key leaders in audiology services in England and Wales
- Visiting a leading audiology service provider in Wales
- Drafting proposed integrated care pathways (CPs) with supporting recommendations designed to meet the needs of the population
- Developing a model for childhood hearing screening
- Developing a service structure supportive of integrated audiology within in the context of HSE organisational reform
- Developing comprehensive and prioritised recommendations regarding workforce, training, and resources designed to enable delivery of the proposed care pathways safely, effectively, and efficiently.

Much of the work of the NARG was done outside of the monthly meetings; the latter were used to discuss findings, develop proposals and sign off sections of the work plan. Subgroups were formed to undertake different tasks, a key one of which was the NARG Childhood Hearing Screening Sub Group (see Chapter 7).

2.4 Public Consultation

An extensive public consultation exercise was undertaken to invite views from users, stakeholders and external organisations. This process was progressed in four distinct phases over the period November 2009 to June 2010.

- Phase I – Announcement in the national press and published on the HSE Website, advising that submissions to the group were invited from members of the public, other interested stakeholders and local advocate groups. The closing date advised for submissions was 31st December 2009.
- Phase II - It was agreed to extend the public consultation exercise, primarily to focus on users and parents of users of the service. The closing date indicated was 16th April 2010, however submissions received after that date were also accepted.
- Phase III – Dedicated focus groups for adults, parents and users were convened in the major urban centres of Dublin, Cork and Galway. This included students and teachers from St. Joseph’s School and St. Mary’s School, Cabra, Dublin.
- Phase IV – Specific interest groups/stakeholders were invited to meet with the Chair and HSE Executive Lead to afford them the opportunity to input to the Review process. These were:

  Department of Education and Skills
  Department of Health and Children
  Irish Society of Hearing Aid Audiologists
  Patient Focus
  Society of ENT

Irish Society of Audiology
Irish Hard of Hearing Association
Technical Staff, North Great Georges Street
Cochlear Implant Programme
Deafhear
Planning team for the proposed National Children's Hospital

CHAPTER 3: THE NATURE AND PREVALENCE OF HEARING IMPAIRMENT AND DEAFNESS, BALANCE DISORDERS, AND TINNITUS

3.1 Introduction

The population of Ireland is 4.24 million (2006 census). Of these, 7.7% were 70 years or over, and 27% were infants, children or young people up to the age of 19 years. In 2009 there were 74,246 live births across the HSE maternity hospitals. Entitlement to services, free of charge by medical card holders under the GMS (General Medical Services) arrangements is held by 1.53 million individuals i.e. 36% of the population, of whom 356,056 (23%) are children under the age of 16 years. The ownership of medical cards is evenly distributed across age groups with the exception of those over 75 years of age, where nearly all have medical cards.

Audiology services are concerned with the problems that adults and children experience with hearing, balance and tinnitus. Hearing problems arise from impairments in function of either the outer/middle or the inner ear, and sometimes both together. Dysfunction of the middle (or occasionally outer) ear gives rise to conductive hearing loss; dysfunction of the inner ear (the cochlea), or to the nerve pathways leading from the cochlea, gives rise to 'sensorineural' hearing loss (SNHL). The degree of hearing loss is most usually expressed by reference to the individual's thresholds of detection (hearing thresholds) across different frequencies as evidenced by the pure tone audiogram. These may be averaged to give a single number which is associated with one of four descriptors: mild, moderate, severe and profound as set out in Table 3.1.

Table 3.1 Descriptors for extent of hearing loss

Description of hearing loss	**dB HL in better ear averaged over range of frequencies (0.5, 1, 2 and 4 kHz)**
Mild	≤ 40 dB HL
Moderate	41 to 70 dB HL
Severe	71 to 95 dB HL
Profound	> 95 dB HL

Middle ear problems leading to conductive hearing loss are potentially managed by surgery. At present there are no surgical or medical interventions for sensorineural hearing loss, and the only effective management available is the provision of amplification via hearing aids and/or cochlear implants, with associated therapeutic rehabilitation. Some conductive hearing losses are not suitable for surgery and also require management via hearing aids.

There are few if any recently published studies of sufficient quality on prevalence of hearing loss, balance disorders and tinnitus in Ireland and therefore studies from the UK, US and Europe are the sources of information for this Chapter and are used as a basis for population estimates and service need.

3.2 Hearing Impairment in Children

3.2.1 Permanent Childhood Hearing Impairment (PCHI)

Most cases of permanent hearing impairment in children are sensorineural in origin, although permanent conductive hearing losses are not uncommon (e.g. associated with meatal atresia, or other cranio-facial anomalies). It must be recognised that, whereas adults develop hearing problems when they already have an established language base, vocabulary and the rules of speech, in children this sensory deprivation can occur during the critical language learning period. Thus, permanent childhood hearing impairment (PCHI) has the potential, depending upon age of diagnosis, severity, quality of family support and other factors, to severely disrupt childhood function and participation by compromising language acquisition, educational achievement, social and emotional development, employment, social inclusion and quality of life.

There is now good evidence that identification and diagnosis of congenital cases in the first six months of life followed by appropriate and timely intervention can significantly improve outcomes[6,7,8] and reduce later costs[2,3] (e.g. on special educational provision) to society. Furthermore, tests have been available for over twenty years, and agreed protocols published, to allow the hearing and auditory function of patients of all ages, from birth onwards, to be specified ear-by-ear and (in the case of detection thresholds) frequency-by-frequency.

Intervention includes, but is much more than, the appropriate fitting of modern digital signal processing (DSP) hearing aids, cochlear implants, and other assistive listening devices. Positive family support, communication advice, educational modifications, and contact with other families with deaf children are crucial aspects of good ongoing care. There is a good evidence-base for what represents optimal fitting of devices (whether hearing aids or cochlear implants), and therefore identifying quality of service in these areas has a good foundation[9]. Non-optimal hearing aid fitting has the potential to seriously disrupt developmental and educational progress.

Data from England suggest that prevalence of permanent bilateral moderate or greater hearing impairment at birth is approximately 1.0 to 1.2 per 1000[10,11] and of permanent unilateral moderate or greater hearing impairment at birth approximately 0.4 to 0.6 per 1000[11]. About a third of children with permanent bilateral hearing impairment will have other complex needs, some syndromic. Approximately two thirds of children with permanent congenital bilateral hearing loss of moderate or greater degree will have one or more of the three main risk factors associated with PCHI: a stay of 48 hours or more on a neonatal intensive care unit (NICU), a family history of permanent childhood hearing loss, or cranio-facial anomalies[12]. The prevalence of permanent bilateral childhood hearing loss of a moderate or greater degree doubles in the under-ten-year-old cohort[10] as a result of acquired or late-onset impairments associated with, for example, meningitis, trauma, congenital CMV (cytomegolovirus), and genetic conditions. A number of both common and rare syndromes are associated with PCHI. Since it is now known that genetic conditions account for a significant proportion of PCHI, genetic investigations and counselling have become an important aspect of need in recent years.

Accurate prevalence figures for PCHI that include mild hearing loss are more difficult to find, or are inconsistent across studies; however data from one area in North London suggests that the total at school entry of all cases (mild to profound, bilateral and unilateral) is approximately 3.5 per 1000[13]. The detrimental effects of so-called 'mild' permanent hearing loss on the child's educational progress are significant, as are those associated with a permanent unilateral hearing loss[14,15,16] and these may present difficulties particularly, even more so in the context of children with more complex needs.

Thus, it is estimated that each year in Ireland, 104 children will be born with a permanent moderate, severe or profound hearing impairment, for 74 of whom the hearing loss is bilateral. Of these 74, approximately 19 will have a profound hearing loss, approximately 19 will have a severe loss, and approximately 36 will have a moderate degree of hearing loss. (Note that these numbers will be subject to considerable year-on-year variability). By the age of nine, it is estimated that there will have been a doubling of the number of permanent bilateral moderate or greater losses for this cohort year, due to late onset, progressive and acquired impairments, resulting in approximately 150 children. Including mild and unilateral hearing impairments, it is estimated that the total number of children with PCHI aged between birth and 14 years in Ireland (based on 2006 census rather than 2009 birth cohort) to be approximately 3,450 (or a prevalence of 4 per 1000).

A proportion (approximately 10%) of children with PCHI, usually from among those who were in NICU, show evidence of auditory neuropathy. This condition, now known as Auditory Neuropathy Spectrum Disorder (ANSD) because of its varied presentation, involves evidence (usually congenital) of good cochlear or end-organ function in the presence of significant disruption of the auditory neural processes. It presents particular challenges to families and services because of the varied presentation, difficult diagnosis and prognosis, and the differing evidence on the value of hearing aids or cochlear implants, and on management and support.

Later in childhood, and into adulthood, some patients present complaining of the difficulty they have listening to speech in adverse, often noisy, conditions. The existence of measurable difficulties with aspects of auditory processing in the presence of 'normal hearing' as defined by detection thresholds has become known as Auditory Processing Disorder (APD). The prevalence, diagnosis and management of people with APD remains controversial, but recent evidence from the UK's Institute of Hearing Research indicates that it is more often a cognitive or attention deficit, rather than a true auditory (non-speech) processing disorder[17,18]. It is a condition that presents to paediatric audiology services in small numbers and requires audiological assessment to rule out an auditory deficit. The current advice on management strategies is an improved environment including listening strategies and amplification, and auditory training.

3.2.1.1 A wider perspective on PCHI

The foregoing description of PCHI is from an audiological perspective. It is, however, important to understand the huge implications for families of having a child with a permanent hearing impairment, particularly if the hearing loss is severe or profound, or if auditory neuropathy is involved. Most such families will have had no prior experience of deafness and will require information, support and advice in a timely and sensitive fashion. The period immediately after diagnosis is a crucial period and has lifelong consequences and requires careful and sensitive management. Even such apparently minor issues as continual provision of well-fitting earmoulds for the child can, and often does, represent a major stumbling block to progress and for the family's confidence in services. This is evidenced in the consultative exercise undertaken as part of this Review. These issues are vividly highlighted in the many submissions we received from parents.

The configuration of services is critical in empowering parents and enable them to make informed choices on behalf of their child[19]. Decisions such as the child's first language (e.g. spoken or signed), their socio-cultural belonging (e.g. deaf or Deaf[IX]), or minor but nonetheless important issues such as the use of their hearing aids when in the car are critical in ensuring a quality service and the recognition of parents as experts.

3.2.1.2 Screening for PCHI: Benefits and Cost-effectiveness

The aim of early diagnosis and appropriate intervention for children with PCHI is for these children to approach school entry with age-appropriate language and communication skills, so that the development of literacy, numeracy and knowledge acquisition is on a typically-developing trajectory, rather than the child, the family and educators having forever to endeavour to 'catch up'. Late diagnosis and consequent delayed development have long-term costs associated with special education and support, as well as personal, family and societal costs resulting from lower educational achievement, poor employment prospects, and potential mental health problems[2,3].

These arguments have led health and education specialists to argue for early screening for PCHI. As technology has advanced, so early screening opportunities have become available, from school hearing screening in the 1930s, to infant hearing screening in the 1950s, and most recently to newborn hearing screening in the 1990s.

The critical review of evidence for newborn hearing screening carried out by the Health Technology Assessment Programme in the UK[12] includes a detailed report on a comparison study of the costs of Newborn Hearing Screening and the 8-month infant distraction test screen. Results indicated a cost ratio of 2:3 (newborn hearing screening: 8-month screen) on a per-child-screened basis. The ratio favours newborn hearing screening even more on a cost-per-case detected basis, due largely to the poorer coverage, higher referral rate, and poorer sensitivity of the 8-month screen. Absolute costs per child screened in 1996 prices were £14 for newborn hearing screening and £21 for the 8-month screen; this includes screening and follow up to the point at which cases are confirmed as true positives or false positives. Current cost in England per child screened by the Newborn Hearing Screening Programme is of the order of £35-£40 (Davis A. Director of NHS Newborn Hearing Screening Programme. Personal communication, May 2010).

The aim of a universal newborn hearing screening programme is the early detection of unilateral or bilateral moderate or greater permanent childhood hearing impairment, enabling early intervention and resulting in much improved outcomes for the child. Early identification is the springboard for the processes of diagnostic and habilitative audiological, medical and educational intervention. Comprehensive intervention and management programmes to meet the child's needs along with support to the family are seen as natural extensions of a universal screening programme[20,21].

There are a number of ways of assessing the benefits and cost-benefits of newborn hearing screening. The age of diagnosis of moderate or greater permanent congenital hearing loss in England resulted in a reduction from a median of 22 months (with some cases very late) to a median of below three months of age following the implementation of newborn hearing screening[11]. Assessment of parental judgements of the benefit of newborn hearing screening have been equally convincing. Intervention before six months of age results in significantly better language and communication skills[7].

[IX] The use of the upper-case 'D' is used in convention to represent Deaf culture, with its own language, mores, and history.

Costs of audiological interventions for identified cases of PCHI (ongoing assessments, device fitting and management etc) during childhood may increase somewhat with newborn hearing screening, since they will take place over a longer period (i.e. 18 years, birth to adulthood, rather than 14 or 15 years from delayed diagnosis to adulthood). Other possible sources of increased costs derive from the extra training and expertise needed to provide good quality early audiological management and support to families of very young deaf children from Visiting Teachers of the deaf and from allied health professionals.

Grosse[2] has developed an evidence-statement on newborn hearing screening. The statement concludes that *'To the extent that improved language leads to lower special education costs and to improved learning potential, the monetary benefits of screening are likely to exceed the costs. The economic benefits of newborn hearing screening include reduced special education costs associated with improved hearing and language and also lower social and community services. A study from England[3] has reported that average education costs among 7 to 9 year-old children with bilateral hearing loss were lower by 22% among children born in districts with universal newborn hearing screening. The savings in special education costs are likely to exceed the costs of screening within five years.'*

3.2.2 Temporary childhood hearing impairment: Otitis Media with Effusion (OME)

Arguably having less impact on an individual child than permanent hearing impairment, conductive hearing loss associated with temporary middle ear disorder (otitis media with effusion, OME) is nevertheless a major public health challenge because of its prevalence. This is in the order of 20% point prevalence, which peaks at two years of age and around school entry, and 80% period prevalence between birth and seven years of age; three per cent of two-four year-olds have a hearing loss due to OME for more than 50% of the time[22,23]. OME is associated with upper respiratory tract infections, eustachian tube dysfunction, and the build up of fluids in the middle ear, which may become 'glue-like' (hence 'glue ear'), causing mild to moderate conductive hearing impairment. Associated symptoms may include sleep disturbance, speech and language delay, attentional and behavioural difficulties; in persistent cases Haggard[23] reports a mean reduction of 16% in quality of life on the Health Utilities Index.

Some three per cent of children have the condition with persistence and severity sufficient to justify considering Ear Nose and Throat (ENT) surgery and/or temporary hearing aids. Based upon the Irish 2006 census this would translate into approximately 9,000 children for the 0-4 year-age group. Identifying these children and separating them from those for whom the condition is transitory and without significant ill-effects is not a trivial task. It involves a combination of judgements of pathology, hearing, and development, as well as periods of 'watchful waiting' for spontaneous remission. These judgements will of necessity involve a variety of different health professionals (primarily ENT staff, audiologists, and speech and language therapists, in cooperation with GPs, parents and sometimes teachers) and may therefore pose a challenge as to how best to bring these judgements and the professionals together with maximum effectiveness and efficiency. They also represent a significant clinical workload for paediatric audiology services which has to be managed in such a way as not to delay the identification of the much rarer cases of permanent childhood hearing impairment.

The relatively large numbers of infants and children referred with symptoms associated with OME requires comprehensive audiological assessment; this is especially so when the temporary conductive hearing loss is combined with a permanent hearing loss or with complex needs. Since this is a fluctuating condition with periods of remission, late diagnosis is generally not an issue (although delayed treatment may be). In children with complex needs such as Downs Syndrome, this type of hearing loss is very common, and the assessment requires particular expertise because of these needs.

3.3 Hearing Impairment in Adults

In the adult population approximately half of those over 70 years of age will have developed a permanent hearing loss which interferes with communication and affects quality of life. The prevalence is approximately halved for each decade decrease in age and the overall prevalence halves for each 10dB increase in hearing loss. Table 3.2 summarises prevalence data, based on pure tone audiometry, from the large MRC study conducted in the UK in the 1980s[24].

Table 3.2. The percentage of people in six age groups whose hearing levels (averaged at 0.5, 1, 2, 4 kHz) were >25, 35 and 45 dB HL, in the better ear.

Age	**% >25 dB**	**% >35 dB**	**% > 45 dB**
21-30	1	1	0
31-40	5	2	1
41-50	10	4	2
51-60	23	10	6
61-70	34	17	12
>70	74	49	25
ALL	**17 ± 2.2**	**8 ±1.5**	**4 ±1.2**

Hearing impairment in adults is most usually sensorineural in origin and is typically caused by aging and/or noise exposure, although some loss of function to the middle ear mechanisms, cognitive deficits, and neurological dysfunction can be additional hazards to effective auditory communication in the elderly. The degree of hearing loss can vary from mild to profound, but typically increases with age (Table 3.3) and is worse in the high frequencies (which are crucial for understanding the spoken word).

Table 3.3. Cumulative estimated numbers of adults (20 years+) in Ireland as a function of degree of hearing loss, based on the MRC prevalence data for the UK[24].

	Level of hearing loss (dB HL, averaged over 0.5, 1, 2 & 4 kHz in better ear)					
	>35	**>45**	**>55**	**>65**	**>75**	**>85**
Prevalence (%)	8	4	2	1	0.5	0.25
Total estimated number in Ireland (adults):	246,811	123,405	61,703	30,851	15,426	7,713

The effects of adult acquired hearing loss on the individual's quality of life are often highly significant and may be experienced through loss of confidence, social isolation etc. Employment prospects may be affected, and isolation in the workplace becomes more common. The economic burden on family and society may increase significantly. Yet the disability is largely hidden, or unseen, and therefore society tends not to make adjustments to accommodate the effects of the disability. Overall, given the prevalence rates and the effect on the individual, adult acquired hearing loss represents a major public health challenge.

A small number of hearing impairments in adults may involve outer and/or middle ear dysfunction (conductive hearing loss) which may be amenable to surgical intervention. For the overwhelming majority of adults with hearing loss the cornerstone of intervention is appropriately-fitted, modern digital signal processing (DSP) hearing aids. In addition, intervention includes the selective use of other assistive listening devices in particular listening environments, combined with hearing aid orientation / counselling, guided by an Individual Management Plan (IMP), negotiated and agreed with the patient. The importance of counselling and rehabilitation is linked not only to the social effects of a sensorineural hearing loss, but also to its perceptual effects: auditory processing mechanisms are compromised such that it is more difficult to separate out different voices, discriminate different speech sounds and, crucially, to separate out speech from noise backgrounds. New DSP hearing aids can do much to alleviate these perceptual effects, but they cannot restore 'normal hearing'. Therefore the management of expectations and the provision of advice and counselling as the patient adjusts to their hearing aids in order to obtain optimal benefit is paramount.

Services should be able to provide timely and authoritative audiological assessments for adult patients followed by ongoing high-quality hearing aid fitting and management based on an IMP, with advice on assistive devices and communication tactics, as well as being able to identify the need for referral to others as necessary. There is some evidence in favour of screening for hearing loss in late adulthood; rehabilitation may lead to better outcomes the earlier the intervention is started[25]. Age-related hearing loss in adults is generally gradual in its onset and (in the absence of screening) comes to light only when the patient (or their family) chooses to seek help. When such help is sought, patients should rightly expect reliable assessment and intervention without undue delay. In some cases there will be a higher level of urgency (e.g. following trauma or infection, or when the hearing loss, balance disorder or tinnitus might be symptomatic of an underlying treatable condition such as Meniere's disease or an acoustic neuroma).

3.3.1 Cost-effectiveness of hearing aids for adults

Data from the Health Utilities Index Mark 3 (HUI3)[26] derived from a modernisation programme in England includes utility values before and after fitting of hearing aids. The hearing aids that were used varied from unsophisticated analogue devices in the pre-modernisation service context, through unilaterally fitted digital devices, to bilaterally fitted digital devices in a modernised service context. Extrapolation of the mean incremental cost and mean incremental HUI3 gain over an individual's future life expectancy, discounting future costs and benefits at 6% per annum, yielded an estimated cost utility of between £500 and £1,000 per quality adjusted life year (QALY) gained. Thus, adult hearing aid services show remarkable cost-effectiveness when compared to other health interventions. In summary, 'substantially improved services are available at highly advantageous cost-effectiveness ratios'[1].

3.4 Balance Disorders

Audiologists undertake vestibular assessments, usually in support of ENT clinics where those with balance disorders may be referred by GPs. They may also be involved with, or lead on vestibular rehabilitation. Most patients seen by audiologists for vestibular investigation or rehabilitation are adults; but there is a growing interest in balance disorders in children, particularly those with hearing loss.

A UK report on balance services estimates that 30% of the population will experience symptoms of dizziness or imbalance by the age of 65 years[27]. Although most of these will not attend their GP, it may lead to referral to a specialist balance unit where one exists. It is the most common cause for visits to a GP by patients over 75 years of age.

The lifetime prevalence of vestibular vertigo was estimated at 7.8% by Neuhauser et al[4]. Vertigo as opposed to non-specific dizziness causes more significant distress and disability and usually results in medical assessment and referral to specialist services.

Those with vestibular disorders are at greater risk of falls which can result in significant disability to the individual and have a significant economic impact. The best practice guidelines to prevent falls and fractures in an ageing population have been set out in a recent HSE report[28]. The current yearly economic cost of falls in older people in Ireland is estimated at approximately €400m.

3.5 Tinnitus

Audiologists and ENT Departments receive referrals for patients whose major complaint is tinnitus, which may 'stand alone' as a symptom or which is often associated with hearing impairment. It may also be associated with other medical conditions which require medical, surgical or clinical management such as acoustic neuroma. An MRC study of ENT symptoms[5] in the UK showed that 36% of adults had tinnitus at the time of the study and that prevalence increased with age. Tinnitus lasted for more than 5 minutes in 13.2% and was there most of the time in 4% of the study population.

The accurate assessment of the nature of the tinnitus is important to ensure that underlying conditions are identified, and appropriate treatment to help the individual manage their tinnitus is initiated. Treatment may include cognitive approaches to therapy, advice on management, and/or noise-making devices which counteract the internal noise of the tinnitus.

Many patients with tinnitus can suffer from concurrent psychological distress which may require appropriate health professional input. They may also complain of sleep disturbance and problems with concentration.

CHAPTER 4: EXISTING SERVICES

4.1 Historical Background

For many years, audiology services in Ireland were provided by the National Rehabilitation Board (NRB) with few, if any, hospital-based services available around the country. Typically, the NRB service provision was split between children and adults. The adult service was largely one of hearing aid provision for older people with medical cards. As hospital-based audiological services were nonexistent in most areas, local ENT consultants would often refer patients for audiological assessment to the NRB and usually the NRB staff tried to facilitate this demand in addition to their own existing workload. The children's service provided both diagnostic assessment and habilitation services (including hearing aids) to children up to third level education, with referrals from a wide variety of sources including public health nurses, ENT consultants, GPs, Senior Area Medical Officers (now Community Health Doctors) and speech and language therapy services.

The adult service was usually provided by what were then known as audiology technicians. For complicated reasons connected with titles and qualifications in the UK, those providing adult services became known as 'audiologists' (nongraduate or graduate qualifications) and those providing children's services became known as 'audiological scientists' (postgraduate qualifications). This confusing distinction is still in place, but (unlike the UK) these are not protected titles with statutory registration, and a variety of qualifications is to be found within these groups. All formal training has been achieved by self-funding or by sponsorships to training programmes (postgraduate, graduate and non-graduate) abroad, mainly in the UK.

The National Rehabilitation Board (NRB) provided many services for people with disabilities across Ireland, including audiology. Under its remit the audiology service provided the following services;

- Hearing aid clinics for adults with medical cards and all children up to third level education
- An earmould service
- A hearing aid repair service
- Support for staff training in audiology
- In-house training in sign language for staff.

The NRB Audiology clinics were based in three main areas around the country:

- Dublin – covering the East Coast from Louth to Wexford
- Galway – covering from Donegal to Galway
- Cork – covering the South West Ireland.

In 2000, the NRB was dissolved and responsibility for its functions was transferred to a number of successor organisations/statutory bodies, with the audiology element of services being taken over by the Health Boards and later by the HSE as community audiology services, which are managed primarily by designated non-clinical administrators.

Hospital-based audiology departments were almost nonexistent in the 1970s, with the audiologists in the Eye and Ear Royal Victoria Hospital in Dublin providing a nationwide referrals service for ENT specialists who needed detailed audiological assessment of their patients. Gradually, hospital-based services began to develop around the country and a number of departments were established, due predominantly to the efforts of individual ENT Consultants who required the development of a local diagnostic service. Today, most of these departments are staffed by audiologists, some of whom qualified under the old non-graduate system and others who have been through graduate or post-graduate training. They support ENT clinical activity, providing audiological assessments for adults and children referred to ENT with possible hearing or balance problems; some departments provide diagnostic audiology for non-ENT health professionals within the hospital setting. Hospital-based services do not provide hearing aid services, for which patients have to be transferred to community audiology services.

4.2 Current Audiology Services: Public sector provision

Thus, for largely historical reasons, the HSE audiology services are currently delivered by two distinct services – Acute Audiology services and Community Audiology services. This has led to many unhelpful practice anomalies in the system, such as;

- Audiologists in Acute Services provide audiology services to children and adults, whereas audiologists in Community Services provide services only to adults, with children's services having to be delivered by audiological scientists
- Hearing aid services to adults and children are available only through community services
- Duplication of assessment across the two services occurs when clients have to access both community and acute services
- Inefficient patient journeys at which long waiting times can prevail at particular points
- Salary anomalies, with staff undertaking similar scopes of practice on different pay scales and different terms and conditions.

4.2.1 Acute Audiology Services are based on diagnostic activity, rather than (re)habilitative activity; and includes age groups from newborn infants onwards. Audiologists in the acute service identify hearing loss or vestibular (balance) abnormality, they employ various assessment techniques based on subjective responses from patients, and otoadmittance, electroacoustic and electrophysiological measurements of auditory function and dysfunction. In three areas of the country (Galway, Sligo/Letterkenny, and Kerry) acute audiology services have pioneered stand-alone newborn hearing screening in the maternity hospitals/units.

4.2.2 Community Audiology Services have traditionally offered assessment and rehabilitation for GMS (Medical) Card Holders and, separately, for children. The following audiology services are provided:

- Audiological assessment
- Aural rehabilitation, and hearing aid fitting and management advice
- Impression-taking for earmould manufacture
- Advice on the use of assistive listening devices (ALDs), and discussion of rehabilitative options
- Onward referral to acute ENT, Cochlear Implant Programme, Speech and Language Therapy or other services as appropriate
- Referral of children with a hearing loss to the Visiting Teacher services
- As part of the transfer of staff and functions from the NRB to the former Health Boards and now to the HSE, former NRB administrative staff have historically provided minor hearing

aid/earmould repairs (e.g. re-tubing). In some areas, this practice continues to be provided on a "walk-in basis" for clients.

The National Audiology Managers Liaison Group was established in 2000 (when the NRB was disbanded) comprising representatives from each of the former Health Board areas. The Group met bimonthly to discuss 'issues of common interest regarding audiology' including finance, hearing aids, staffing, and the audiology database.

4.2.3 Entitlement

Under the Health Act 1970 children and young people up to 18 years are entitled to access HSE audiology services free of charge; this covers screening, assessment, diagnostic and related investigations, treatment, (re)habilitation, and devices (hearing aids, cochlear implants, etc). Other than cochlear implants, this entitlement ceases upon third level education, even for those who have had severe or profound deafness from birth.

All adults (with or without a medical card) can access acute-based ENT services and associated audiology assessments free of charge. Adults and children with a medical card who require a hearing aid are entitled to be referred to community audiology service for a hearing aid which is covered under the scheme. The GMS (medical card) scheme currently applies to 1,533,511 people, who are deemed to be eligible for services, if required, free of charge under this scheme. This approximates to 36% of the national population.

Section 67 of the Health Act, 1970 places a statutory obligation on the HSE to make an aural service available to patients with full eligibility (medical card holders) and persons with limited eligibility (the remainder of the population). In the interest of equity patients attending an ENT clinic on a private basis should not be given preferential treatment in terms of access to the public audiological service. Patients (with or without a medical card) may choose to see an ENT Consultant privately in order to avoid long waiting times. Since most audiological assessments for such private patients are carried out 'on demand' by audiologists in acute hospital settings, where the equipment and appropriate test conditions are to be found, it is the ENT out-patient department waiting list which applies. There should be a common waiting list for the service and referrals should be placed on that list by reference to the agreed criteria. Therefore the fact that a referral is arising as a consequence of a patient's attendance at a private ENT clinic should not, in itself confer a priority status over other referrals to the public audiological service .

There is good anecdotal evidence that this rule is not being enforced in all hospitals with private patients having their assessment done in public hospitals 'on demand', thus increasing the waiting time for non-private patients including children who have been referred to ENT services because of suspected hearing impairment.

4.2.4 Screening

Screening is defined as a process whereby apparently healthy people are offered a test to identify those who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition. There are internationally accepted criteria[29] which guide the selection of conditions for screening and for delivering screening as part of a well-organised programme to ensure that more benefit than harm is achieved. Newborn hearing screening is recognised internationally[30,31] as one such condition.

There are no (full) population screening programmes for adult hearing impairment in Ireland.

For babies, there is the 'Infant Distraction Test (IDT) screen' (a behavioural test of hearing, based upon the child's ability to turn to a sound) usually performed by Public Health Nurses on babies at around eight months of age. In some areas where a baby fails the distraction test screen a further test is undertaken by the Community Health Doctor in a second tier clinic and if the baby fails the second test he/she is referred for further assessment. There are no national data on coverage or refer rates, and no nationally-agreed case definitions.

At school entry, there is a hearing screening test based upon the pure tone audiometry 'sweep' test performed by Public Health Nurses. There are no national data on coverage or refer rates, and no nationally-agreed case definitions.

Systematic reviews in the UK have raised serious questions about the 8-month IDT screen[12] and led to its abandonment and the introduction of newborn hearing screening. The review of the school entry screen in the UK[13] has confirmed its use in the short term but long term confirmation of its role will depend upon the outcome of currently commissioned primary research.

There is no national programme of newborn hearing screening in the Ireland; it has however been pioneered in three areas through the efforts of local acute-service clinicians (Galway, Sligo/Letterkenny, Kerry). The screen is based upon automated otoacoustic emissions (OAE) and/or automated auditory brainstem response (AABR) tests performed at the bedside in the maternity hospital before baby and mother are discharged home. Some limited performance data are available[32].

4.3 Current Audiology Services: Private Sector Provision

According to the Irish Society of Hearing Aid Audiologists (ISHAA) there are thought to be some 300 hearing aid audiologists (some part-time) providing hearing aids to adults in the private sector, based mainly in high-street premises (ISHAA, personal communication, May 2010). About half of these are members of ISHAA which, *inter alia*, runs voluntary regulation based upon the requirements for statutory registration of hearing aid audiologists in the UK, and manages a system of continuing professional development (CPD).

Self-referral to hearing aid audiologists is typical. Adults who have paid full contribution PRSI for at least two years are entitled to a grant from the Department of Social Protection towards the cost of purchasing hearing aids in the private sector, up to €760 per aid every two years. The average cost in the private sector is approximately €1600 per aid, including rehabilitative support, advice and warranty on the device.

Some ENT Consultants run private services which include basic audiological assessments performed by themselves or by audiologists employed by them. There are a number of private practice audiologists and audiological scientists in Ireland who provide diagnostic services, taking self-referrals and referrals of private patients from ENT Consultants. Some of these audiologists also work in the public sector, either fulltime or part time.

4.4 Current Audiology Services: Voluntary Sector Provision

There are a number of voluntary organisations including DeafHear, the Irish Hard of Hearing Association, the Irish Deaf Society, and an online information service that can be accessed at www.irishdeafkids.ie, providing support for hearing impaired children and their families, and adults with hearing impairment. Deafhear is the largest provider of such services and reported that 32,546 people used its services in one way or another in 2008[33]. DeafHear receives significant funding from the HSE (approximately €5m (DearHear, personal communication, May 2010) of their reported €6 million annual income in 2008[34]).

The services offered by these organisations include family and support services (social work, counselling, respite and family activities), assistive technology and assistive listening devices, communication therapy and lipreading classes, information and advice, sign language classes, and a mental health and deafness service[33]. These organisations receive funding in two ways from the HSE, through local grants of varying amounts and/or direct funding. Each organisation may have a single or multiple SLA in place with each SLA setting out particular performance arrangements. There is a need in the context of a single unified HSE to bring congruence to these "piecemeal" arrangements. It is necessary to co-ordinate and structure these arrangements to ensure value for money, consistent with the service priorities as set out in this report.

4.5 Staffing of the Public Sector Audiology Services

Staffing level details of the public sector audiology services were obtained through an information request issued to all audiology services seeking the position at that time in relation to staffing numbers. This request was prompted due to the non-availability of standardised national data on WTE (whole time equivalent) positions and their status in audiology services. These indicative data therefore have been provided by local audiology managers drawing on best available local knowledge.

Currently there are reportedly approximately 66 WTE 'Audiologist' or 'Audiological Scientist' posts providing HSE's audiology services for children and adults across community, acute and voluntary sectors (see Table 4.5). There are three grades of Audiologists working in Community Audiology Services: Basic, Senior and Chief. Community Audiology Services for children are provided primarily by Audiological Scientists. There is no national pay and grade structures for Audiological Scientists. Current pay scales (as at January 2010) are shown in Tables 4.1.

Table 4.1 Audiology staff pay scales as at January 2010

Post Name	**First Point**	**Last Point** (incl. LSI where applicable)
Chief Audiologist	€48,321	€62,113
Senior Audiologist	€41,808	€48,321
Audiologist	€33,005	€39,830
Principal Audiological Scientist (aligned to Principal Physicist)	€76,277	€103,496
Senior Audiological Scientist (aligned to Senior Physicist)	€60,795	€84,862
Audiological Scientist (aligned to Physicist)	€39,435	€61,893

There are no competency-based Scopes of Practice for these differing grades or titles.

There are no staff at 'assistant' level in the service, and no associated Scope of Practice for such.

A small number of staff have an additional qualification in Hearing Therapy, a specialism within audiology which focuses on the rehabilitative needs of adults with hearing or tinnitus problems from a counselling and therapeutic perspective. This is an important aspect of audiology dealing with expectations and psychosocial adjustment.

4.6 Clinical Governance in the Public Sector Audiology Services

Clinical governance for acute audiology services is provided via the ENT Consultant-led service and acute audiology services to date have been considered a component part of the overall ENT service.

Clinical governance is limited or non-existent in the community audiology services and in many cases clinicians work in isolation. There is administrative management of the service in most areas.

Clinical governance of children's hearing screening programmes is undefined. The three stand-alone newborn screening programmes are within acute sector audiology services and are therefore ENT Consultant-led and clinically governed by this arrangement.

4.7 Support for Children with PCHI: Linkage with the Visiting Teacher Service

The Visiting Teacher (VT) service for children and young people with a hearing or visual impairment is provided by the Department of Education and Skills from the time of referral through to third level education[35]. Each VT is responsible for a particular region and is allocated a caseload of children. The VT supports the children, parents/guardians, teachers and other professionals involved with the child. The nature and frequency of visits will depend on a range of factors, including the age of the child, severity of impairment, educational placement and individual learning needs. The service is available at pre-school, primary, post-primary and at third level. Such a service may include:

- Guidance and support to pre-school children and their parents in the home, including unbiased information to support parents in making informed choices for their child
- Specialist teaching, support and monitoring of progress
- Advice on curricular and environmental implications, including the use of assistive technology
- Supporting, advising, training and liaising with parents, teachers and other professionals
- Ensuring reasonable accommodations are provided to post-primary students by the State Examinations Commission
- Advising and liaising with disability and access officers to ensure appropriate supports at third level.

Referrals to the VT service are accepted from:

- Parents
- Schools
- HSE Audiology Services
- Speech and Language Therapy services

- Cochlear Implant Programme
- National Association for Deaf People
- National Council for Special Education.

Visiting Teachers supporting children with PCHI are qualified teachers with a further qualification at postgraduate Diploma or Masters level in deaf education, most commonly attained by attendance on one of the UK programmes. (There is no longer a training programme in Ireland). The deaf education training is usually generalist, covering the needs of all age groups from preschool to secondary.

Currently there are 29 WTE Visiting Teacher posts. Data from the HSE indicate that at June 2010 there were 3,739 children (preschool through to secondary) wearing hearing aids that had been issued via HSE services (very few children obtain hearing aids from the private sector)[X]. For a child population of approximately 1.15m (2006 census) this suggests a prevalence of PCHI of around 3.1 per 1000—a figure broadly in line with prevalence evidence from elsewhere. The implementation of newborn hearing screening, when it occurs, will have important consequences for the distribution of the ages in the caseload, affecting the type and complexity of issues to be addressed, although limited effect on total numbers (since children with PCHI are identified eventually, albeit late).

4.8 Registration Issues; the Health and Social Care Professionals Council

Statutory registration of a profession is an accepted route towards protecting the public from possible harm caused by poor or dangerous practice, and to ensuring high standards of training and practice within a profession. There is currently no requirement for the registration of audiologists, audiological scientists, or hearing aid audiologists in Ireland. In the absence of registration, there is nothing to prevent an individual from practicing as an audiologist, audiological scientist, or hearing aid audiologist irrespective of qualifications and competencies.

The Health and Social Care Professionals Council (Coru) was established in 2007 to set up statutory registration for the following 12 professionals:

- Clinical Biochemists
- Medical Scientists
- Psychologists
- Occupational Therapists
- Chiropodists/Podiatrists
- Dieticians
- Orthoptists
- Social Care Workers
- Physiotherapists
- Radiographers
- Speech & Language Therapists
- Social Workers

The National Social Work Qualifications Board, the Pre Hospital Emergency Care Council (PHECC) (regulators of Emergency Medical Technicians, Paramedics and Advanced Paramedics)

[X] National Audiology Database 2010

and the Opticians Board (regulators of Optometrists and Dispensing Opticians) will join the Council within the next 18 months to 2 years. Statutory registration will apply across public, voluntary, and private sectors. It is accepted that statutory registration will protect the public by promoting high standards of education, professional conduct and competence. The legislation protects titles and indicates that only suitably qualified people can use certain titles, as well as allowing the establishment of codes of conduct and ethics; standards of proficiencies, education and establishes the means to deal with complaints, inquiries and discipline.

As each registration board opens for the first time, there will be a two year "grandparenting" period, to allow current practitioners who have been working for a minimum period of time to be considered for the registers even if they do not have the prescribed educational approved courses or relevant experience. After this period, only people meeting the established criteria will be able to register.

It is planned to open the first register by the middle of 2011 (for Social Workers) and it is anticipated that it will take another 2 ½- 3 years to establish the remaining professions, including the transfer of the other two agencies, subject to resources. Coru has acknowledged a request from the Irish Society of Audiology (ISA) for the registration for Audiologists and from ISHAA for the registration of Hearing Aid Audiologists.

The Act does allow for the Minister for Health and Children, if he or she considers it to be in the public interest and after consultation with the Council, to designate a health and social care profession for statutory regulation, once they meet the following definitions and criteria as laid down in the Act (Part 1 Section 4):

A Health and Social Care Profession is any profession in which a person exercises skill or judgement relating to any of the following health or social care activities:

- The preservation or improvement of the health or wellbeing of others
- The diagnosis, treatment or care of those who are injured, sick disabled or infirm
- The resolution, through guidance, counselling or otherwise, of personal, social or psychological problems
- The care of those in need of protection, guidance or support.

The Minister will also have regard to the following factors:

- The extent to which the profession has a defined scope of practice and applies a distinct body of knowledge
- The extent to which the profession has established itself, including whether there is at least one professionals body representing a significant proportion of profession's practitioners[XI]
- The existence of defined routes of entry into the profession and of independently assessed entry qualifications
- The profession's commitment to continuing professional development

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[XI] Most of the Audiologists and Audiological Scientists employed by HSE are members of the Irish Society of Audiology; about half the Hearing Aid Audiologists in the Ireland are members of the Irish Society of Hearing Aid Audiologists

- The degree of risk to the health, safety or welfare of the public from incompetent, unethical or impaired practice of the profession.

Note that the Minister will only be in a position to consider new professions once registers have been established for the 12 designated professions.

4.9 Initial Training for Audiology Professionals

Audiology is the study of, prevention of, assessment of and intervention for disorders of audition, hearing and balance in children and adults. It is therefore a large field deriving knowledge and competencies from a wide range of component disciplines: psychology, child development, geriatrics, social science, epidemiology, physics, acoustics, psychoacoustics, genetics, medicine etc.

In developed countries, training in audiology is largely at graduate, postgraduate or professional doctorate levels. In the US, Canada and South Africa basic pre-registration training is via a BSc degree in Audiology and Speech-Language Pathology; in the US this is now followed by a Professional Doctorate (AuD) which leads to full clinical competence and registration. In Canada, the AuD route exists side by side with the previous postgraduate MSc route to registration. In Australia and New Zealand, a suitable first degree (e.g. Psychology, Speech and Language Therapy, Physiology) is necessary for access to a two-year postgraduate MSc in Audiology leading to full registration.

There are no initial training programmes for audiology in Ireland. Thus, audiology services in Ireland have either to recruit from overseas or second suitable people onto initial training programmes abroad, invariably the UK. The following training routes were/are available in the UK:

- BAAT (British Association of Audiology Technicians) Parts 1 and 2: leading to qualification as an 'Audiologist'. This route was discontinued in 2004.
- BSc Audiology: Introduced in 2002. Four year degree, accredited by the British Academy of Audiology (BAA), including clinical competence for adult diagnostic and rehabilitative practice, and for routine practice with older children. This leads directly to registration as a Clinical Physiologist and employment as an 'Audiologist'. It also covers and includes registration as a Hearing Aid Audiologist.
- MSc Audiology: Introduced in 1974. One year theoretical training with limited practical components for those with a suitable first degrees (or suitable experience and alternative qualifications). For registration as a Clinical Scientist and employment as an 'Audiological Scientist', the MSc has to be supplemented by a further three years of work-based supervised practical training culminating in practical and written examinations run by the BAA and the Association of Clinical Scientists (ACS). Since 2005 it has covered and includes registration as a Hearing Aid Audiologist.
- Hearing Aid Council examinations following pre-registration as a Hearing Aid Audiologist (HAA) and supervised employment with a registered HAA led to registration as a HAA, and practice as an independent hearing aid dispenser in the private sector. This route was closed in 2008.
- Foundation Degree in Hearing Aid Audiology. Introduced in 2007, a two year 'Foundation' degree, largely work-based, leading directly to registration as a Hearing Aid Audiologist.

As a result of recruiting from overseas, seconding people to UK programmes, the complexity and changing format of UK programmes, the lack of a registration framework in Ireland, and the historical duality of services in Ireland, the Irish audiology workforce has a variety of backgrounds, training and qualifications.

4.10 Audiology Waiting Lists, Activity, Staffing and Finance Information

As part of the information request referred to earlier (see section 4.5) a request was issued to all audiology services requesting information at that time in relation to waiting lists, activity data, WTE and finance data. However, it should be noted that the information detailed reflects **indicative figures only** as many of the audiology services do not routinely collate waiting list or report on activity information. Therefore, it is not possible to provide accurate or comprehensive information on finance, staffing, waiting lists or activity data for audiology as systems are not in place in all services to maintain or report on this information at local level. However every effort has been made by local services to provide approximate information.

4.10.1 Audiology Waiting Lists

4.10.1.1 Acute Audiology Service – Waiting Lists

From collation and review of local acute audiology services, it is evident that there is no consistent approach to the maintenance of audiology waiting list data or activity data. It appears that there is no application of consistent data definitions in line with local waiting list or agreed definitions for activity data maintained across the services. In the main, audiology waiting list data or activity data are not reported as a unique entity across the acute services, or broken down between public or private mix for local acute management review, but are simply included as part of ENT services under relevant Directorates. What data are available indicated approximate ENT waiting times of between three and 36 months for children's ENT appointments, and between three and 48 months for adult ENT appointments; and for audiology appointments, three weeks to 36 months for children and three weeks to 48 months for adults.

4.10.1.2 Community Audiology Service – Waiting Lists

The Community Audiology Service has developed a national dataset for the collation of waiting list activity. However, the collation of these data to reflect a national position is not routinely undertaken as it is not required for inclusion under any of the national datasets collated for HSE Management or Board review. The last routine collation of community waiting list data was June 2008. The Hearing Service in North Great George's Street and the National Audiology Managers Liaison Group are the main repositories for community audiology information. The national community audiology database has experienced systems failures over the past number of months and the integrity of the data is cited as being uncertain by clinicians. There is no national co-ordination of data and no identified individual in a national context responsible for the routine monitoring and management of the community audiology service. Responsibility for the service is at Regional level but data are not routinely collected at this level. Table 4.2 summarises the waiting list data obtained from the national community audiology database, following the information request from the NARG in October 2009.

Table 4.2. Community Audiology summary indicative waiting list data, as at end of October 2009.

	Numbers awaiting initial assessment*					**Numbers awaiting hearing aid fitting following assessment****					**Numbers awaiting review assessment (inc. hearing aid reviews)*****				
	Months on list					**Months on list**					**Months on list**				
	0-3	**4-6**	**7-9**	**10+**	**Sub Total**	**0-3**	**4-6**	**7-9**	**10+**	**Sub Total**	**0-3**	**4-6**	**7-9**	**10+**	**Sub Total**
Child 0-4 years	1,127	729	609	1,699	4,164	14	0	0	2	16	591	177	237	1,250	2,255
Child 5-17 years	688	386	260	1,915	3,249	57	2	0	0	59	508	245	176	1,497	2,426
Adults 18 +	1,034	704	463	753	2,954	1,228	252	27	125	1,632	1,763	956	675	2,231	5,625
	2,849	1,819	1,332	4,367	**10,367**	1,299	254	27	127	**1,707**	2,862	1,378	1,088	4,978	10,306

**Numbers Awaiting Service* relates to the number of new referrals on the Community Audiology Database on the last day of any month

***Numbers Awaiting fit following assessment* relates to the number of clients who have had an assessment of hearing loss by a Community Audiologist and are awaiting the fitting of hearing aids by the last day of any month

****Numbers Awaiting Review* relates to the number of clients who have had an assessment of hearing by a Community Audiologist who need to return for a review of their hearing status.

The following points are evident from Table 4.2 compared with a previous data report of June 2008:

- There were 4,164 children (0-4 years) awaiting an initial assessment as compared to 3,214 in June 2008.
- There were 3,249 children (5-17 years) awaiting an initial assessment as compared to 4,099 in June 2008.
- There were 2,954 adults awaiting an initial assessment as compared to 3,921 in June 2008.
- There were 16 children (0-4 years) awaiting hearing aid fitting following assessment as compared to 22 in June 2008.
- There are 59 children (5-17 years) awaiting hearing aid fitting following assessment as compared to 74 in June 2008.
- There are 1,632 adults awaiting hearing aid fitting following assessment as compared to 1,131 in June 2008.
- There are 2,255 children (0-4 years) awaiting a review as compared to 1,517 in June 2008.
- There are 2,426 children (5-17 years) awaiting a review as compared to 4,891 in June 2008.
- There are 5,625 adults awaiting a review as compared to 8,271 in June 2008.

As at October 2009, there were approximately 22,380 patients (12,169 children and 10,211 adults) waiting on community audiology waiting lists compared to 27,140 in June 2008.

4.10.2 Audiology Activity Data

4.10.2.1 Acute Audiology Service Data

From review of local acute audiology services activity data, it is evident that there is no nationally consistent approach to the maintenance of audiology activity data. Similarly, there is no application of consistent data sets across acute based audiology services. Audiology activity data are not requested or reported independently. The structure of the data does not take account of public or private activity.

4.10.2.2 Community Audiology Service Data

Table 4.3 shows the activity data for the month of October 2009[XII] in community audiology services.

Table 4.3 Activity data for community audiology services (for October 2009)

From 1st - 31st October 2009	Numbers receiving initial assessment	Numbers receiving fitting service	Numbers receiving review service	Number of hearing aids issued	Number of DNAs	Total Activity in month
Children 0-4 years	425	85	211	105	93	**721**
Children 5-17 years	183	49	281	30	94	**513**
Adults 18 +	915	608	887	529	267	**2,410**
	1,523	**742**	**1,379**	**664**	**454**	**3,644**

In June 2010, the PCCC audiology database indicated that there were a total of 71,750 adult clients with hearing aids fitted by HSE audiology services. Additionally there were 3,321 children between 4 and 17 years of age, and 418 children under four years of age[XIII]. Based on 2006 population statistics, for children this equates to a rate of 3.72 aided children per 1000, which is broadly in line with estimated prevalence rates for PCHI. For adults, it equates to approximately 2.2% of the adult population fitted with hearing aids by HSE audiology services. Based on data, from table 2.2 this is lower than the estimated 8% of the population with a hearing loss that can expect improvement in their quality of life from modern DSP hearing aids. However, some will choose not to pursue this option, and in any case, some 34% of adults have a medical card (and can therefore access HSE community audiology services). Thus, the 2.2 % adult fitting rate looks on this basis to be not unreasonable. There are, of course, other important markers of a satisfactory service, not least of which is the extent to which clients are making use of their hearing aids, how well they are fitted acoustically, how many are modern DSP aids, and ultimately the extent to which quality of life is being improved. This type of information is regrettably not available.

4.10.2.3 Age at Diagnosis and Intervention for PCHI

A retrospective ascertainment study on PCHI cases born in the period 1985-1990 in Ireland[36] showed that children with congenital PCHI were first referred to diagnostic services at a median age of 11.3 months for severe/profound loss and 18.7 months for moderate hearing loss. Fitting of hearing aids subsequently occurred at 20.7 months and 49 months respectively.

A more recent ascertainment study in South East Ireland, including counties Kilkenny, Carlow, South Tipperary, Waterford and Wexford (Pitt T., unpublished data submitted to the Review) used the PCCC database and Visiting Teacher records to identify all children with congenital PCHI born between January 1997 and December 2002 (n=36). The median ages in months at referral and

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[XII] October 2009 is the point in the National Audiology Review Group's work at which this information was requested
[XIII] HSE National Community Audiology Database

fitting of hearing aids is shown in Table 4.4. These are compared with similar data from England following the introduction of newborn hearing screening (n=143)[11].

Table 4.4 Median ages at referral and fitting of hearing aids for children with PCHI in South East Ireland 1997-2002 (T Pitt study), compared with similar data from England since the introduction of newborn hearing screening

	Median age at referral (months)		Median age at hearing aid fitting (months)	
	Moderate PCHI	Profound PCHI	Moderate PCHI	Profound PCHI
SE Ireland study:	34.2	16.8	60.0	24.0
England study:	1.0*	1.3*	6.0	3.8

(* the figures from England refer to age at first diagnostic assessment; referral from newborn screening is within a few days of birth).

4.10.3 Community and Acute Audiology Services Summary Staffing Data

Information provided by local audiology services to the review process indicated that there were approximately 35.36 WTE audiologists/audiological scientists/clinical engineering technicians providing community audiology services and 35.16 WTE audiologists/audiological scientists providing acute audiology services[XIV] (Table 4.5).

Information provided to the review at that time indicated that there were 6.34 unfilled audiology posts in the community setting.

Table 4.5 Actual Community and Acute Audiology Service Staffing WTE as reported by local services at October 2009.

	Community	**Acute**	**Total**
Current Staffing Position - October 2009	**No of Audiologist employed (WTEs)**	**No of Audiologist employed (WTEs)**	
Audiologists	13.06	9.3	22.36
Senior Audiologist	7.3	10.2	17.5
Audiological Scientist (incl. Senior)	8.6	7.5	16.1
Chief Audiologist	2.4	7.66	10.06
Clinical Engineering Technicians	4	0	4
Associate Audiologist	0	0.5	0.5
	35.36	**35.16**	**70.52**

4.10.4 Acute and Community Audiology Services Summary Financial Data

4.10.4.1 Acute Audiology Finance

Acute audiology budgets in most services are included in the overall ENT budgets, and disaggregation for many acute audiology services is not possible. It is therefore not possible to provide the definitive national acute audiology budget. Only three acute audiology services were in a position to provide an overview of their devolved financial budgets, which totalled

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[XIV] Audiology WTE information obtained October 2009 approximately €327,202. These areas cover 8.9% of the national population (2006 Census), and were used to calculate an extrapolated approximate estimate of what the total acute audiology budget might be: €3.7 million.

4.10.4.2 Community Audiology Finance

Indicative community audiology financial information was obtained from each of the local services in October 2009. At that time, the national budget position was as follows for the year 2009:

- Pay - €3,250,020
- Non-Pay - €314,503

Based on current trends at that time, it was forecast that local community budgets would be in an end of year deficit with no expected supplementary funding available to meet this deficit and therefore this deficit being a reported first charge on 2010 budget allocations.

4.11 Hearing Aids, Hearing Aid Repairs and Earmoulds: Central Activity and Budgets

The budget for the purchase of hearing aids, earmoulds and accessories is managed and reported by HSE North East on behalf of the national community audiology services. Periodic reports are issued via the National Audiology Liaison Group to Community Audiology Managers with a view to managing hearing aid budgets locally.

The total national budget for hearing aids, earmoulds and accessories in 2010 is €1,596,180. The spend on these items in 2009 is shown in Table 4.6, broken down by area and children/adults. It should be noted that budgets for the provision of hearing aids, earmoulds and accessories were not moved to reflect new HSE structures but are instead reflective of geographic former health board areas. This has led to a lack of ownership and accountability for the provision of this service.

Table 4.6 2009 National expenditure (€) on hearing aids, accessory, moulds, remakes and BAHA repairs. (Percentages rounded to nearest decimal point)

	Allocated Budget	*Adult*	*Children*	*Accessories*	*Moulds*	*Remakes*	*BAHA Repairs**	*Total Expenditure*	*Under/ Over(-) Spend ***
West	156,686	97,582	50,038	4,180	12,627	686	641	165,755	-9,068
% spend of total expenditure	%	59	30	3	8	0	0	100	
Midlands	86,324	82,404	9,318	4,494	5,435	809	0	102,459	-16,135
% spend of total expenditure	%	80	9	4	5	1	0	100	
East	481,856	332,027	55,563	14,886	25,983	404	634	429,496	52,360
% spend of total expenditure	%	77	13	3	6	0	0	100	
Mid-West	116,549	210,778	26,116	8,464	11,537	81	0	256,976	-140,427
% spend of total expenditure	%	82	10	3	4	0	0	100	
North East	146,470	136,773	14,381	7,286	12,009	485	335	171,269	-24,799
% spend of total expenditure	%	80	8	4	7	0	0	100	
North West	139,293	145,579	17,733	8,149	16,276	207	0	187,944	-48,651
% spend of total expenditure	%	77	9	4	9	0		100	
South East	212,458	171,081	30,320	12,511	9,172	1,042	0	224,126	-11,668
% spend of total expenditure	%	76	14	6	4	0		100	
Southern	256,544	228,952	118,768	11,811	24,070	1,131	0	384,732	-128,188
% spend of total expenditure	%	60	31	3	6	0		100	
Total	**1,596,180**	**1,405,176**	**322,237**	**71,781**	**117,108**	**4,845**	**1,611**	**1,922,757**	**-326,577**
National % spend		**73**	**17**	**4**	**6**	**0**	**0**	**100**	

** there is no budget allocation for BAHA repairs*

*** The following areas provided additional budget allocation in 2009 to fund overspends – MidWest €100,000, North West €30,000, Midland €10,937*

Hearing aids that are provided through HSE's Community audiology services to medical card holders are purchased via a central contract, allowing larger volumes to reduce device costs. Actual device costs are somewhat higher than those supplied to the UK NHS, the largest purchaser of hearing aids in the world. The estimated costs in 2009 associated with the provision of bilateral DSP hearing aids and necessary rehabilitation for adults in the UK NHS were in the order of £350, of which less than half were costs attributable to the devices (Davis A, personal communication 2010).

The current contract in Ireland (due for renewal in 2011) includes analogue aids as well as Digital Signal Processing (DSP) aids; the successful tenderers are Widex (formerly Bonovox), Unitron, Puretone and Acoustic Technologies. Postaural and in-the-ear options are available on the contract. About half of the adults fitted by HSE have in-the-ear analogue aids; however, this is changing quite rapidly with the introduction of postaural DSP hearing aids.

Most if not all children in the service are now wearing postaural DSP hearing aids. The features and requirements (for example, size, colour options, and signal processing capabilities) for children's hearing aids will be different from those for adults. In addition children will very often benefit from access to personal FM systems which improve the signal to noise ratio in adverse acoustic conditions such as the home, nursery, or classroom. The personal FM system has to be appropriately integrated with the child's hearing aids, which is not a trivial matter particularly since the advent of DSP hearing aids.

Personal FM systems are provided by Education services since in their original form they were regarded as educational aids. Following the establishment of the National Council for Special Education all applications for special equipment must be submitted by school management authorities to the Special Educational Needs Organiser (SENO) with assigned responsibility for the school. In relation to pupils with hearing impairment the Visiting Teacher service assesses and gives advice to the SENO. The SENO takes account of the VT recommendations when considering applications for equipment for individual pupils. The SENO considers the application in the light of the needs of the pupil, the school facilities and the criteria laid down for provision of grants for equipment. The SENO will decide whether to recommend that grant aid be made available to the school by the Department of Education and Skills (DES). If agreed, the school purchases the equipment which then becomes the property of the school, and the school's management authority has responsibility for the maintenance, repair and insurance of the equipment.

The provision of earmoulds is organised through a contract with a single supplier. Currently this is awarded to Starkey Laboratories. In one month of 2010 (February), 752 impressions were taken nationally (588 adult and 144 child). The cost of manufacturing the finished earmoulds ranged from €8.50 to €13.50. When impressions are taken they are sent from the service that took them direct to the manufacturer in England; the finished earmoulds are returned to the same service and an appointment given for fitting. Typical delays within this system are currently as follows[XV]:

Children:

Sent to Manufacturer:	Mainly 1-2 days / some cases a week after impression is taken
Returned from Manufacturer:	Between 7-10 days

[XV] However, note that some of the comments from parents (see Appendix A) show that on occasion the earmould service has broken down to the extent that the parents purchased earmoulds privately at very great expense

- Next Available Appointment: Average 4 weeks (dependant on each area &availability of appointments)

Adults:

- Sent to Manufacturer: Mainly 1-2 days / some cases a week after impression is taken
- Returned from Manufacturer: Between 10-14 days
- Next Available Appointment: Average 3 weeks or more (dependant on each area &availability of appointments)

The main role of the Technical Support Services Team based at North Great George's Street in Dublin, is to provide a national hearing aid repair service. Staff here are trained and certified to repair all types of hearing aids to the manufacturer's specification. This training is provided by the successful hearing aid tenderers as part of the contractual arrangement. Repairs are achieved as follows:

- Patients with access to Dublin can avail of a walk-in service during office hours Monday to Friday
- Other local audiology services nationally use postal services to send the aid(s) to the national repair service, which repairs and returns them by post and
- Clients may also forward by post defective hearing aids directly to the technical support service team.

There are reportedly equal numbers of walk-in repair requests to postal repair requests, with the majority of walk-in requests from the Dublin area. In 2009, repairs on 14,087 hearing aids were undertaken, at a rate of approximately 20 per technician per working day. Repairs range from minor, to complex fault diagnosis and replacement of electronic components, with consequent re-mapping of amplification settings. In some cases the fault lies with the earmould and/or tubing. ITE (In-the-ear as opposed to postaural or behind-the-ear) aids represent a disproportionate number of repairs. In some of the walk-in cases, it is clear to the technical staff that advice, support and/or information are required as well as device repair. All postal repairs are repaired on the day of receipt and returned by next post[XVI].

4.12 Bone Anchored Hearing Aids[XVII]

An implantable bone conduction system (also known as bone anchored processor or osseointegrated auditory implant) is a bone conduction hearing processor where contact with the skull is maintained by surgical implant. It is an amplification system by which sound is conducted to the cochlea via direct bone conduction. Benefits for particular patient groups (e.g. with meatal atresia, chronic suppurative otitis media) include:

- For patients suffering with middle ear disease the implant allows the ear canal to be left open allowing the ear infection to clear
- It is a safe intervention with predictable and reversible outcomes
- Patient compliance has been proven to be extremely high: nearly 90% of patients are reported to wear the devices all their waking hours.

[XVI] Information provided by Technical Support Service based in North Great George's Street

[XVII] Thanks to Nina Reade, Audiologist Scientist, Mater Hospital, Dublin for parts of this section

To date more than 65,000 patients have been fitted worldwide, ranging in age from 18 months to over 85 years of age. In Ireland, 84 patients were fitted with BAHA devices between 2007 and mid-2010 (data from Cochlear Europe, cochlear implant manufacturer). The number waiting to be assessed nationally is reported to be approximately 150 (Reade N, personal communication, 2010), and the expected annual number of patients requiring a BAHA is between 25 and 35.

Costs of BAHA provision in Ireland have not been estimated, but the average cost of BAHA surgery in the UK is approx £7,000 - £8,500; this cost is the one-off price for surgical fees and components. The sound processors themselves range from £1,820 to £2,295. Cochlear Europe recommends that a maintenance plan is also taken out with the purchase of the BAHA, at a cost of about £700 per device per annum for three years.

There is no national funding or procurement contract for BAHAs in Ireland, nor concentration of skills for what is a low-volume, low risk specialty. Surgery is carried out by ENT Consultants with this direct cost funded through acute services ENT budgets. The purchasing and fitting of the sound processor is in some cases undertaken by the community audiology services, however no national budget exists for this service (funding is taken from the hearing aid budgets) and so approval for these aids is limited.

The national technical support service were not empowered by manufacturers to undertake BAHA device repairs, which have to be sent back to manufacturers at a minimum cost of €300.

4.13 Cochlear Implants

There are three target groups that could benefit from cochlear implantation:

- Pre-lingually severely or profoundly deaf children from one year to five years of age
- Post-lingually severely or profoundly deaf children from six to 17 years of age
- Post-lingually deafened adults.

There is good evidence on the benefits of cochlear implantation, and on the added benefit of bilateral implantation for children[37]. Benefit is greater the sooner implantation is effected, within certain limits (e.g. implantation below 12 months of age remains controversial unless strongly indicated for clinical reasons). However, with the significant recent improvements in Digital Signal Processing hearing aids, the choice of whether to implant or to use DSP aids, or indeed to implant one ear and use a DSP hearing aid on the other, is by no means trivial, and depends in part upon the patient's observed progress, or lack of progress, with DSP aids. This presupposes quality fitting and management of the DSP aids—again, not a trivial issue—and a trial period with acoustic hearing aids of at least three months. By way of general advice, guidance from the UK's National Institute for Health and Clinical Excellence[37] states:

'…cochlear implantation is recommended as an option for people with severe to profound deafness who do not receive adequate benefit from acoustic hearing aids…
For the purposes of this guidance, severe to profound deafness is defined as hearing only sounds that are louder than 90 dB HL at frequencies of 2 and 4 kHz without acoustic hearing aids. Adequate benefit from acoustic hearing aids is defined for this guidance as:

- *For adults, a score of 50% or greater on Bamford–Kowal–Bench (BKB) sentence testing at a sound intensity of 70 dB SPL*
- *For children, speech, language and listening skills appropriate to age, developmental stage and cognitive ability…'*

The national cochlear implant (CI) centre is based at Beaumont Hospital. This was set up as a national specialty in 1995 by the Department of Health and Children (DoHC) and was strategically located at Beaumont Hospital which also provides neurosurgery services on a national basis. The cochlear implantation programme is based within the surgical directorate of the hospital and to date the team has implanted some 500 patients drawn from all parts of the country. In addition to providing the surgical services, the programme provides a comprehensive assessment service to potential candidates and a rehabilitative service to those actually implanted. The programme does not accept private patients.

As a national specialty the CI programme receives funding directly from the DoHC via the HSE. Currently the programme provides follow-up care for the 500 patients currently with cochlear implants (life long follow up is required) and provides assessment and implantation of new patients (approximately 90 per year, of whom about half will be children) on a base budget in 2009 of €2.6 million. This covers staffing, devices, equipment, and surgical costs.

For children, waiting time from referral to initial assessment is 2 to 3 months, and from assessment to implant is 6 to12 months. For adults, waiting time from referral to initial assessment is 12 to18 months, and waiting time from assessment to implant is 12 months. In cases of post-meningitic deafness, patients are placed at the front of the lists because of the danger of cochlear ossification.

4.14 Examples of current patient journeys

The current arrangement of services coupled with under-resourcing leads to inefficient patient journeys. By way of examples, in the following sections clinicians from the NARG outline (in note form) typical patient journeys, including waiting times, for three common or important conditions: childhood glue ear accompanied by temporary hearing loss, permanent childhood hearing loss, and an elderly client with age-related hearing loss. Note that in the case of the child with glue ear, it is not possible to rule out an underlying permanent hearing loss until the full audiological assessment has been undertaken—this implies that there should be efficient triage and/or short waiting times. There are no agreed Care Pathways for audiology services in Ireland, so these are 'typical examples' of patient journeys taken from real cases; there will in reality be a wide variety of journeys undertaken by patients such as these, faced with services of variable quality and structure.

4.14.1 Child with temporary but persistent hearing loss associated with longstanding glue ear

Parental concerns regarding hearing of child aged 30 months who passed previous screens.

Step 1

- Parent contacts Public Health Nurse (PHN). Waiting time 1-2 weeks
- PHN consultation (as part of other sibling consultation). PHN refers to Community audiology

Step 2

- Community audiology initial appointment waiting time of 12 months
- Audiological assessment by audiological scientist
- Audiological scientist refers to ENT services in acute sector

Step 3

- ENT initial appointment waiting time one year (routine or non urgent)
- Audiological assessment at acute hospital
- ENT consultation at acute hospital
- Child is scheduled for further ENT review which takes place, with repeat audiological assessment in acute sector, in three to six months. Decision made with regard to intervention (insertion of ventilation tubes, adenoidectomy, etc.); child put on waiting list

Step 4

- ENT waiting time for ventilation tube insertion with adenoidectomy nine months
- Overnight stay as in-patient for operation
- Post operative ENT consultation with audiological review
- Discharged to care of GP services

Note: Cases such as these are often referred directly to ENT by GP, thus omitting steps 1 and 2. However, if an underlying permanent hearing loss is confirmed, referral to Community audiology services will be necessary.

4.14.2 Child with suspected permanent hearing impairment

Step 1

- At nine months of age, child fails the Infant Distraction Test screen performed by a Community Medical Doctor (CMD) or PHN and is referred to community audiology services
- Community audiological assessment appointment waiting time 12 months
- Audiological assessment by audiological scientist. Significant hearing loss (suspected permanent because of severe degree of loss) and middle ear effusion identified
- Audiological scientist refers to ENT services in acute sector for urgent treatment of OME and ABR tests; agrees with parents to fit hearing aids and involve VT service
- Hearing aid trial completed within 1 month

Step 2

- Priority ENT consultation, seen within 3 months
- Audiological assessment at acute hospital
- ENT consultation at acute hospital
- Child listed for urgent ventilation tubes with ABR (electrophysiological test of auditory function) under GA

Step 3

- Waiting time for ventilation tubes and ABR 1-2 months
- At operation, ears clear of OME; ABR indicates severe or profound bilateral hearing loss
- Referral to Community audiology for hearing aid trial/review and Cochlear Implant assessment
- Review assessment by Audiological scientist and subsequent hearing aid fitting within 2 months, if not already fitted

Step 4

- Child seen by Cochlear Implant (CI) team within 2 months for initial assessment
- Ongoing assessment by CI team. Decision regarding implantation within 6 months. Unilateral implantation within 8 months. Unilateral hearing aid use may continue
- Audiological management by CI Team in collaboration with local community audiology service for hearing aid management and local VT service for family support and communication advice

4.14.3 Adult with age-related hearing loss

Step 1

- 79 year old lady attends G.P. and reports hearing loss over the past few years. She also indicated a sudden onset of reduced hearing loss unilaterally following previous syringing of wax
- G.P. refers to Community audiology

Step 2

- Community adult audiology initial appointment waiting time (6 months)
- Audiology consultation and assessment by an Audiologist
- Letter to G.P. recommending ENT referral regarding her additional sudden unilateral hearing loss
- G.P. refers to ENT for further investigation. Meanwhile:

Step 3

- Appointment arranged (2-3 months later) for fitting of hearing aid to other ear

Step 4

- Review appointment with Community audiology 6-8 weeks after her first fitting. Progress reported on hearing aid use and any adjustments to aid carried out

Step 5

- ENT appointment takes place approximately 3 months later; seen by audiologist at same time. Affected ear now recovered, leaving bilateral moderate hearing loss. Information by letter back to Community services for consideration of second hearing aid.

CHAPTER 5: USER and PROVIDER PERSPECTIVES — THE PUBLIC and PROFESSIONAL CONSULTATION

5.1 Introduction

The consultation exercise undertaken by the NARG is considered by the HSE to be a way of working that is identified as best practice. The Consultation with parents and children, adult users, professionals, professional groups and potentially affected parties was considered to be an essential part of the work of the NARG. In essence it has been the cornerstone upon which the recommendations of this report have been developed. This exercise has provided to the NARG the reality of experience of the service for the service user – be they adult or child/family. The "lived experience" can be heard in not alone the content of what's expressed but in so many cases the expression itself. It is hoped that the exercise undertaken in structuring these comments for this chapter does justice to their meaning and intention.

What is set out below, are the methods employed, who was consulted and the key findings that emerged as a result of the extensive consultation exercise.

There were examples of patients offering positive comments about their experiences, but it also has to be accepted that there were a number of highly critical comments and examples of unacceptable practices. Whilst the former was welcomed, it is the latter comments that has proved to be the driving force in identifying the changes necessary and in informing the recommendations.

5.2 Methodology

The NARG identified the following stakeholders for consultation:

- Children
- Parents
- Adults
- Professionals
- Professional Groups
- External Stakeholders

A range of consultative methodologies were employed. These included Public Invite for written submissions, Focus Groups and meetings with external organisations/stakeholders.

5.2.1 Public Invite

A general public invite was issued through the media for written submissions to the NARG. Issued with this invite was the website link to more detailed information on the NARG and its terms of reference.

5.2.2 Focus Groups

Service users were invited to attend facilitated focus groups (see Table 5.1). Whilst every effort was made to target this audience, some people may have been inadvertently overlooked. Focus groups were convened in each of the four HSE regions, targeting adult users, parents of children accessing audiology services and children and young people themselves. The focus groups were facilitated by an experienced facilitator with a local audiology staff member and a parent representative from the steering group in attendance at each focus group. A set of questions was designed and tailored to the specific audience to elicit their experiences of accessing and receiving audiology services, and to contribute to the formulation of appropriate recommendations for the future design, development and delivery of audiology services. All participants were requested to sign a consent form before the groups commenced. The form explained the purpose of the focus groups and participants' willingness to engage in the event. The expertise and support of Consumer Affairs was provided in ensuring a robust process throughout with key themes and findings recorded.

Table 5.1. Focus Group sessions

Focus Groups Members	Location	Date Carried Out
Older Children	St Joseph's School Cabra	16th March 2010
Older Children	St. Mary's School Cabra	16th March 2010
Adult User and Parent groups	Cork: HSE South	19th March 2010
Adult User and Parent groups	North Great George's Street: Dublin/ North East	25th February 2010
Adult User group	North Great George's Street: Dublin/Mid-Leinster	4th March 2010
Adult User and Parent groups	Galway: HSE West	11th March 2010

5.2.3 External Organisations/Stakeholder Meetings

Specific meetings were convened with external organisations/stakeholders and interest groups that had specific roles or interest in audiology services. They were invited to contribute to the deliberations of the NARG and raise any issues that they felt should be considered in line with the terms of reference. As an outcome of the meeting they were provided with a note of the discussion. These included:

- The Dept of Education and Skills
- The Dept. of Health and Children
- Irish Society of Hearing Aid Audiologists
- Deafhear
- Patient Focus
- Society of ENT
- Irish Society of Audiology
- Irish Hard of Hearing Association
- Technical Staff North Great Georges Street
- Cochlear Implant Programme

5.3 Overall Key Findings from Consultation Exercises

Table 5.2 summarises the main views/expressions from the consultation.

Table 5.2 Summary of Recurrent Themes emerging from the consultation

Recurring Themes Need for-	**Children/ Parents**	**Adults**	**Focus groups**	**Professionals**	**Professional Groups**	**External Stakeholders**
Need for Newborn Hearing Screening - IDT	√		√	√	√	√
Poor Access/ Ill -Defined Carepathways	√	√	√	√	√	√
Resourcing of quality hearing aids/Earmoulds provision and Repair service	√	√	√	√	√	√
Lack of Registration & Regulation	√	√		√	√	√
Poor quality Equipment Facilities/Infrastructure	√		√	√	√	√
Need for Integration	√		√	√	√	√
Unacceptable Waiting times/ Staff Shortages	√		√	√	√	√
Lack of multidisciplinary team	√		√	√		√
Lack of Standardised services/Policies & procedures	√		√		√	√
Competency /Training				√	√	√
Leadership/Clinical Governance		√			√	√
Lack of Information and poor Communication	√		√		√	
Lack of Pre-school needs/supports	√					√
Good experience with Cochlear implant programme	√		√			
Need to review provision of BAHA				√		√
Satisfaction with adult service experience once accessed			√			
Satisfaction with children's service once accessed in some of regions			√			

5.4 Elaboration of Key Findings by Grouping - Public Invite, Focus Groups and External Stakeholder Meetings

5.4.1 Key Findings from Public Invite

A breakdown of the total written submissions received under the Public Invite is detailed in Table 5.3. All submissions received were acknowledged by the Review group.

Table 5.3 Breakdown by Groupings of Submissions received under Public Consultation Exercise.

Category	Total
Parents	56
Adults	6
Professionals	15
Professional Bodies/Groups	15
Total	**92**

5.4.1.1 Key Findings from Public Invite - Parents

- The majority of submissions indicated a clear and unequivocal need for newborn hearing screening and the life changing benefits to be gained from the child and family perspective and from a service provision perspective for the HSE.

"The countless questions that I have asked myself on what could I have done differently are endless but the one that keeps recurring is, why did it take so long for this diagnosis to be made? My child has a 'hidden disability, and is at a constant disadvantage because of her 'hearing age 'is over two years less than her 'chronlological age', her speech intelligibility is inferior to her peers which leads to frustration and isolation and she is not even six years old yet! We are continuously trying to catch-up for the missing hearing years with speech therapy, special needs assistants, resource teaching hours, and I have reduced my working hours to the bear minimum in a bid to do extra curricular work to ensure that she doesn't regress because of the late diagnosis".

"Our son was not diagnosed until he was 2 years and 4 months old. No infant screening was offered, or was available to him. Why would we even have asked for it, as we had no reason to think our child might possibly be deaf? The lack of availability of infant screening, as a matter of course, is an absolute disgrace and a failing on the part of our health services ... This screening is widely recognised as a matter of best practise. Early diagnosis permits early intervention. It allows children access to resources and services, and key access to sound in the provision of hearing aids from infancy, which in turn reduces language and social developmental delay, and ultimately avoids higher expenditure over the years in the provision of support. Early diagnosis in some cases practically negates the effect of hearing impairment".

"It is our belief that the central element is Infant Screening, as this early intervention with the correct supports in place, will circumvent the developmental and language delays which are so crippling ….These children deserve to be given a fair chance".

- The use of the current Infant Distraction Test screen was cited as not useful and inappropriate for children who are too old for the test which is done as part of the child developmental check.
- The need to reduce the time it takes to receive a diagnosis, as late diagnosis results in delayed development at such an important time in the child's life. Users and parents cited the journey to diagnosis as long and complex. Also cited is the need to reduce the waiting

time between hearing tests following "inconclusive" results, as this waiting time is valuable time lost in the child's speech and language development.

"My son has a progressive, terminal disease, his hearing is only part of his disability. It is a shock the audiology department …it is desperate, something has to be done. My child depends on his hearing aids, one was broke and I left it with the department. We got it back 4 months later, meanwhile my son couldn't hear anything, his behaviour got worse and he began to un-learn some of his language skills as he could not hear us speaking, so I ask you, if this was your child would you be happy with this 'service'? ..."

- The need for a multidisciplinary "Audiological Team" to support the provision of an integrated service for users. This includes more audiological clinicians and ENT services and adequate support services such as Speech and Language Therapists and Visiting Teachers who are included as part of these teams.

"Beaumont seems very different; when we attend appointments there we meet a whole team and it is much easier for us to make decisions regarding our son's needs. We meet everyone from surgeon to audiologist to visiting teacher to speech therapist under one appointment and the service is very efficient with no time lost. This is easier on our son and on us as his parents".

- The need for more appropriate care pathways for access and navigation of services.
- Best practice policies and procedures should be in place, all necessary equipment should be in working order and onward referral system should be in place.
- The need for an improved quality and efficient system in the provision of hearing aids and ear moulds to include, choice in hearing aids and functionality, addressing whistling noise in hearing aids, provision of low battery signal warning sound, waterproof covers for aids and colour choice for moulds and aids. The improvement in waiting times through the provision of walk-in clinics supporting easy access to technical services. Concern expressed over the length of time it takes to have hearing aids repaired.

"She was fitted with just one hearing aid one and half weeks later the mould was too small, we had a second set done 3 months ago and we are still waiting for these, which when we receive will be too small again".

- The need for more communication and integration between all the various bodies involved with children. There is no cohesive approach in either the provision of services or the dissemination of information.

"One thing we have discovered, is that there is little or no communication between all the various bodies involved with deaf children. There is no cohesive approach in either the provision of services, or the dissemination of information. This must change as no needs are being served in the manner in which agencies "hold close" their information, resources and skills".

- Sensitivity in communicating a diagnosis of deafness; this is a key moment in the parent's journey and has to be managed sensitively by someone with the appropriate training; there is also the suggestion that audiologists should have basic proficiency in sign language.

"Whilst there can be no doubt that there is a relief in the certainty of diagnosis, the manner in which the diagnosis was conveyed, was in our view, entirely inappropriate"

- The need for more information for users and parents on services. Full information should be given at diagnosis about the various options available to children in the areas of device aids and first language choices (sign and spoken language). Information on how to access services and other support information such as correct maintenance and cleaning of hearing aids is also a requirement.

"To sum up my experience as a parent of a child with hearing impairment would be to say that I am frustrated and have met with incredible challenges. Including delay in accurate diagnosis, delay or gaps in appointments for hearing tests, very limited access to speech therapy, and generally no proper information for parents on what to expect. No one in the hearing services explained to me the implication of hearing loss at the level my son has, no one explained to me what I should expect in the management, or what I should aim for".

"At no stage in all of this had anyone explained the plan of care my son should get or what I should expect. No one explained the management of hearing aids, the planned follow up, the assessments, the time frame, nothing …. I felt I was totally alone with the care of my son and had no idea what the future would hold".

"We were never given any information about the hearing aids e.g. left/right cleaning them, batteries or how to put them in. We were left to learn all this for ourselves"

- A number of parents of deaf children commented positively about the help they received from DeafHear; some mentioned that would like to have been told about these services at the point of diagnosis or hearing aid fitting.
- There is a lack of consistency in the provision of services throughout the country e.g. children's services are not available in all counties. There is the need for a national standardised service ensuring equity across the regions as well as standardised operational policies and procedures to ensure consistency.
- The need for a simpler system to navigate in order to gain access to services.
- Support for the Cochlear Implant Programme and the need for adequate funding for the programme.
- The need for a network that would allow parents and children to link and support each other. Better support including pre-school support from services was also identified as a need.

"Being young parents of young children with a hearing loss is very frightening and one feels very vulnerable and it is a time when you really want the best for your child and the supports from the service are vital to help one cope"

"We were given no information beyond the fact that our son was deaf. We were neither offered the possibility of counselling or other parent support, nor were we pointed in any direction to obtain this for ourselves. We were given no information about the implications for (name deleted) of a profound hearing loss. We remember clearly leaving that building to sit and cry in our car, with no sense of direction, only a sense of loss. We floundered about using online internet information, and spent days on the telephone reaching out for contacts which could be of help and support. We were at sea".

- Regard should be had on a more formal basis to the pre-school system and the support services provided within the pre-school period.
- Facilities should be "fit for purpose" and clinically suitable for conducting the standard audiology testing required for children.

- Need for more monitoring of the private system in the form of registration and regulation.
- Forum for airing grievances should be in place and parents should be advised of how this operates.
- Standardised approach required in the provision of ABR.
- Anger over the lack of children's service in Galway.

5.4.1.2 Key Findings from Public Invite - Adult Users

- Lack of audiology leadership role in the HSE.
- Concern over the expansion of the private sector and ensuring quality standards of private service.
- Need to ensure a simpler system to navigate to gain access to services including appropriate care pathways.
- Concern over system for provision of earmoulds.

5.4.1.3 Key Findings from Public Invite - Professionals

- The urgent need for newborn hearing screening and for change in the provision of infant/children's hearing service. Early intervention will significantly improve the lives of children suffering from hearing difficulties and can help mitigate the development of further problems in the future.
- Concern over the effect of waiting lists due to staff shortages and the length of time children are waiting for assessment and earmould service.
- Concern over the length of time it takes to have hearing aids repaired.
- Need to review the ways we can improve our service provision by making the best use of the skills and staff that currently exist and the division between acute and community audiology service. Existing hospital based audiology services should become independent Departments in the hospital. A more seamless integrated system for the referral of babies from newborn hearing screening to diagnostic audiology.
- Facilities should be fit for purpose and clinically suitable for conducting the standard audiology testing required. Lack of properly sound proofed rooms for undertaking audiology testing. More appropriate use of facilities to support an integrated audiology service.
- Little capital investment in equipment.
- The need for a formal training programme to support career development and structure.
- Need for provision of walk in clinics in order to provide easy access to technical services for patients and to reduce the waiting time patients' encounter in the provision of earmoulds and repairs.
- Need to review the provision of Implantable Bone Conduction Systems (BAHAs) and it was suggested that a separate budget should be assigned to this programme.

5.4.1.4 Key Findings from Public Invite - Professional Groups

- Newborn hearing screening should be introduced urgently and ensure appropriate follow up services are in place for services required.
- Unacceptable waiting times for audiology services.
- The need for national management, clinical leadership and governance structures in audiology supporting an integrated audiology service.
- Lack of adequate budget for hearing aid provision.
- The need for evidence based, clear and defined care pathways in ensuring ease in navigation of services.
- Lack of consistency in service provision and clear links to other primary care services.

- Need to consider future service provision for children with auditory processing disorder.
- Need to address infrastructural issues and hearing aid repair issues.
- No formal education for audiologists in the country and lack of career progression.
- Lack of registration and validation of qualifications and regulation of audiology professionals. There is a need to ensure that audiologists dealing with children are suitably trained.
- Lack of uniform national guidelines and recommended procedures.
- Need to ensure that users/parents are informed about their/their child's hearing difficulty appropriately.

5.4.2 Key Findings from Focus Groups

Across the country it was evident from discussion at the focus groups that audiology services are delivered by many differing combinations and variations of skill mix and services. This it would seem is due to a multiplicity of reasons such as different local service models, staff numbers, technological progress and local support services. There would also appear to be, well recognised difficulties and variations in relation to the recruitment and training of some professional groups across the country.

Attendees at the focus groups cited that there are several aspects of the Irish audiology service that are to be commended particularly with regard to the courtesy, respect and compassion shown by staff to users during their service experience. In general, participants report an overall positive service experience.

The challenges/difficulties cited through the public consultation focus groups exercises appear to lie outside the actual service encounter, and the main themes (in order of priority) to emerge include:

1. The absence of Newborn Hearing Screening and subsequent early diagnosis
2. Lack of integrated associated services delivery
3. Difficulties with access to services and aids; particularly in respect to screening, waiting times for appointments, receipt of hearing aids and replacements/repairs
4. Lack of information and education for users and/parents
5. Lack of effective communication between disciplines and agencies supported by appropriate care pathways and clear channels of communication.

Key suggestions emerging to improve the audiology services in Ireland are invariably linked to the main challenges outlined above. Comparisons were made with the services available at the Cochlear Implant Programme Beaumont Hospital, with an emphasis being placed on the following elements of good practice:

- Timely appointments
- Multi-disciplinary team working
- Good sharing of information
- Provision of support/training and information
- A team that meets the needs of parents
- Standards of care.

The development of standards of care that adults, young people and children and their families can expect to receive on their journey through audiology services was cited as a national requirement.

5.4.2.1 Key Findings from Focus Groups – Adult Users

The key challenges/difficulties to emerge across all of the regions include accessibility *"Delay in actually getting into the service i.e. between the GP referring and getting the initial appointment"*, waiting times *"Waiting list for 3-4 months for hearing test and then 3-4 months wait for an appliance"* and functionality of hearing aids "*Hard to adjust to hearing aid; don't think have proper volume"*.
In terms of what is working well there is certainly satisfaction with the service experience, once accessed *"Service good, with personalised treatment; Good courtesy, respect, consideration and compassion"*.

Suggested improvements highlight issues such as improved waiting times *"reduce waiting times for an ear mould and availability of digital hearing aids"*, access to greater information and education, improved functionality of hearing aids, continuity of service *"same Audiologist all the time (have named audiologist)"* and integrated services and effective communication.

5.4.2.2 Key Findings from Focus Groups - Parents

In respect to the parents of children accessing audiology services the key challenges/difficulties to emerge across all of the regions include accessibility *"parents have to consistently chase the office for appointments – no late appointments or no lunch time service"*, waiting times *"appointments to see an audiological scientist are like gold dust"*, communication *"there is an assumption that you know all the services"*, the functionality of hearing aids *"there needs to be sessions for the parents in how to use and maintain aids"* and delayed diagnosis. There is currently no standardised national newborn screening programme.

In terms of what is working well there is certainly commonality in respect to satisfaction with the service experience, once accessed and the facilities available in some of the regions. *"Would be lost without teacher of the deaf"*

Suggested improvements highlight issues such as integrated care "w*ould have liked all of the services to be connected*", improved waiting times, access to greater information and education *"when a child is diagnosed, they should be given an information pack"*, support services and improved functionality of hearing aids *"explain what hearing aid is and how take care of it"*.

5.4.2.3 Key Findings from Focus Groups - Children and Young People

There were two Focus Groups convened with students from St. Joseph's and St. Mary's Schools in Cabra, Dublin. Students cited the following when asked what was the best thing about their experience of audiology services:

- Cochlear implant service
- To hear clearly with the aid
- Generally good experience with the service
- Short wait for specialist service
- Friendly staff (North Great Georges Street service)
- Central access / location good
- Hearing aids are free and quick delivery of earmoulds.

Students cited the following when asked what they would change about the service:

- Batteries – there is no indication of when they are low, there should be a warning sound or beep
- Provision of waterproof covers for aids especially for sports and protection from rain for implant
- The headphones for hearing tests are too big and awkward
- There is a problem with whistling noises in hearing aids
- Use of laptop and matching with aids should be improved. Servicing via Northern Ireland. Average of one week to fix or change
- Feedback from whistling noises in aid, none reported from implants
- Need visits to the school in relation to earmoulds
- Earmoulds not fitting well
- Shorten waiting time for appointments and emergency service. e.g. 4-5 months waiting time
- Repairs of hearing aids take too long.

Students cited the following when asked 'if there was one piece of advice that they could give the hearing services what would it be?'

General

- Clinician - '*please be gentle*!'. Consultant - '*Listen to needs more and give more choices*'
- Cochlear implants – long words difficult to pick up
- Sounds being picked up e.g. open windows
- At first access of service, more explaining and demonstration of using the aid. Also, how do you know if it is working well when first fitted?
- Implants, more sign language needed.

Information and Communication

- Would like to see hearing tests results from audiologist directly
- Better information for parents and students
- Audiologists should know basic sign language for better direct communication with clients. (Have to bring a hearing relative to appointments). Audiologist has British Sign Language not Irish
- Audiologist – first diagnosis of deafness in child, negative. Put the positive points across also
- More sign language known, used by staff in school
- News about new/improved hearing aids from the HSE to be sent to client directly.

Hearing Aids

- Frustration with lack of choice for hearing aids
- Functionality of hearing aids '*Hope that aids will get as good as implants soon*'; 'Aids should be waterproofed' (sports, rain etc)
- Free batteries
- Colour choices for moulds and aids
- Hearing aids should be more freely available
- Availability of hearing aid models.

5.4.2.4 Key Findings from Focus Groups with School Staff Members

The main theme to emerge in discussion with school staff members include the gradual reduction of access to hearing services in the school and the variability of appointment schedules throughout the county. *"For example the taking of earmoulds was previously done regularly once a month, now they are scheduled once or twice a year, but only if requested".* Suggested improvements to the service are as follows:

- Regular scheduled visits from an audiologist and earmould technician
- A more accessible procedure for dealing with lost and broken aids
- For several members of staff to be trained to meet some audiological needs
- A member of staff trained to do audiograms
- School entrants and school leavers to have a full audiological assessment
- Meeting with the Hearing Service annually to assess the schools audiological needs.

5.4.3 Key Findings from meetings with External Organisations

An overall suggested vision for a future audiology service was agreed in principle by all. This vision being a responsive audiology service based on meeting the needs of children and families, a service that is evidence based and delivered by trained and competent staff and providing audiology services that are felt by families to meet their needs. Integration with disciplines and external agencies being deemed to be a fundamental element to integration.

The following key findings emerged through discussion

- The need for national leadership with supporting clear governance structure, including clinical governance for an integrated audiology service – the system needs to be governed in a coherent integrated way
- The service split between Audiologist and Scientist and Community and Acute was deemed to be unhelpful to the delivery and management of audiology services
- The clear need for Newborn Hearing Screening and appropriate phasing out of the IDTS (the 8-month infant distraction test screen) but continuation of school entry screen
- The need for early pre-school specialist support and intervention
- Clear eligibility criteria needs to be developed and applied nationally
- Need for clear and defined care pathways
- The need for regulation and registration
- The need for a formal training programme to support career structure
- The need for adequate adult rehabilitation service
- The walk-in hearing aid repair service available in Dublin should be available nationally
- Need to address waiting lists, with a more creative approach to addressing waiting lists agreed and applied
- There is a clear need for consistent service provision across the country especially in children service
- Clear links with other primary and community care services needs to be defined and applied nationally e.g. Speech and Language Therapy service, Psychology services etc.
- Review of budget allocation: to include hearing aid, aid and appliances budget
- Separate budget allocation for BAHA programme similar to Cochlear Implant funding model
- More appropriate use of facilities to support an integrated service utilising facilities in the community setting that could provide outreach services
- Need to address infrastructural issues to support audiology service i.e. appropriate infrastructure for clinics, support ICT system, accommodation, sound proofing etc.

- Clear agreement on how aetiological investigations and developmental assessments on newly-identified permanently hearing impaired children should be provided
- The need for Associate Audiologists/Assistant Audiologists grade in the system
- Review the option of Technical staff carrying out national calibration including maintenance registers for equipment, BAHA repairs and School FM system installation and maintenance work
- The need to improve procurement process and inclusion of batteries in national contract.

5.5 Conclusion

The finding of the focus groups with parents/children clearly tell their story. These findings are strongly echoed in the input received from the public, other professionals and external agencies/organisations. The findings have been reconstructed to develop "the vision for audiology services" and to inform the recommendations of the report which have been categorised under the following headings:

- Patient Focus
- Workforce Service Structure and Governance
- Clinical Service
- Infrastructure and Support Service

The National Audiology Review Group would like to express, our sincere appreciation to the many parents and children who gave of their time and experience to inform this report and to the public, professionals, agencies and organisations who provided invaluable guidance and information on the way forward.

CHAPTER 6: PROPOSED OUTLINE CARE PATHWAYS

This and the remaining chapters of the report focus on proposals for improving audiology services in Ireland. This chapter should therefore be read in conjunction with the recommendations in Chapters 7 and 8, particularly the section in Chapter 8 on workforce, service structure and governance. In many cases, especially the Care Pathways (CPs) for cochlear implants and newborn hearing screening, the NARG have drawn from pathways published in the UK (NHS Newborn Hearing Screening Programme; http://hearing.screening.nhs.uk/carepathways).

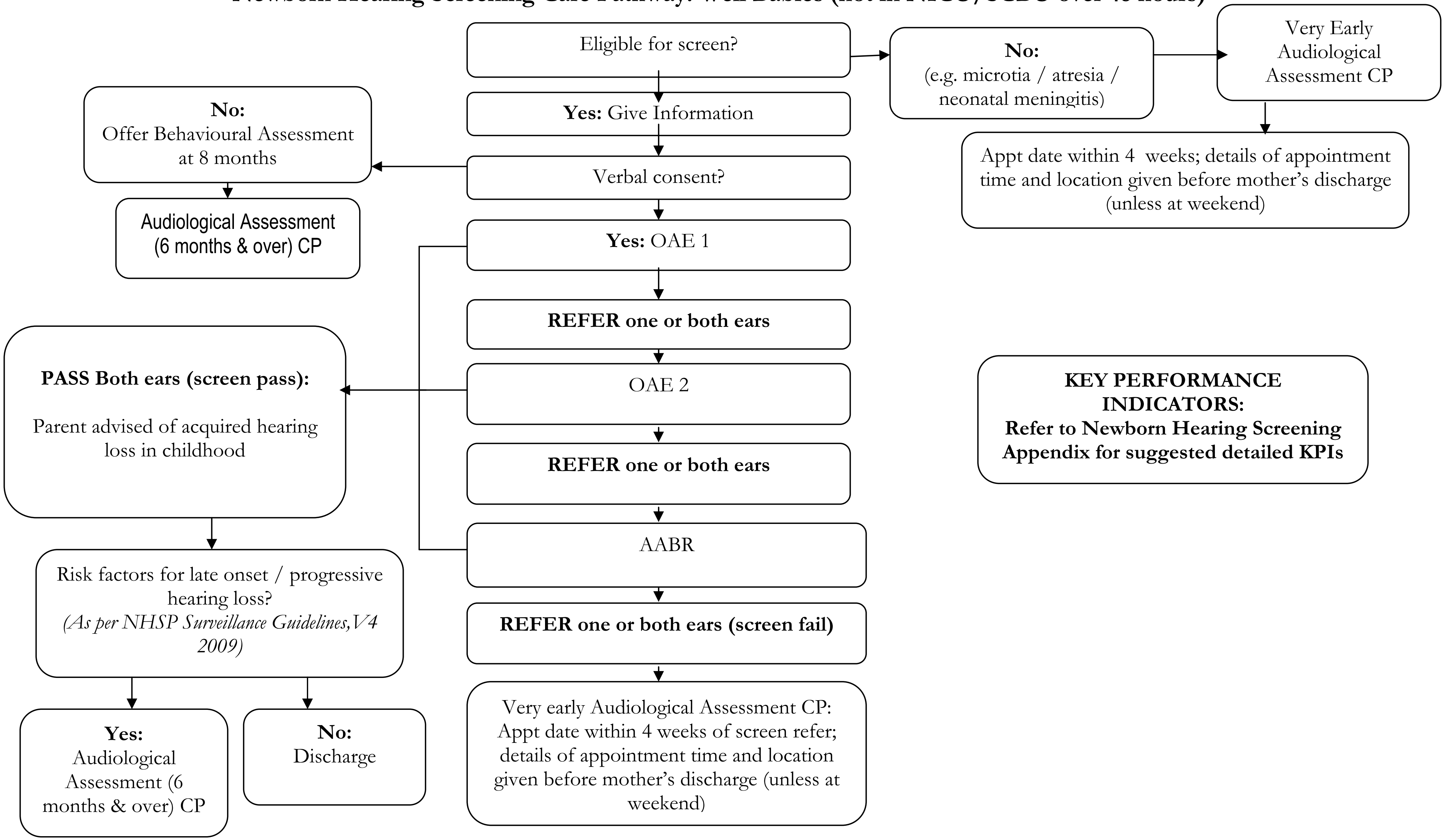
Care Pathways are outlined for:

- Newborn hearing screening
- Very early audiological assessment (0-6 months of age)
- Audiological assessment (children over six months of age)
- Audiological management of children with permanent hearing loss
- Children with glue ear
- Audiological assessment of adults
- Audiological management of adults with acquired hearing loss
- Tinnitus
- Bone anchored hearing aids (BAHA) (for adults and children)
- Cochlear implants

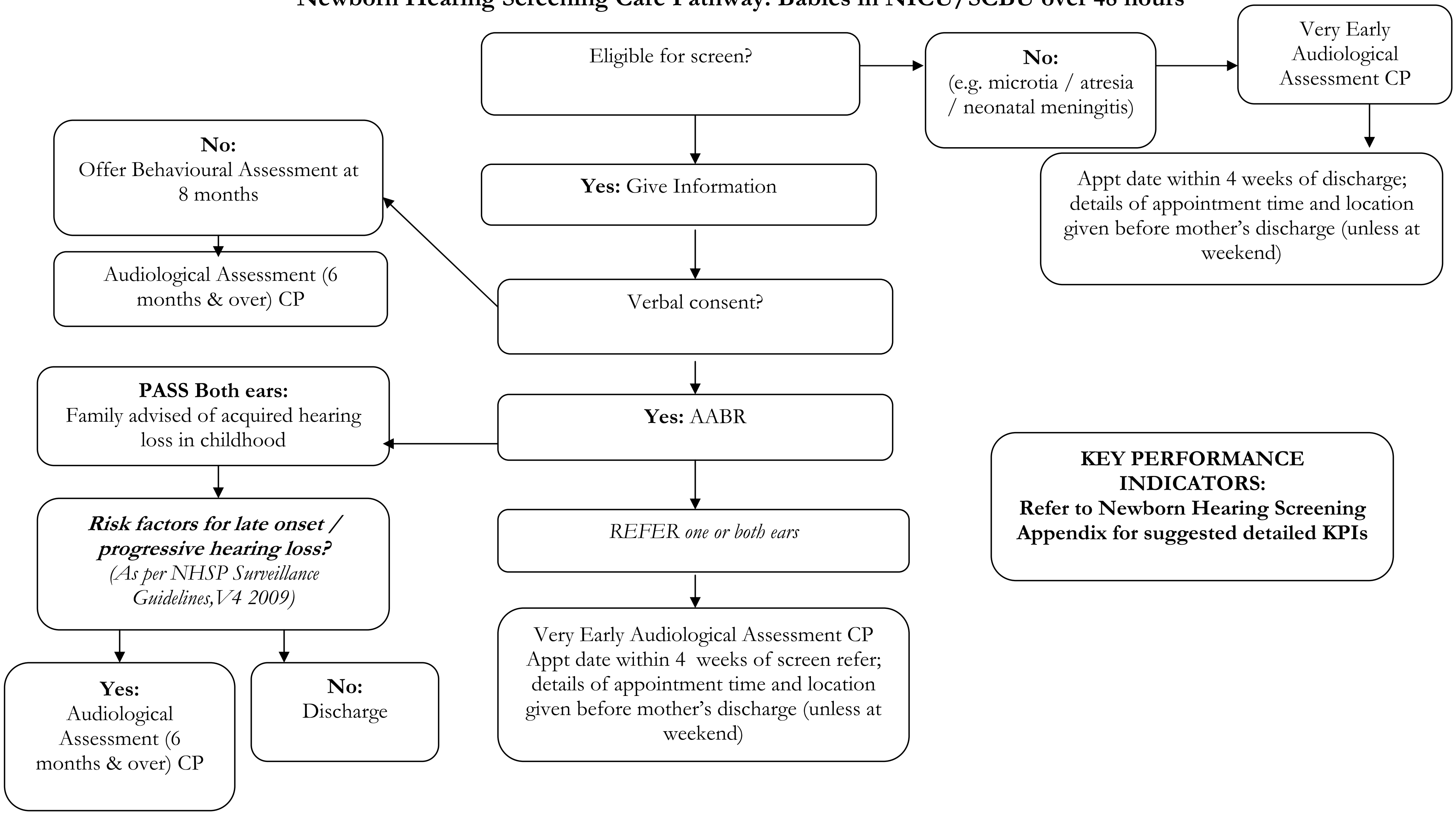
Explanatory or supportive notes follow some (but not all) of the pathways in this chapter. There are of course other conditions and assessments undertaken by audiology teams (e.g. those associated with possible balance disorders). We have not outlined CPs for all possible conditions seen by audiology teams. A reference guide for major diagnostic and therapeutic activity by audiologists with a summary of procedures, suggested times and level of staff required is also available in Appendix D.

6.1 Newborn Hearing Screening Care Pathway

Newborn Hearing Screening Care Pathway: Well Babies (not in NICU/SCBU over 48 hours)



Newborn Hearing Screening Care Pathway: Babies in NICU/SCBU over 48 hours



6.1.1 Notes on the Newborn Hearing Screening Care Pathway

Neonates excluded from the screen

The two groups who should not undergo the newborn screen are babies with:

- Microtia/atresia - where there is no patent ear canal in one or both ears
- Neonatal Meningitis – Confirmed or strongly suspected bacterial meningitis or bacterial septicaemia. (Strongly suspected in this context is a strong suspicion, based on the clinical judgement of Paediatrician. In practice it may be problematic and potentially confusing to try to separate bacterial meningitis from viral cases, and many are treated before diagnosis. It is simpler and probably more effective to allow all cases to be referred).

Screening is inappropriate for these babies because those with microtia/atresia will always have a degree of loss, and the risk of SNHL following bacterial meningitis is very high. These children should be immediately referred by the Paediatrician to audiology and given an early hearing assessment (usually ABR) within four weeks of discharge from hospital.

Pre Screening Information for Parents and Consent to Screen

Prospective parents should be provided with written information about the hearing screen (available in multiple languages), at around 28 weeks of pregnancy. After delivery, the same written information must be made available to parents that have not already received it. The mother (or person with parental responsibility) will also be provided with verbal information by a trained member of the screening team, before the screen is offered. It will be the responsibility of the screening team member giving verbal information to determine if an interpreter is required. Informed consent must be obtained prior to screening. Consent to screen will cover the entire screening process, including audiological assessment. Consent may be withdrawn at any time. If the screen is declined, parents will be offered an appointment at an Audiology centre when the baby is 8 months (corrected). Even when there is agreement to attend the 8 month assessment, parents should be advised to request an immediate appointment with Audiology if they have any concerns about the hearing, regardless of their child's age. Information checklists should be provided that outline the age appropriate sounds babies make and age appropriate reactions to sound.

Post Screening Information for Parents

Parents of all babies screened will be given a verbal explanation along with a written record of the result. Information checklists will be provided that outline the age appropriate sounds that babies make and age appropriate reactions to sound. Other information to be given to parents will depend on whether there is a clear response in both ears and whether the child’s history indicates that there is a high risk of late onset or progressive hearing loss. When there is a clear response in both ears and no known risk factor for late onset or progressive hearing loss, a follow up appointment at an Audiology centre will not be offered. However, parents should be advised to request an appointment with Audiology if they have any concerns about the hearing, regardless of their child’s age.

When there is a clear response in both ears and a high risk of late onset or progressive hearing loss, an appointment at an Audiology centre will be offered for when the baby is 8 months (corrected). Even when there is agreement to attend the 8 month assessment, parents should be advised to request an immediate appointment with Audiology if they have any concerns about the hearing, regardless of their child's age.

When there is no clear response in one or both ears, an audiological assessment will be arranged immediately. The appointment date should be within four weeks of referral. It is the responsibility of the screening team to provide parents with a leaflet giving contact details for the Audiology centre and information about what will take place during the appointment.

Surveillance Criteria; Assessment by Audiology at 8 months (corrected) or sooner

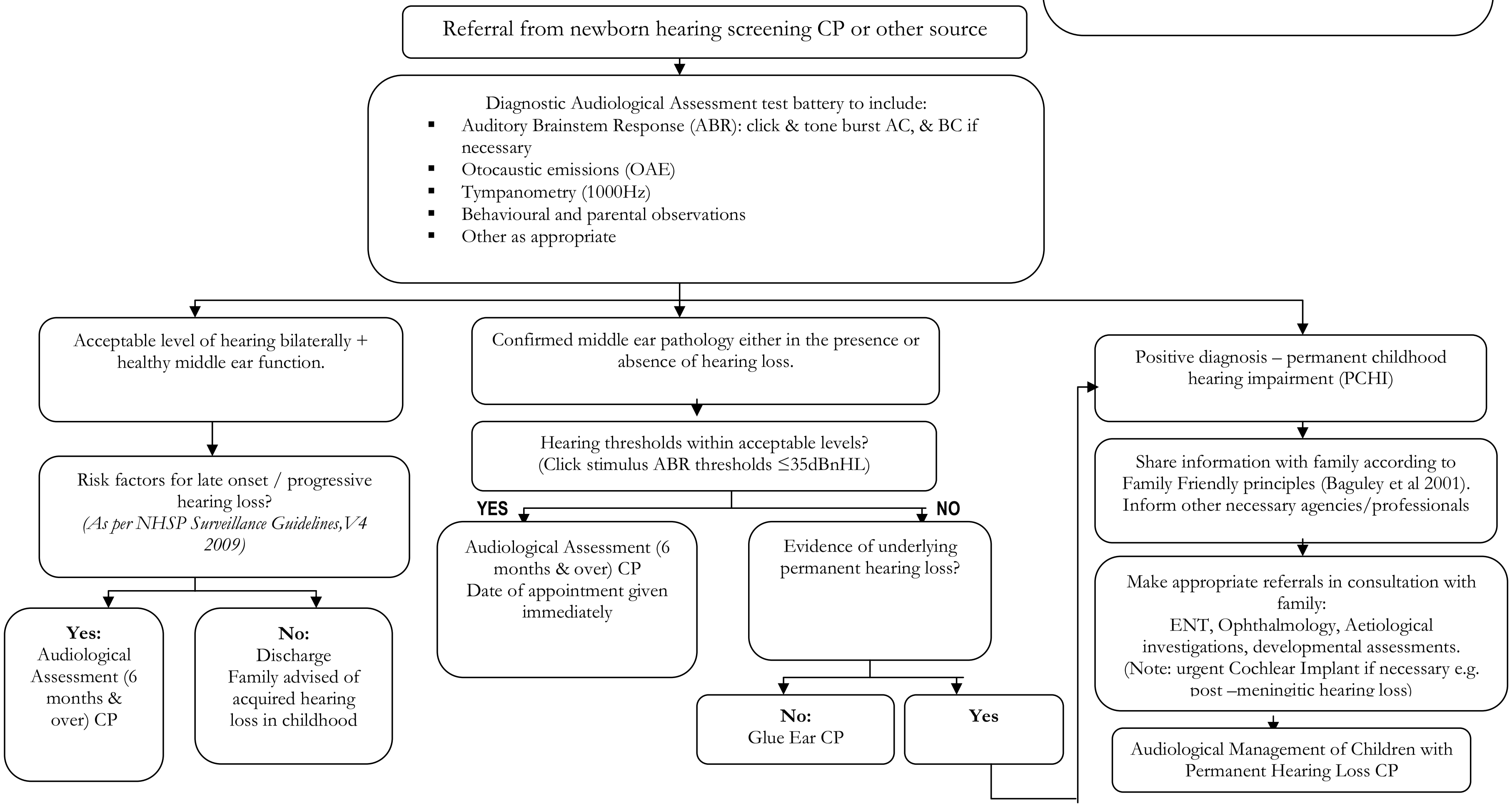
1. Missed screen or audiological follow-up
2. Syndromes associated with Hearing loss / Cleft palate / Other cranio-facial abnormalities
3. Other specific high risk factors for late onset or progressive deafness
    - Congenital infection (CMV, Rubella, Toxoplasmosis)
    - Family history of permanent SNHL from childhood (in parents or siblings)
    - Severe jaundice / hyperbilirubinaemia (exchange transfusion level)
    - Mechanical ventilation over 5 days, or who have undergone ECMO
    - Neuro-degenerative or neuro-developmental disorders
4. High levels of ototoxic drugs

In the event of professional or parental concern, an immediate referral should be made to Audiology, regardless of the child’s age.

6.2 Care Pathway for very early audiological assessment (0-6 months of age)

Key Performance Indicators
First assessment within 4 weeks of referral

- PCHI identified within 6 weeks of referral 80% of babies with PCHI identified before 6 months of age and 100% before 12 months
- Other agencies informed of PCHI cases within two working days of diagnosis.



Referral from newborn hearing screening CP or other source

Diagnostic Audiological Assessment test battery to include:
- Auditory Brainstem Response (ABR): click & tone burst AC, & BC if necessary
- Otocaustic emissions (OAE)
- Tympanometry (1000Hz)
- Behavioural and parental observations
- Other as appropriate

Acceptable level of hearing bilaterally + healthy middle ear function.

Risk factors for late onset / progressive hearing loss? *(As per NHSP Surveillance Guidelines,V4 2009)*

Yes: Audiological Assessment (6 months & over) CP

No: Discharge Family advised of acquired hearing loss in childhood

Confirmed middle ear pathology either in the presence or absence of hearing loss.

Hearing thresholds within acceptable levels? (Click stimulus ABR thresholds ≤35dBnHL)

YES: Audiological Assessment (6 months & over) CP Date of appointment given immediately

NO: Evidence of underlying permanent hearing loss?

No: Glue Ear CP

Yes

Positive diagnosis – permanent childhood hearing impairment (PCHI)

Share information with family according to Family Friendly principles (Baguley et al 2001). Inform other necessary agencies/professionals

Make appropriate referrals in consultation with family: ENT, Ophthalmology, Aetiological investigations, developmental assessments. (Note: urgent Cochlear Implant if necessary e.g. post –meningitic hearing loss)

Audiological Management of Children with Permanent Hearing Loss CP

6.2.1 Notes on the very early Audiological Assessment Care Pathway

Parental or professional concerns

Parental concern about an infant's hearing, development of auditory or vocal behaviour should always be taken seriously. Direct referral to audiology should be available to families. All professionals who may be in contact with a child should feel able to refer to Audiology if there is parental concern, or if they themselves are concerned. These children should be offered a hearing assessment as soon as possible carried out by an appropriately trained team.

Pre-testing Considerations

- Tests and procedures should be explained to parents
- Where possible, the first assessment should be done at age 4 weeks (corrected age) with subsequent assessments soon after this. It may be appropriate to test earlier in some premature babies. Assessment should be completed by age three months
- Sedation is not necessary in babies under three months and should only be considered in babies under age 12 months in exceptional circumstances
- For babies unable to settle for the tests (approx. 3-6 months corrected age) consider timing of appointment to fit in with infant sleep and/or testing at home where babies may settle better

History and observation

Take prenatal, perinatal and postnatal history including:

- Whether baby was in special care baby unit, or not, and for how long
- Use of ototoxic drugs
- Presence or history of infections e.g., CMV or rubella
- Jaundice or exchange transfusions
- Bilirubin levels
- Apgar score at birth, any hypoxia or asphyxia
- Any history of ventilation
- Any family history of permanent deafness since childhood
- Parental concerns about hearing
- Any illnesses, colds or ear infections
- Any parental observations of response to sound
- Major developmental issues or ongoing health concerns
- Other clinic appointments and visits to other specialists

ABR Testing

For protocol for neonatal ABR assessment see www.hearing.screening.nhs.uk. Maturation may affect ABR responses. Therefore when testing very young or developmentally delayed babies the results need to be interpreted with care and testing will need to be repeated later.

High frequency tympanometry

The use of 1000Hz probe tone is a requirement when carrying out tympanometry on babies under six months corrected age. Tympanometry using 226Hz tone should not be used.

Referral for Other Assessments in Consultation with Parents

Within assessment process consideration of child's needs for further assessment/referral to other professionals is often required. This may include Speech and Language Therapy, ENT services, developmental paediatric assessment. Discussion with and consent of parents is required.

Acceptable Level of Hearing

NHSP guidelines recommend AC Click ABR ≤ 35dBnHL and Tone Pip or High frequency ABR ≤ 40dBnHL as acceptable levels of hearing in neonatal audiological assessment (see Guidelines for the Early Audiological Assessment and Management of Babies referred from the Newborn Hearing Screening Programme at www.hearing.screening.nhs.uk).

Maturation may affect ABR responses. Therefore when testing very young or developmentally delayed babies the results need to be interpreted with care and testing will need to be repeated later. A child referred for audiological assessment should not be discharged until testing clearly and definitively shows they do not have an impairment.

Hearing Loss Present

The purpose of the audiological assessment is to determine (in detail and as soon as possible):

- For each ear, if a hearing impairment is present
- Where the impairment is present
- The degree, type and configuration of the hearing impairment
- Testing may not be completed in one session, particularly if a hearing impairment is present
- Further test sessions should be carried out within two weeks.

Risk Factor(s) Present

Infants requiring follow-up or further assessment include those with:

- Post-meningitis; referral: immediate, assessment: within 4 weeks. follow-up within 6 months of initial date of infection
- Cranoifacial anomalies (CFA) including children with cleft palate and Down syndrome or other syndromes/conditions where hearing is implicated
- Immediate family history of significant permanent hearing loss or late onset/progressive hearing loss
- Serious jaundice or hyperbilirubinanemia, to level where exchange transfusion is considered
- High levels of ototoxic drugs e.g. cisplatin, aminogycosides, frusemide
- Maternal congenital infections such as rubella, CMV etc.
- SCBU/NICU screened babies with no clear OAE in either ear but pass on AABR
- Neurodevelopmental or neurodegenerative disorders
- SCBU/ NICU screens with mechanical ventilation of 5 days or more

Discharge with information

Parents should be provided with information on how to contact the children's assessment services should they have any concerns regarding their child's hearing at any stage.

Severe/Profound Hearing Loss in both ears

Severe to profound hearing loss at high frequency is defined as click ABR/high frequency (HF) or tone pip (tp) or ABR threshold of 80dBnHL or greater. Click ABR threshold of 80dBnHL has a high positive predictive value as a test for permanent childhood hearing impairment (100%).

Mild/Moderate hearing loss in both ears

Moderate hearing loss is defined as click ABR threshold 50-75dBnHL; or tone pip high frequency threshold 55-75dBnHL. Click ABR threshold of 70dBnHL has a positive predictive value of about 60% for permanent childhood hearing loss.

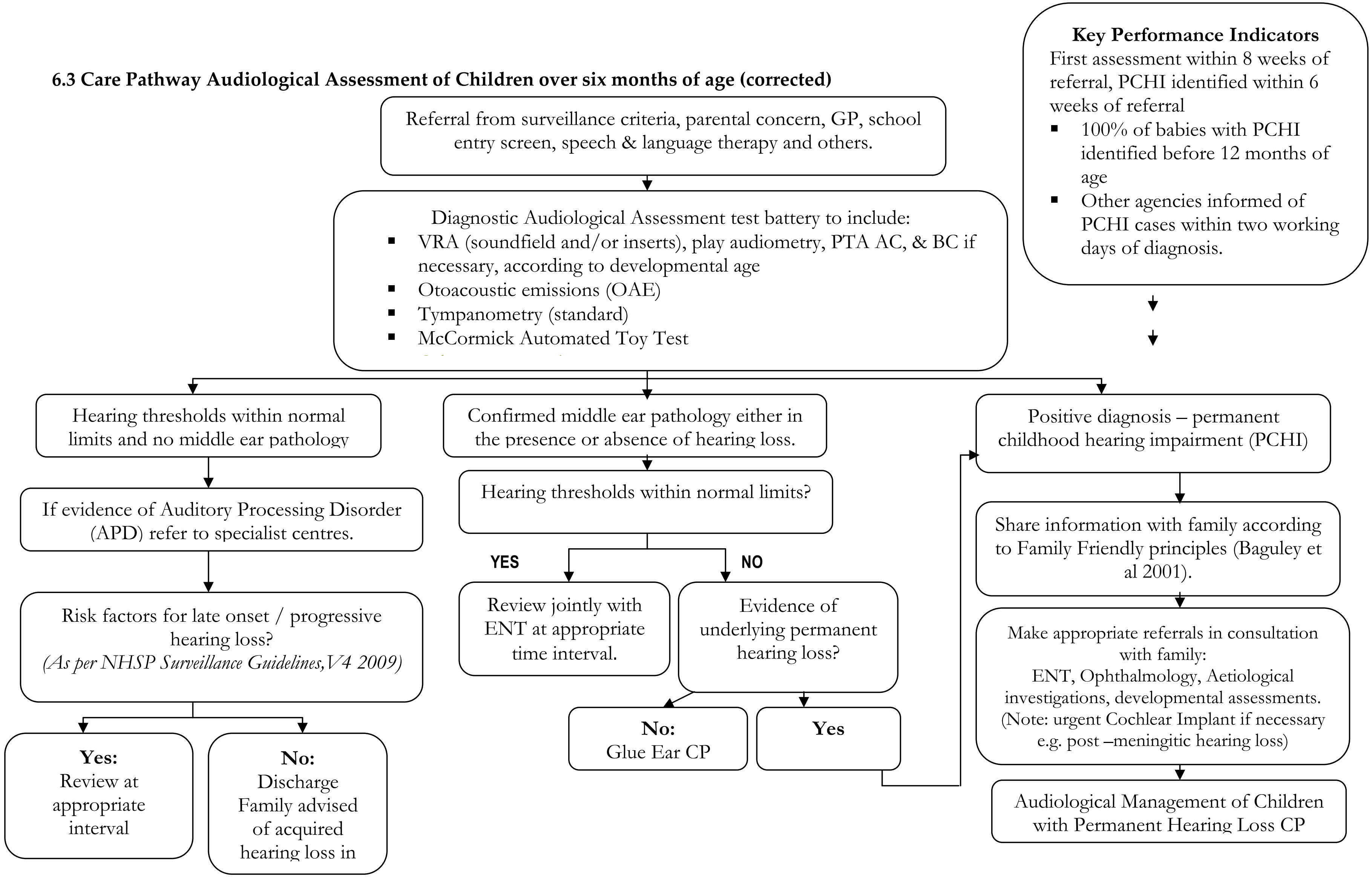
Unilateral hearing loss

Monitor and consider management options (6) in consultation with parents.

Investigate ANSD

Auditory neuropathy spectrum disorder (ANSD) is a disorder which affects neural processing of auditory stimuli. The disorder reduces a child's ability to understand speech and may affect their ability to detect sound to various degrees. Referral to specialist centre is required.

6.3 Care Pathway Audiological Assessment of Children over six months of age (corrected)



6.3.1 Notes on the Audiological Assessment of Children over six months of age Care Pathway

(Refer also notes under very early assessment Care Pathway)

Visual reinforcement audiometry (VRA)

The use of VRA rather than distraction testing for behavioural testing of infants is strongly recommended. Ear-specific testing via insert earphones should be available. Consider bone conduction (BC) VRA to ascertain type of hearing loss. Consider conditioning requirements and delayed response schedule of children with additional disabilities. Highly visual toy reinforcers are useful for children with visual impairment and developmental delay.

Acceptable levels of hearing

- VRA soundfield ≤ 25dBHL average across .5,1.and 4KHz
- Where child is noisy/attention is difficult to control, minimal response levels (MRLs) of 30dBHL may be acceptable if noted and explained
- VRA bone conduction ≤20dBHL
- VRA inserts ≤ 25dBHL
- Play Audiometry (soundfield) ≤ 25dBHL
- Insert Play Audiometry ≤25dBHL
- Pure Tone Audiometry (PTA) averaged ≤25dBHL across 500, 1000, 2000 and 4000Hz in both ears.

Hearing Loss Present

- It is paramount that ear-specific information is obtained at the earliest opportunity using either behavioural hearing assessment alone (i.e. insert VRA or PTA) or a combination of behavioural (i.e. SF VRA or performance audiometry) and objective (OAE or ABR L+R) assessment. Efforts should be made to obtain ear specific information upon each attendance either through behavioural assessment alone or a combination of behavioural and objective information
- It is important to consider bone conduction assessment to ascertain type of hearing impairment as soon as possible
- Further assessment is necessary whenever uncertainty about hearing status remains. A child referred for audiological assessment should not be discharged until testing clearly and definitively shows they do not have a hearing loss.

Non-organic hearing loss

- Defined as where child is not giving consistent responses and hearing is suspected as being within normal limits
- Non-organic hearing loss should be sensitively assessed to ascertain the rationale behind the child or young adult's needs
- Applies to older children usually
- Unreliable/inconsistent AC/BC thresholds over 1 or more tests often indicative
- Normal comprehension to quiet tone of voice in clinic, highlighting discrepancy between audiogram and speech perception
- Consider careful history taking with regard to school progress and social development; consider appropriate action carefully.

Explain results to parents

- Copy of assessment results written in clear unambiguous format should be forwarded to parents
- Clear information both verbal and written on disclosure of disability are considered good practice
- Staff involved in providing information should have experience and sensitivity in working with families or work under close supervision
- Written information should be provided on types of hearing loss.

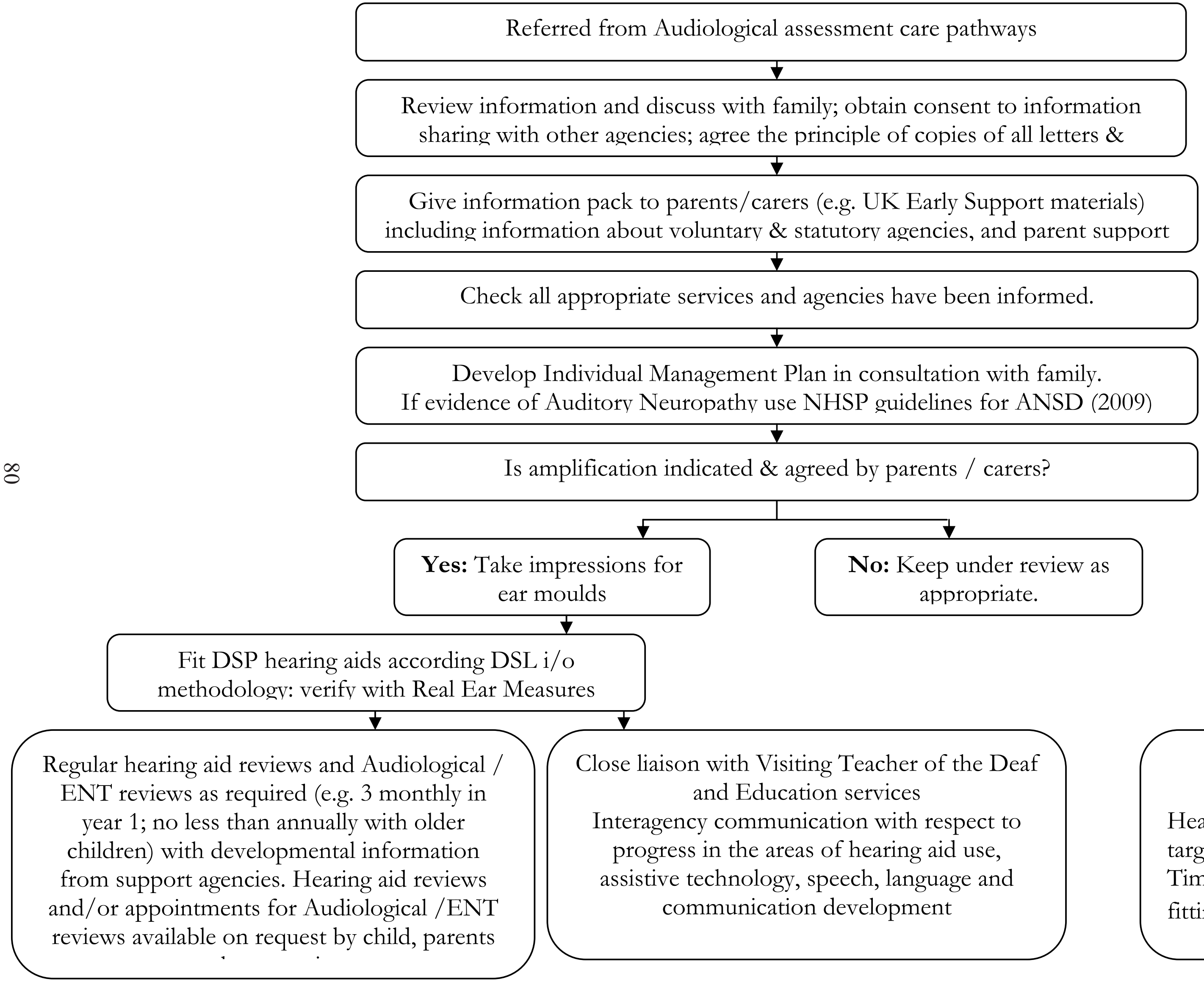
Discharge with Information

- Parents should be provided with information on how to contact their local paediatric hearing assessment service should they have any concerns regarding their child's hearing at any stage.

Rapid referral for cochlear implant assessment

- For acquired severe/profound hearing loss, rapid referral to cochlear implant programme is mandatory and should parallel initiation of paediatric habilitation care pathway
- Post- meningitic children with severe to profound losses require urgent cochlear implant assessment.

6.4 Care Pathway for Audiological Management of Children with Permanent Hearing Loss



Key Performance Indicators

Hearing aids fitted & matching amplification targets within 4 weeks of entry in CP.
Time between impression taking & ear mould fitting < 5 working days.

6.4.1 Notes on the Care Pathway for Audiological Management of Children with Permanent Hearing Loss

Immediate Requirements

- Refer for diagnostic and aetiological investigations led by upskilled named paediatrician or paediatric otologist; referral for ophthalmological investigation
- Referral for early intervention educational/communications support (Visiting Teacher service)
- Referral for support for parents including voluntary contacts e.g. DeafHear, parental support groups
- Discussion of management options (including hearing aids and cochlear implant at an early stage)
- Provision of key contacts list e.g. VT, Public Health Nurse, DeafHear with phone numbers
- If possible middle ear effusion, fast track referral pathway to ENT; if persistent or interfering with use of hearing aids consider increasing hearing aid gain.

Sharing information with families

- Be sensitive to parental anxieties and requirements for information
- An appropriately trained professional should explain test results close to time of test, and offer the chance to visit again and discuss within five working days
- Immediate call to VTOD, GP and Public Health Nurse on the same day
- Provide a family-friendly environment with privacy; allow enough time for emotional responses and for explanations
- Support verbal information with written information (e.g. the Early Support Information for Parents)
- Give unbiased, comprehensive, clear, accessible and accurate information in preferred language (with interpreter if necessary)
- Obtain consent for referral or information sharing with other agencies
- Involve extended family where appropriate.

Amplification options

Factors to be considered:

- Degree of loss
- Unilateral or bilateral loss
- Physical characteristics of baby
- Medical condition of baby
- Parental views

Options are:

- Immediate amplification
- Delay amplification - possible reasons (the reason must be justified and documented):
- Not physically possible
- Medical condition
- Parental decision
- More counselling required

Outcome Measures and Resources for Evaluating Children's Hearing Aids

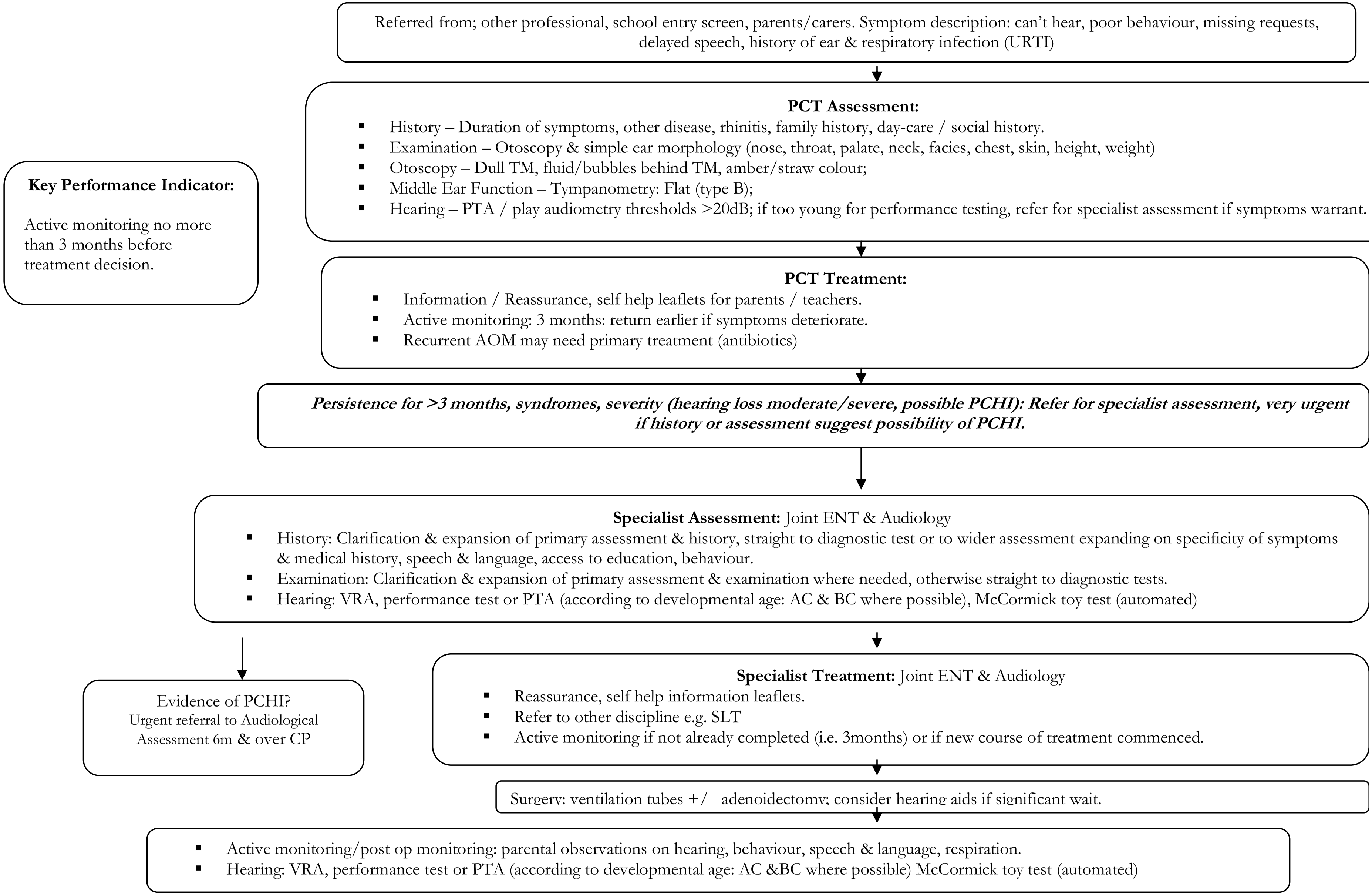
Speech Test Resources

- Ling Speech Sounds http://www.bionicear.com/UserFiles/File/Ling_Six_Sound_Check-6.pdf)
- McCormick Toy Test
- Parrot (Recorded versions of the McCormick toy test, including English as an additional language (EAL) toytest, Manchester picture test and AB word lists (http://www.soundbytesolutions.co.uk/products.htm)
- Phoenix - Automated McCormick toy test with algorithm for establishing thresholds for speech in quiet and speech in noise
- Consonant confusion task (http://www.chears.co.uk/downloads/sptestinfo.pdf)
- Auditory Performance test (http://www.chears.co.uk/downloads/sptestinfo.pdf)
- AB word lists (http://www.ihr.mrc.ac.uk/products/index.php?products=15)
- BKB Sentence lists(http://www.ihr.mrc.ac.uk/products/index.php?products=15)
- FAAF test (http://www.ihr.mrc.ac.uk/products/index.php?products=15)

Questionnaires

- Listening Situations Questionnaire - developed in the UK to provide a means to evaluate a child's benefit from hearing aids in the real world (http://www.psych-sci.manchester.ac.uk/mchas/eval/quest/LSQ.pdf)
- PEACH (Parents Evaluation of Oral Performance in Children) PEACH booklet, questionnaire and score sheet can be accessed via http://www.psych-sci.manchester.ac.uk/mchas/eval/quest
- CHILD: Children's Home Inventory of Listening Difficulty: CHILD (Anderson & Smaldino, 1996)
- LIFE: Listening Inventory for Education (LIFE) (Anderson & Smaldino, 1996)
- IT-MAIS; Infant Toddler-Meaningful Auditory Integration Scale: (Zimmerman-Philips, 1997)
- The Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS) (Zimmerman-Phillips 2000) is a modification of the Meaningful Auditory Integration Scale (MAIS) (Robbins et al. 1991). It is a structured interview schedule designed to assess the child's spontaneous responses to sound in his/her everyday environment. The assessment is based upon information provided by the child's parent(s) in response to 10 probes. These 10 probes assess three main areas: 1) vocalization behaviour, 2) alerting to sounds; and 3) deriving meaning from sound.

6.5 Care Pathway for Children with suspected Glue Ear



Referred from; other professional, school entry screen, parents/carers. Symptom description: can't hear, poor behaviour, missing requests, delayed speech, history of ear & respiratory infection (URTI)

PCT Assessment:

- History – Duration of symptoms, other disease, rhinitis, family history, day-care / social history.
- Examination – Otoscopy & simple ear morphology (nose, throat, palate, neck, facies, chest, skin, height, weight)
- Otoscopy – Dull TM, fluid/bubbles behind TM, amber/straw colour;
- Middle Ear Function – Tympanometry: Flat (type B);
- Hearing – PTA / play audiometry thresholds >20dB; if too young for performance testing, refer for specialist assessment if symptoms warrant.

Key Performance Indicator:

Active monitoring no more than 3 months before treatment decision.

PCT Treatment:

- Information / Reassurance, self help leaflets for parents / teachers.
- Active monitoring: 3 months: return earlier if symptoms deteriorate.
- Recurrent AOM may need primary treatment (antibiotics)

Persistence for >3 months, syndromes, severity (hearing loss moderate/severe, possible PCHI): Refer for specialist assessment, very urgent if history or assessment suggest possibility of PCHI.

Specialist Assessment: Joint ENT & Audiology

- History: Clarification & expansion of primary assessment & history, straight to diagnostic test or to wider assessment expanding on specificity of symptoms & medical history, speech & language, access to education, behaviour.
- Examination: Clarification & expansion of primary assessment & examination where needed, otherwise straight to diagnostic tests.
- Hearing: VRA, performance test or PTA (according to developmental age: AC & BC where possible), McCormick toy test (automated)

Evidence of PCHI?
Urgent referral to Audiological Assessment 6m & over CP

Specialist Treatment: Joint ENT & Audiology

- Reassurance, self help information leaflets.
- Refer to other discipline e.g. SLT
- Active monitoring if not already completed (i.e. 3months) or if new course of treatment commenced.

Surgery: ventilation tubes +/ adenoidectomy; consider hearing aids if significant wait.

- Active monitoring/post op monitoring: parental observations on hearing, behaviour, speech & language, respiration.
- Hearing: VRA, performance test or PTA (according to developmental age: AC &BC where possible) McCormick toy test (automated)

6.5.1 Notes on Glue Ear Care Pathway

Presentation

Otitis media with effusion (OME, "glue ear") presents mostly from parental report if age 4 yrs and over, but may be prompted by behaviour reports from school or nursery. Speech delay often the main concern in parents of children under 3 years. Some parents of neonates may ask for reassurance following identification of fluid in ears by follow-up testing after failed neonatal screening for permanent childhood hearing impairment (PCHI).

Prevalence and incidence

Most children have some episodes of fluid in the ears after cold or AOM, but 50% resolve within 3 months. Slight peak point prevalence around 18 months and 4-5 years, due to increased social contacts. This is a self-limiting condition in which over 90% cases resolve within 12 months.

However, there is very high and persistent incidence of OME in children with Down's syndrome and children with Cleft Palate; these children should be kept under ongoing review at the specialist assessment level (joint ENT and audiology).

In an area of population one million, annual birthrate of c. 15,000, there will be c. 90k children age 5 years or below, and if 20% seek PCT referral on basis of OME symptoms (or hearing screen), that is 18,000 PCT appointments with primary audiological assessment required in many/most cases. About half of those (10%) will be referred for specialist assessment. Only the 5-8% severe/persistent minority should be considered cases for treatment.

Symptom Description

Problems with hearing and communicating (e.g. needing TV very loud), slow general development relative to other children, poor attention, often frequent upper respiratory tract infections and/or acute otitis media (AOM), sleep problems, earache especially on lying down, popping or noises in ears, blocked/ full feeling, family history of atopy. In children with comorbidities including syndromes and craniofacial anomalies, with PCHI including sensorineural hearing loss and cochlear implants, symptoms should be actively sought.

Confirmation of OME and hearing loss

Must be able to not only to confirm OME but also severe retraction, perforations, ossicular erosion, possible cholesteatoma and other middle & external ear abnormalities. Pneumatic otoscopy may be useful but difficult to perform with accuracy.

Confirmation of hearing loss at specialist level: should be able to test children from 7 months of age obtaining separate ear information on air and bone conduction by recognised behavioural methods (VRA, not distraction test).

Treatment

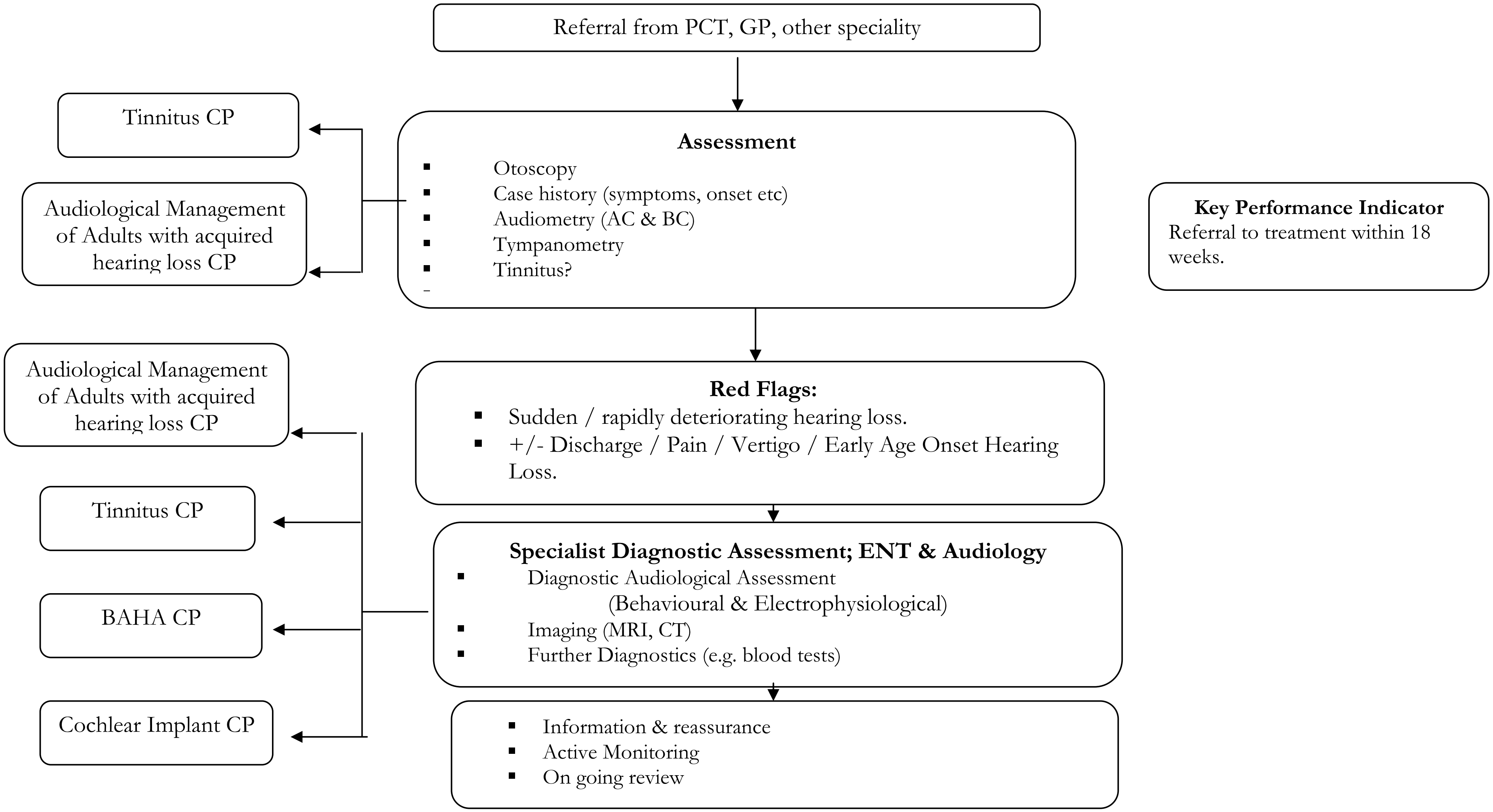
Watchful waiting and careful monitoring; consider temporary hearing aids during this period or any time waiting for surgery. Ventilation tubes ("grommets") offer short-term benefit to hearing while patent & in place (6-9 months). Adenoidectomy gives more persistent benefit to hearing & hence reduction in future surgery. It confers extra benefit for frequent URTI & is generally advised for those who have already had ventilation tubes once, upper airway obstruction or rhinosinusitis. Caution required in syndromic or comorbid children, balancing outcome against complications of surgery & anaesthesia including velopharyngeal insufficiency (transient <2%). Where new surgical techniques are used for adenoidectomy, comprehensive audit of bleed rate is necessary.

Those children with severe ear disease, sleep apnoea, PCHI, hearing aids, cochlear implant should see consultant paediatric otologist.

Short-form parent questionnaires have been developed for the UK specialist caseload and are available from the UK ENT website http://www.entuk.org/patient_info/ . These permit systematic assessment of health and developmental impacts of OME, reducing the variability that otherwise arises from individual clinician styles and local caseloads.

Decisions on the balance between specific treatment and supportive management must be made through clinician guidance and parental/patient choice.

6.6 Care Pathway for Audiological Assessment of Adults



6.6.1 Notes on Care Pathway for Audiological Assessment of Adults

Assessment

The level of assessment required varies in each individual case and depends on severity and onset of symptoms and presence/absence of "red flag" symptoms.

The point of entry to audiology services is generally at primary care level and most often in the context of Consultation with GP or other Primary Care Team Member. In the context of primary care assessment consideration should be given to:

- History of hearing loss and associated symptoms
- Onset/progression/unilateral/bilateral
- Family history of hearing loss/tinnitus
- Previous ear surgery
- Use of hearing aids
- Past medical history
- Impact on Quality of Life
- Audio-vestibular history and status
- General medical history
- Noise exposure including gunfire
- Ear infections
- Head injuries
- Medication including ototoxic drugs
- Otoscopy results
- Medical examination as required
- Audiometry results

Ongoing assessment

The facility to refer for further assessment should be available and this could be undertaken in cases where there is:

- Indication for Hearing Aids
- Failure to arrive at clear diagnosis
- Failure of patient to respond to treatment
- Extreme distress of patient
- Disproportionate disability relative to audiometric findings

Specialised assessment

Referral for specialist assessment should be made in the case of lack of diagnosis, failure to respond to previously indicated appropriate interventions and where "red flag" symptoms are indicated, including the following:

- Unilateral/asymmetric hearing loss
- Sudden/fluctuating hearing loss
- Sudden deterioration of existing hearing loss
- Vestibular symptoms
- With normal peripheral hearing but difficulty hearing in noisy environment
- With otological, neurological +/- general medical conditions
- Tinnitus unresponsive to earlier interventions
- Pre/post operation assessments
- Pre/post ototoxic meds including chemotherapy
- Suspected intracranial pathologies

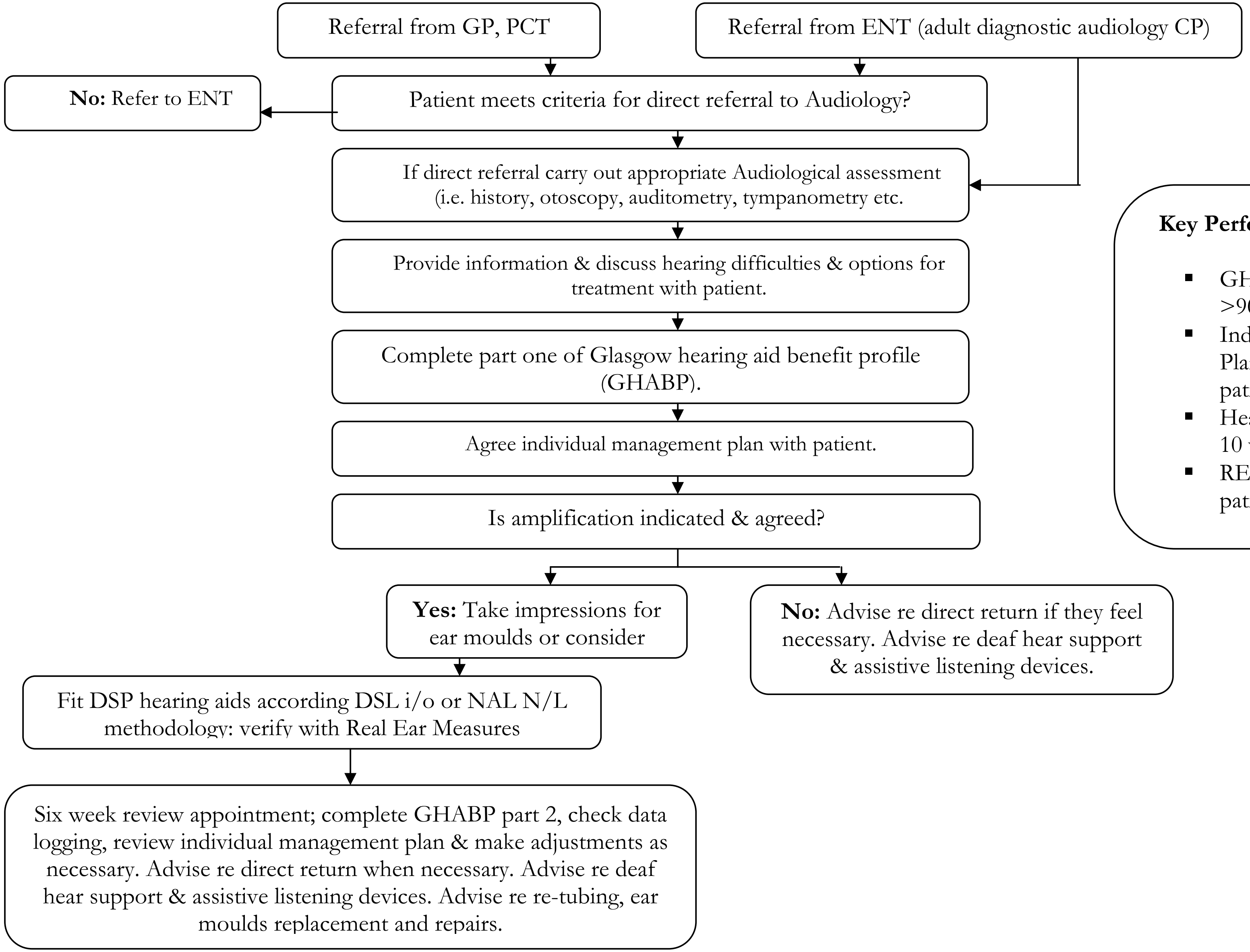
- Audiovestibular pathologies requiring specialist neuro-otological interventions
- Profound hearing loss

In addition to specialist assessment, for more complex cases or where particular interventions are indicated, assessment at this level could require: cochlear implant, BAHA, surgery or medical treatment (e.g., neuro-radiology treatment). Assessment at this level should clarify and expand history gathered along the pathway to include emphasis on co-morbidities and psychosocial factors.

Urgent referral for ongoing assessment should be made on the basis of "red flag" symptoms, e.g., vertigo, conductive hearing loss, dysacusis, sudden/fluctuating hearing loss, rapid progression of hearing, distress++, pulsatile/unilateral tinnitus, suspicion of neurological signs or intracranial pathology.

Red Flag signs should by definition expedite progress along the care pathway towards more specialist services; this procedure should be available within 24 hours if necessary.

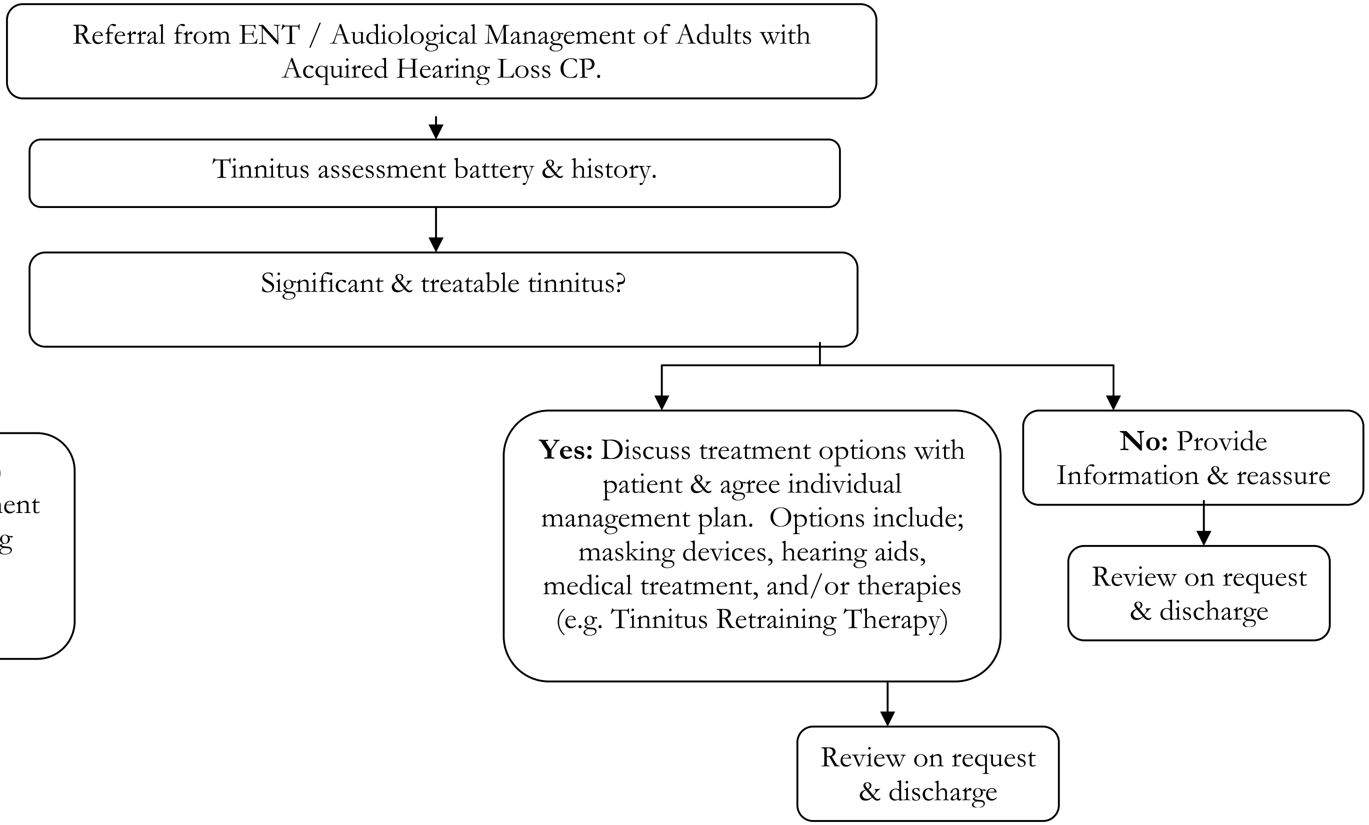
6.7 Care Pathway for Audiological Management of Adults with Acquired Hearing Loss



Key Performance Indicators:

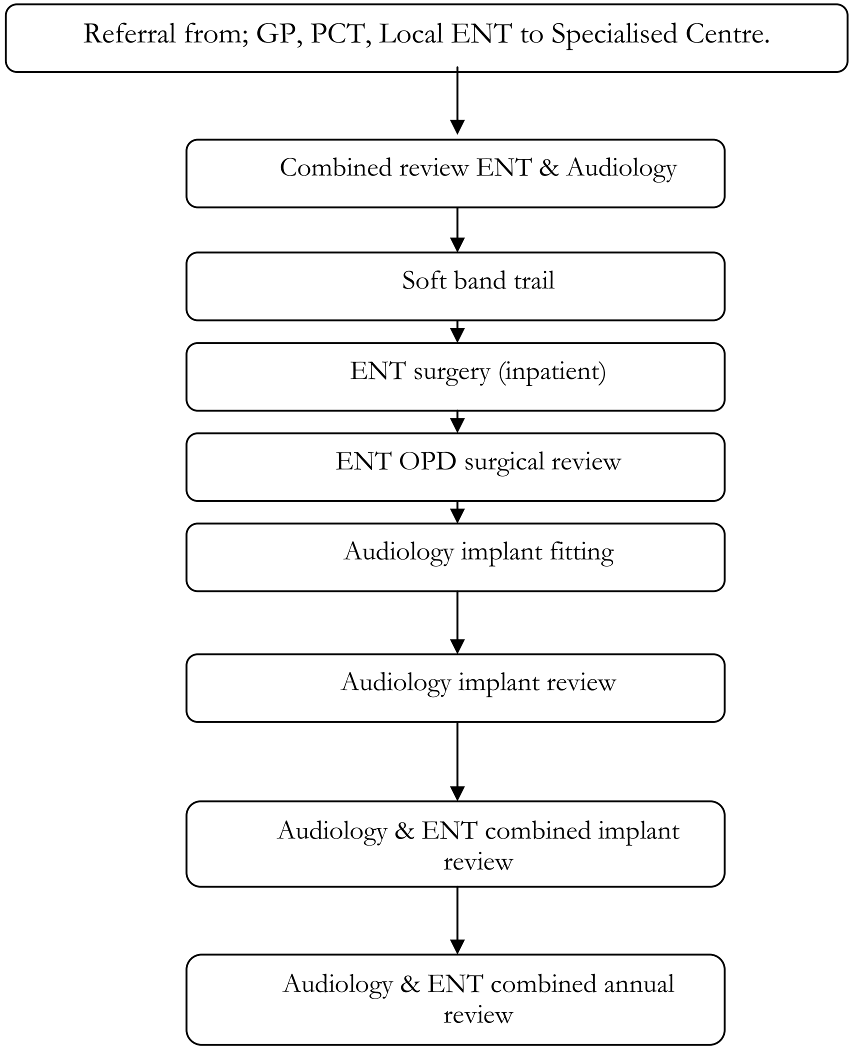
- GHABP completed on >90% of patients.
- Individual Management Plans on >90% of patients.
- Hearing aids fitted within 10 weeks of entry to CP.
- REM's on >95% of patients.

6.8 Care Pathway for Clients with Tinnitus



Key Performance Indicator)
Evidence of significant improvement in patient's quality of life following treatment using standard Tinnitus questionnaires.

6.9 Care Pathway for Clients requiring Bone Anchored Hearing Aids (BAHAs)



6.9.1 Notes on BAHA Care Pathway

Numbers

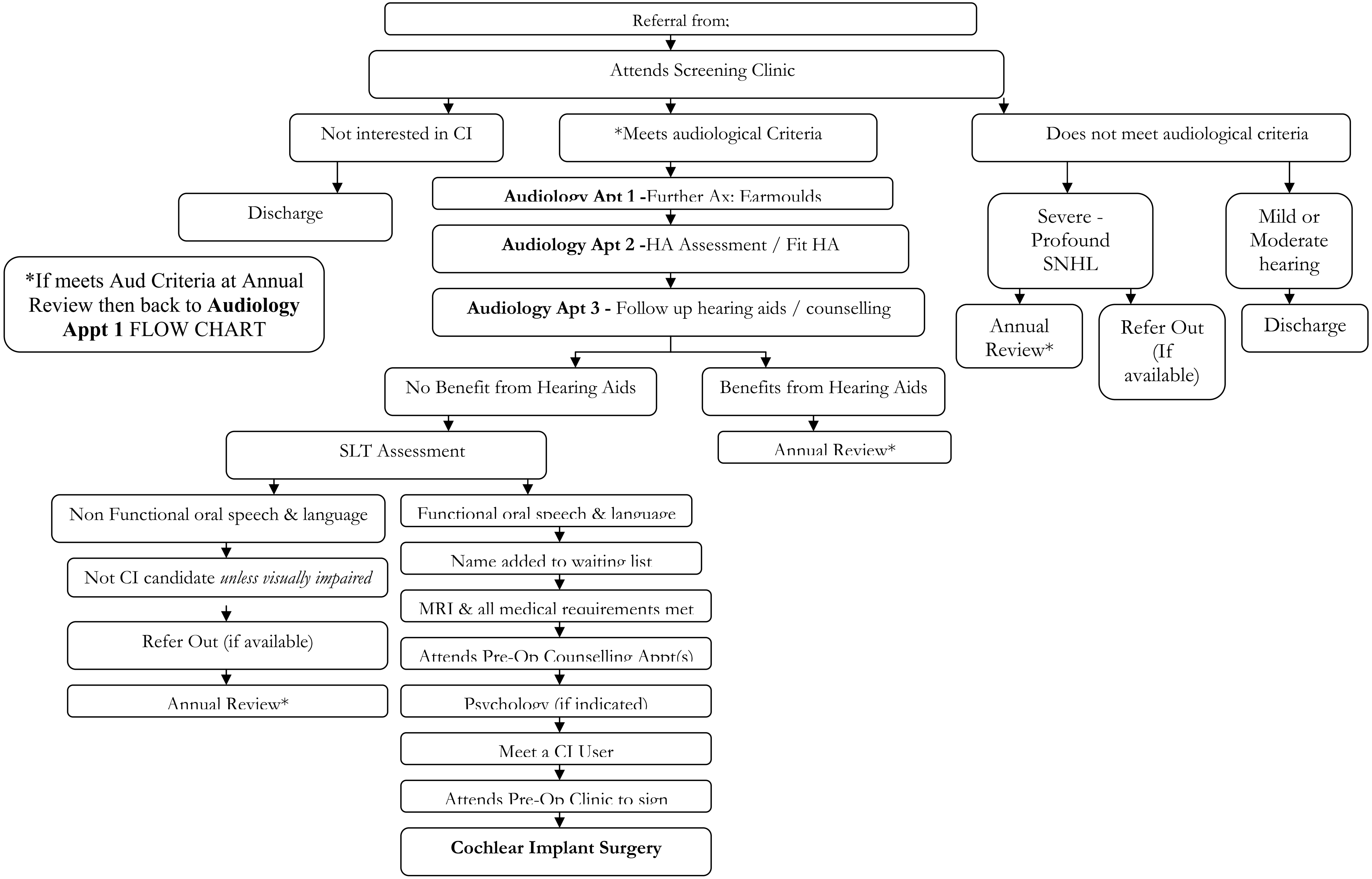
To date more than 65,000 patients have been fitted worldwide, ranging in age from 18 months to over 85 years of age. From the year 2007 to 2010 approximately 84 implants have been fitted in Ireland. The number of patients fitted abroad who require continued care has increased.

The incidence of bilateral congenital atresia (absence or closure of a tubular organ/structure) of the external auditory canal with associated middle ear abnormalities is estimated at 1 in 10,000 live births. There are no firm data on prevalence of bilateral chronic suppurative otitis media (long-term discharging and inflammation of the middle ear), which is severely exacerbated by air conduction hearing aids.

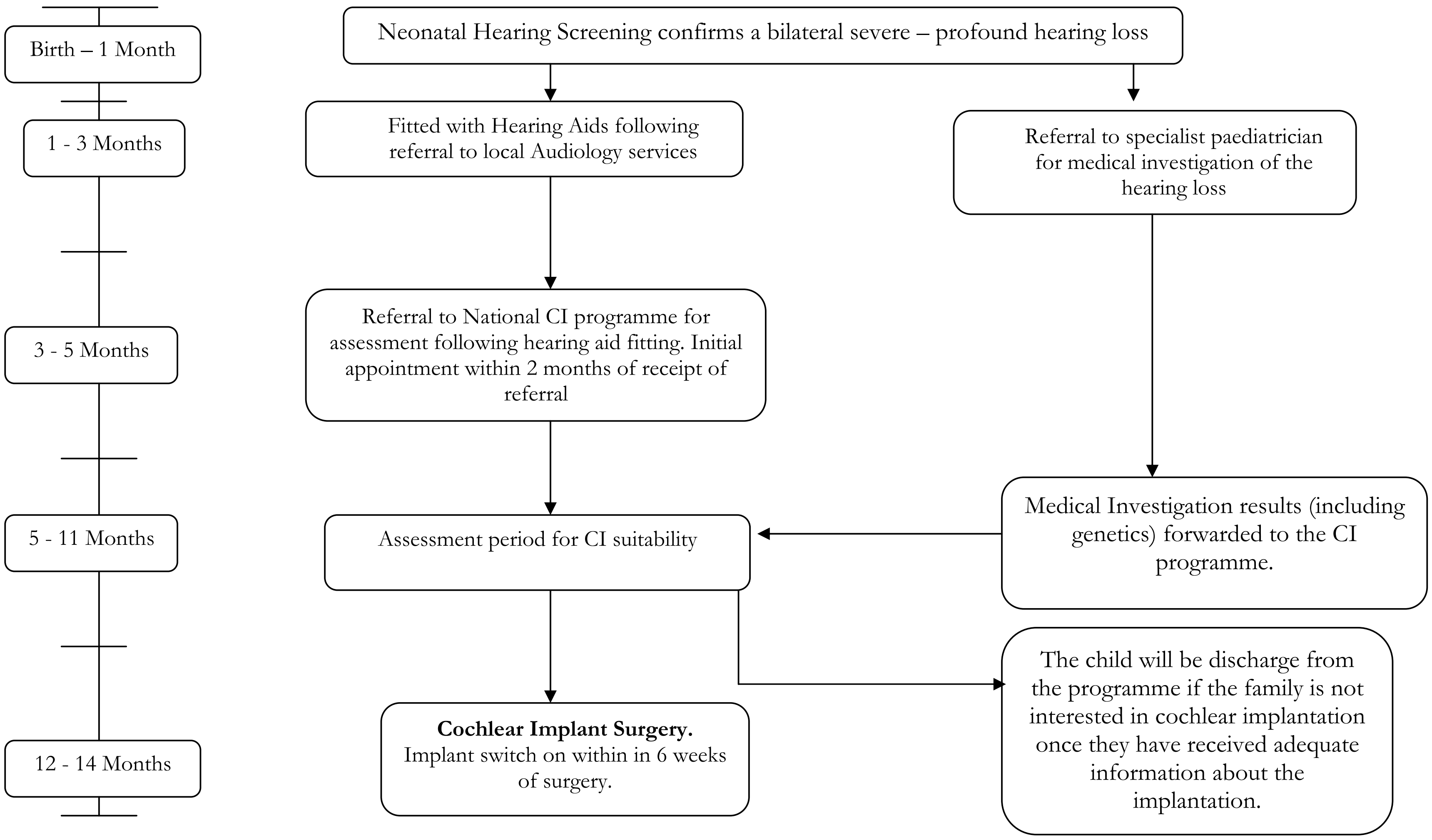
Cost

The average price for BAHA surgery in the UK is £7,000 - £8,500.

6.10 Care Pathways for Cochlear Implants – Adult Programme



Care Pathways for Cochlear Implants – Child Programme



NOTE: A child diagnosed with meningitis needs to have audiology prior to discharge from the local hospital. Referral to the CI programme needs to be made on an urgent basis and the child will be seen within 2 weeks of receiving the referral. If the child is diagnosed with a hearing loss, cochlear implant surgery will take place within 2 months of the child being seen through the CI programme.

CHAPTER 7: FUTURE DEVELOPMENTS IN CHILDHOOD HEARING SCREENING AND THEIR SERVICE IMPLICATIONS—SUMMARY REPORT

This Chapter provides an executive summary of the report 'An Integrated Care Approach to Childhood Hearing Screening in Ireland', developed by the Childhood Screening Subgroup of NARG (full report in Appendix E). It outlines the evidence base, service specification, clinical care pathways and service structure in relation to requirements for an integrated childhood screening service in Ireland. Detailed care pathways supporting the well baby's journey and the SCBU/NICU baby's journey have been developed (see Chapter 6).

7.1 Universal Newborn Hearing Screening (UNHS)

7.1.1 Rationale and Background

Congenital Permanent Childhood Hearing Impairment (PCHI) may disrupt the process of communication and normal language acquisition, leading to poor language, communication and literacy skills. The disruption is likely to be greater the later in the child's life that the hearing impairment is identified. This has long term consequences for child, family and society in terms of educational achievement, mental health and quality of life. Newborn screening involves screening all newborn infants. This results in the early identification of PCHI leading to early intervention and much improved outcomes for children. Neonatal screening needs to be complemented by a system of ongoing surveillance through infancy and early childhood to ensure that progressive, late onset and acquired hearing loss is also identified as early as possible.

This report builds on earlier work undertaken to support and enable implementation of newborn screening in Ireland, such as the Report of the Universal Neonatal Hearing Screening Working Group[38]; the experience of the stand alone sites implementing newborn screening; the work of the Universal Neonatal Hearing Screening Programme Steering group[XVIII], and the report An Integrated Approach to Neonatal Screening in Ireland[39]. Despite the compelling case made by these earlier reports for the introduction of neonatal hearing screening, the enthusiasm of those working in this area, and the benefits to be gained for children with hearing loss, the present position is that implementation of a Universal Neonatal Hearing Screening Programme in Ireland has not yet happened.

7.1.2 Aim of a Universal Newborn Hearing Screening Programme

The aim of a universal neonatal hearing screening programme is the early detection of unilateral or bilateral moderate to profound permanent childhood hearing impairment, to reduce the age of identification of such hearing loss to not more than three months and to undertake/commence amplification, fitting and enrolment in early intervention programmes by six months of age. Early identification is the springboard for the processes of diagnostic and habilitative audiological, medical and educational intervention. Comprehensive intervention and management programmes to meet the child's needs along with support to the family are seen as natural extensions of a universal screening programme[20,21].

[XVIII] Universal Neonatal Hearing Screening Programme Steering group established by Professor Drumm in 2007 until May 2008

7.1.3 Objectives of implementing a Newborn Hearing Screening Programme

The objectives of implementing a newborn hearing screening programme are:

- To offer a hearing screen to all eligible newborn babies in Ireland using an agreed national protocol for screening.
- To screen all eligible babies using the agreed national protocols for screening within 4 weeks of birth, and by 44 weeks gestational age for babies who have been in a Special Care Baby Unit (SCBU) or Neonatal Intensive Care Unit (NICU) for more than 48 hours.
- To ensure timely referral and assessment to integrated audiology services of babies identified as requiring assessment. This includes:

    all babies referred from the newborn hearing screen

    babies requiring targeted follow-up assessment at 7-9 months of age e.g. babies who did not start/complete their screen or

    babies who satisfactorily complete the screen but who require on-going surveillance due to the presence of specific high risk factors.
- To ensure that all babies with PCHI receive effective and acceptable intervention, care and support that meets their individual needs, including appropriate referral to other services e.g. ENT and allied health professionals and other statutory bodies/agencies such as Department of Education and Skills.
- To provide all screening and paediatric audiology services in a seamless family-friendly way.
- To provide families with accurate, up-to-date and comprehensive information at every stage of the care pathway, enabling them to make informed decisions about their child’s care. Such information should be offered in a range of formats and in such a way as to ensure that it is meaningful to, and comprehended by all, regardless of social, cultural or ethnic background.
- To provide timely and accurate information about the effectiveness and quality of the service as required.
- To ensure that there is a system of clinical governance in place, with clear and robust lines of responsibility and accountability, enabling the delivery of a quality and standards-driven service[40].

7.1.4 Limitations of a Newborn Hearing Screening Programme

Newborn hearing screening tests have high sensitivity and high specificity. However, it is acknowledged that a newborn hearing screening programme will miss a very small number of babies with a hearing loss, as no screening programme has perfect sensitivity. Moreover, there will be some children whose hearing deteriorates over time (late onset and progressive permanent childhood hearing impairment). Thus, ongoing monitoring of childhood hearing as part of the child health surveillance programme is critical as well as audiological monitoring of children with risk factors for hearing loss. Care Pathways for access to paediatric audiological assessment have been developed and supports this requirement, followed by appropriate management/habilitation.

If mild, temporary or fluctuating hearing impairment is identified following audiological assessment, the child’s hearing impairment should be managed appropriately, in line with best practice.

7.1.5 Eligibility for Newborn Hearing Screening

- The newborn hearing screen should be offered to all newborn babies born in Ireland, and to those babies under a certain age (three months) who have missed the hospital screen or moved into the area without having completed a hearing screen elsewhere. Babies between three and six months who have missed the screen/moved into the area who have not had a screen should be offered an age appropriate audiological assessment.
- All babies are considered eligible for the screen unless there is unequivocal evidence of hearing impairment (e.g. meatal atresia) as per the agreed national protocols.

7.1.6 Newborn Hearing Screening Process

Newborn hearing screening involves screening all eligible neonates. Testing may take place in either the hospital or the community setting. For well babies screened in hospital the screen can take place within hours of birth. Babies that have been cared for in SCBU or NICU for more than 48 hours should ideally be screened as close to discharge as possible in accordance with agreed national protocol. Screening care pathways are developed for SCBU /NICU and well babies.

7.1.7 Proposed Screening Model

The selection of the most appropriate model, either hospital- or community-based, was considered using the evidence available and a recommendation for the adoption of a hospital based model agreed. Internationally, the hospital based model is the predominant model adopted in the implementation of newborn hearing screening programmes and has been shown in many studies to be effective. This model is used in most local screening programmes in the UK. The hospital model is where the baby is screened in the birthing hospital, or if necessary the screen completed in a follow-up outpatient's clinic. The hospital-based model with its captive population facilitates high coverage with easy access to infants.

The success of this model (whilst reliant on a range of factors, in particular a multidisciplinary effort) is dependant on an integrated approach between hospital and community with integrated discharge planning a key element. It is important however that arrangements for babies born at home/private hospital and babies who miss screening are put in place at local level to ensure comprehensive coverage in providing a population based approach.

7.1.8 Baby's Journey from Screening to Identification of PCHI

Figure 7.1 illustrates the route from screening through to intervention. Critical to the success of a screening programme is the smooth and timely journey of the baby from one stage of the process to the next. In addition there will be ongoing monitoring of childhood hearing as part of the child health surveillance programme as set out in Best Health for Children Revisited, October 2005[41]. In terms of the number of live births, the 2009 HSE maternity hospital data were used i.e. 74,246 births and remains constant for planning purposes for subsequent years.

The quality standard for most international screening programmes is a referral rate of less than 3%. At the start-up phase of the programme, evidence suggests a referral rate of 3% or higher. Experience from the UK suggests that this rate is lower for an established programme. The prevalence data used are based on international evidence and the experience of the UK screening programme.

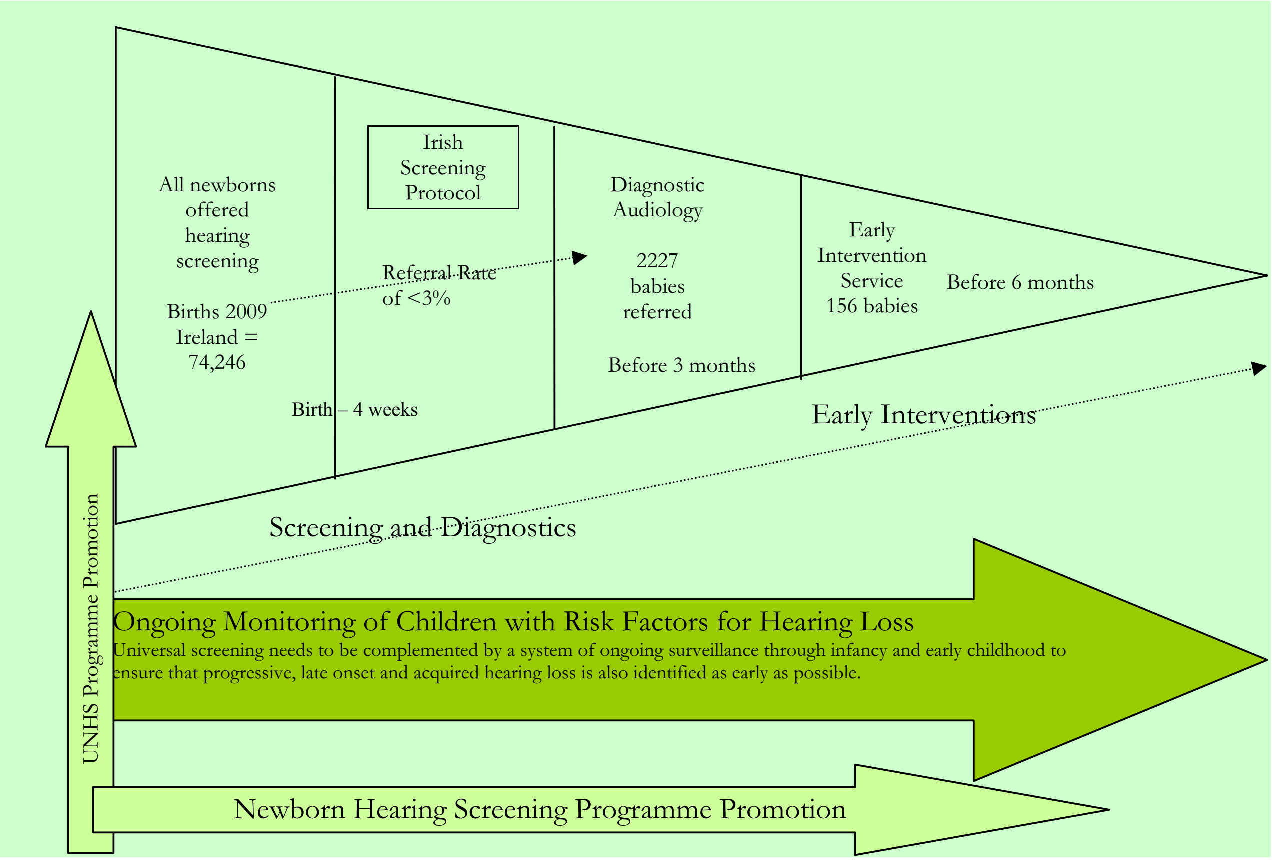


Figure 7.1 Diagrammatic summary of newborn hearing screening and likely numbers

7.1.9 Early Intervention Needs

In the context of early intervention needs, it is important to understand the nature of the population of children with PCHI, and thereby the differing needs of this varied group. The proportion of moderate to severe to profound PCHL is approximately 2:1:1. There will also be a number of children identified with a mild hearing loss. About 30% of the children with congenital PCHI will have other conditions of varying degrees of severity, requiring other support or intervention (e.g. developmental delay, impaired vision, syndromes, other medical conditions), and a small proportion of these will have very complex needs[42]. Well over 90% of babies with PCHI are born to hearing parents, with a small number born to parents who are deaf and who may belong to the Deaf community.

The potential of newborn hearing screening to improve outcomes in children with PCHI is crucially dependent upon timely and effective early support and intervention services from a range of service providers.

Good quality paediatric audiology services include:

- Good authoritative audiological assessment
- Fitting appropriate small DSP hearing aids to prescriptive methodologies
- Selecting and setting up features appropriate to the needs of the individual child and family
- Fine tuning the hearing aids according to developmental progress at appropriate review appointments

- Providing well-fitting earmoulds rapidly as required (which is very often in growing young infants)
- Reassessing hearing status frequently and
- Recognising when other devices (e.g. implants) might be required.

Good quality child and family support services are provided by a number of professionals including Visiting Teachers of the deaf, Speech and Language Therapists and allied health professionals. They are crucially involved in supporting the child and family in home and school settings, according to individual need.

A critical input in the provision of quality home-based child and family support from pre-school through to third level education is the services of the Visiting Teacher of the deaf (VT), Department of Education and Skills. Upon diagnosis the child is referred to their service. The VT is key in;

- Coordinating and providing information
- Explaining audiological and developmental assessments
- Advising on language, communication, social and emotional play
- Monitoring progress and implications of the individual audiological management plan (IMP)
- Advising others professionals on deaf awareness and the implications of hearing loss for the child and family.

With parents the VT;

- Develops individual strategies for encouraging language, communication and general development, in the context of the child's particular hearing loss
- Advises on hearing aid or implant use and its management in the home, nursery and elsewhere.
- Liaises with the audiology services with regard to hearing aid use, benefit and needs
- Advises on trouble-shooting strategies for hearing aid and ear mould problems
- Provides a structured programme of support or intervention for the child and family on the basis of the whole child and degree of hearing loss.

As described by one parent in the consultation process, the visiting teacher is *"an invaluable link in the communication chain between the child/parents and the school, hospital, speech therapist, audiologist etc. They should be provided with greater resources and support and given a greater voice in making change"*. It is important to understand that the early and very direct involvement of the VT with the family and child does not imply any particular approach to communication mode (e.g. sign language or spoken language). Parents are not required at an early stage to choose between different 'models' of intervention provided by different agencies; but they are enabled to make informed choices at appropriate points in their child's life.

7.1.10 Newborn Hearing Screening Programme Design

The establishment of newborn hearing screening is one of the key elements of an integrated childhood screening and paediatric audiological service in Ireland and should ideally be set within an overarching HSE national childhood screening programme governance structure.

The proposed national integrated audiology service structure (see Chapter 8) would encompass responsibility and support for the implementation of the Newborn Hearing Screening Programme:

- The proposed National Audiology Clinical Lead role would have, as part of its remit, responsibility for the national oversight, management and quality assurance of the Newborn Hearing Screening Programme along with all audiology service delivery.
- The proposed Regional Audiology Clinical Leads would have, as part of their remit, responsibility for the day to day management, audit and quality assurance of the Newborn Hearing Screening Programme within their geographic areas. This structure is designed to complement the current HSE Regional design structure whilst ensuring that Audiology is provided with a governance structure and an integrated framework. It is recommended that the Regional Audiology Clinical Leads should be in post in advance of the screening programme for planning and implementation purposes.
- Work is underway within the HSE in the design of a national governance structure for childhood screening programmes. It will be important that these structures complement each other.

Based on international evidence, the experience in the UK and the competency requirements to perform screening it is recommended that screening be undertaken by dedicated screeners in each of the HSE maternity hospitals. The experience of other programmes has been that the use of part-time screeners (screening a minimum of 20 babies per week) provides a greater level of flexibility enabling greater coverage than exclusively fulltime screeners. Additionally the incorporation of the administrative function into the screener's job, as has been suggested in some of the literature, (rather than distinct administration and screener posts) enables greater screening capacity/coverage as well as providing administrative support.

The programmes in England and Wales suggests the required ratio of screening staff to births to be 1 WTE screener for every 1,250 births[40] (Davis A, Director of NHS Newborn Hearing Screening Programme, personal communication, 2010; Minchom S, Associate Director Newborn Hearing Screening Wales, personal communication, 2010). Based on this ratio, the 2009 Irish HSE maternity hospital birth rate of 74,246 suggests a requirement of 59.4 WTE screeners. However, evaluation of the first phase of the roll out of screening will help to inform this ratio.

7.1.11 Programme Roll-Out

It is proposed that the newborn hearing screening programme be rolled out on a phased basis by region with the initial phase evaluated. It should incorporate all maternity hospitals, home births and arrangements with private maternity hospitals in a region thus providing a population-based approach. A national implementation team and supporting programme plan should guide implementation.

7.1.12 Equipment

The National Audiology Review Group Childhood Screening Sub-Group has compiled a list of recommended equipment specifications for newborn hearing screening. In addition a national needs assessment of equipment requirements in terms of diagnostic audiology has been undertaken by this group. Limited funding has been provided for key diagnostic equipment for each of the Regions in 2010.

7.1.13 Paediatric Audiology Facilities/Accommodation

For babies who are screened in hospital, the screen may take place at the mother's bedside. Alternative suitable accommodation close to the maternity ward should be made available to the screening team to carry out screening if the level of ambient noise on the ward is too high. Office accommodation and storage will be needed for screening staff to perform tasks associated with screening such as data entry. Patient confidentiality should be maintained[40.] Where babies complete their screen at an outpatients clinic or community clinic, the accommodation used should be appropriate, preferably in rooms that minimise distraction or sound pollution from other activities. The environment needs to be as family-friendly as possible.

The facilities required for diagnostic paediatric audiology should include a sound proof room whose specification should be defined in accordance with recognised international standards (Hospital Technical Memorandum (HTM) 08-01, 2006[43]). Good international practice also emphasises the need for a family friendly environment. An assessment of requirements should be undertaken. Audiology facility standard specifications should be included in the planning and design of new HSE facilities/centres being developed e.g. Primary Care Centres.

7.1.14 Information Management System

Fundamental to having a quality screening programme is a national information management system that identifies the cohort of babies requiring screening, that enables effective monitoring of performance (coverage, refer rates, etc) and supports the tracking and follow-up of babies. This is crucial to the delivery of high quality continuous clinical care, and in the organisation of clinics and efficient record keeping[44]. It is accepted that there is a need for a single national system that is integrated, where data can be entered at local level. The development of such a system should only be undertaken within a national framework and in the context of the broader HSE child health requirements. The development of a partnership approach with ICT is required.

7.1.15 Training for Screeners

A formal training program for screeners should be developed/sourced, tailored to the needs of the Irish setting. The content of the training program should:

- Be guided by the job specification requirements
- Address all aspects of screening responsibilities with clear definition of limits in the role and function of screeners
- Include specific competency-based training through formal instruction and supervised practice
- Include instruction in the operation of the screening equipment.

Individual observation/assessment to determine the ability of the screener to perform duties associated with newborn hearing screening safely and competently should be completed with documentation or certification of proficiency. Personnel should complete a recertification of proficiency every two years, as a minimum, with ongoing assessment and re-training as needed.

7.1.16 Training Needs of Audiology Staff

There will be a specific need for training/upskilling of the paediatric audiologists who will provide paediatric ABR and VRA assessments, and for those paediatric audiologists who will be fitting and managing hearing aids for infants in each HSE Region. In preparation of roll out in one RDO area, training courses have been organised for those involved in the diagnostic assessment of babies who will be referred from the screening programme and further national training is required. In the longer term, an urgent priority is to secure a well-trained, competent, stable audiology workforce with much better recruitment and retention statistics than at present.

7.1.17 Training Needs of Other Professionals

Once babies, infants, children and young people have been identified with PCHI, a number of other professionals are crucially involved in supporting the child and family in home and school settings, according to individual need. Additional training will be required in working with very young deaf babies and their families. Visiting Teachers of the deaf and Speech and Language Therapists in particular, are a vital component in the delivery of services, and upskilling will be required as well as a review of the curricula of existing pre-registration training programmes for these professionals.

7.1.18 Public Awareness/Information

Public and professional awareness of the benefits of the screening programme to infants/families is fundamental to the success of the programme. A campaign to heighten awareness of newborn hearing screening is an essential prerequisite to programme implementation and will be an ongoing requirement.

Appropriate information materials should be developed and available for the different stages of the screening process as follows:

- Before screening
- For the screening tests
- For the audiological assessment of those referred by the screen
- For those who are found to have a permanent hearing loss.

These materials should be available in a range of languages and culturally appropriate. There is a comprehensive range of materials available in the UK and the National Audiology Review Group recommends sourcing and adapting these materials subject to copyright permission.

7.1.19 Service Workload: Follow-up Assessments for Screen Referrals

Babies who do not show clear responses to the screening tests will be referred on for audiological assessment. Audiologists with expertise in evaluating infants determine the presence, type and degree of hearing loss, if any. The purpose of audiological assessment is to provide sufficient audiometric information for subsequent audiological, educational, social and medical/surgical management, organised around an individual management plan. An individual management plan is a key tool and best practice requirement for an integrated multidisciplinary approach that has the client at the centre.

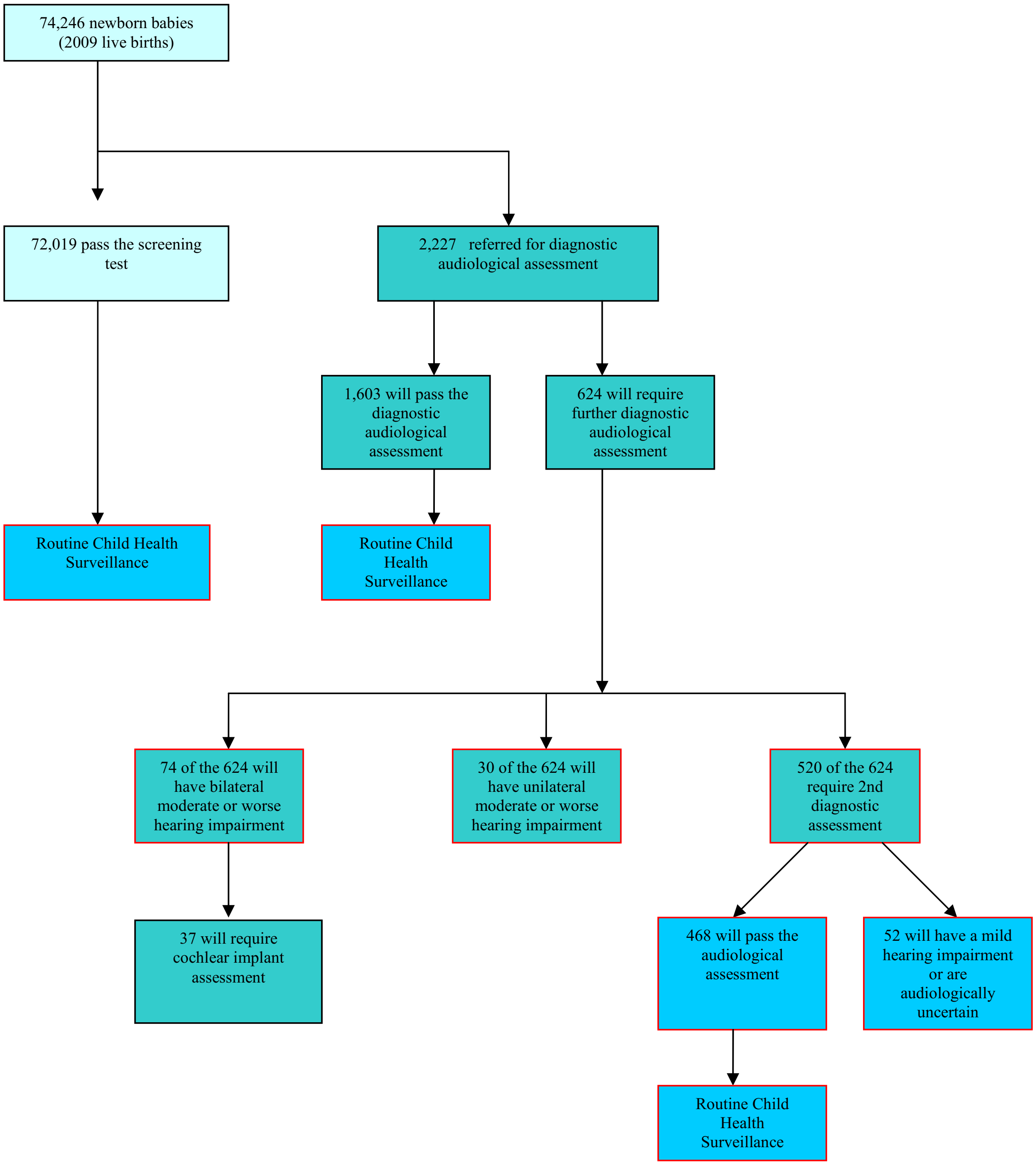
Audiological assessment needs to be completed by three months of age for early identification to occur and to allow intervention to begin at least before six months of age in accordance with nationally agreed protocols and best practice. Children who are identified with PCHI will need aetiological investigation, which may include genetic testing, developmental assessments, and ophthalmological assessment; these needs require a medical input to the team from suitably upskilled Paediatric Otologists, Paediatricians, or from Audiovestibular Physicians.

Figure 7.2 outlines the expected number of babies to be present at various points of the follow-up programme. The number of expected appointments at each stage of the follow-up journey has been determined using service requirement data from the British Colombia Report[45], international evidence and in consultation with the National Audiology Review Group.

Number of Expected Appointments Year 1 *(2009 HSE national birth data applied)***:**

- Based on a 3% referral rate of babies screened, 2227 babies will require diagnostic services. The other 72,019 will continue to undergo routine child health surveillance.
- Of the 2,227 babies screened, 1,603 (72% using British Columbia calculation) will be found to have normal hearing and be discharged from the programme. These babies will continue to undergo routine child health surveillance. The 624 babies remaining will require further diagnostic assessment.
- Based on a prevalence rate of 1 per 1,000 live births[10], 74 of the 624 babies will have a bilateral moderate or worse hearing loss. These babies will need three more appointments/hearing aid assessments in Year 1 and a further 6 in Year 2. Based on the Greater Manchester Service Specification document[40] approx 50% of these babies will be assessed for cochlear implant. Assessment for cochlear implant is recommended for those with a profound hearing impairment and in some cases with severe hearing impairment.
- Based on a prevalence rate of 0.4 per 1,000 live births (UK annual report 2006/-2007[46]), 30 of the 624 babies will have a unilateral moderate or worse hearing loss. These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.
- 520 of the 624 will need a second (1 further additional) diagnostic appointment. Of that 520, 468 will be found to have normal hearing and be discharged from the programme. These 468 will continue to undergo routine child health surveillance. The remaining 52 will have either a mild hearing loss or are audiologically uncertain and require further monitoring (0.7 per 1000 live births--prevalence rate based on the UK Annual Report 2006/2007[46]). These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.

Figure 7.2 Expected annual numbers for screen follow-up assessments



Number of Expected Appointments Year Two and Subsequent Years

- Annual Year 1 numbers repeat as new children are identified in the screened population
- Ongoing hours are required for children identified the previous two years. These are calculated as follows;
- The 74 children with bilateral moderate or worse hearing loss will need 6 assessments/hearing aid appointments in Year 2 and Year 3.
- The 30 children with unilateral, moderate or worse hearing loss and the 52 children with mild hearing loss or have audiological uncertainty hearing loss will need 2 assessments/hearing aid appointments in Year 2 and Year 3.

For clarity, these data are summarised in Table 7.1, along with estimated appointment times and consequent staffing needs. Note that none of the children identified with PCHI by screening are new cases for services—rather they are cases which are found earlier than would be the case if no screening were in place. Note also there are aspects of the audiological clinical work that are easier with younger babies and infants than with older infants, as well as longterm outcome improvements associated with early intervention which will reduce later costs.

Table 7.1 Estimates of workload associated with referrals from newborn screening

		Year 1			**Year 2**			**Year 3**		
Diagnostic Audiological Assumptions		**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**	**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**	**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**
Hours per Appointment				2.5			2.5			2.5
2009 live births - 74,246										
Number of babies referred from screen (3% referral rate)		2,227	1	5,568						
Number of babies who require 1 additional diagnostic appointment		520	1	1,300						
Number of babies with bilateral moderate or greater hearing loss		74	3	555	74	6	1110	74	6	1,110
Number of babies who have either a mild hearing loss or are audiologically uncertain and require further monitoring These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.		52	2	260	52	2	260	52	2	260
Number of babies who have a unilateral moderate or worse hearing loss. These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.		30	2	150	30	2	150	30	2	150
Audiological Diagnostic Requirement Direct from UNHS Programme		**2,903**		**7,833**			**1520**			**1,520**
Cumulative Audiological Diagnostic Requirement Direct from UNHS Programme				**7,833**			**9,353**			**10,873**
Children who missed screen/did not complete screen Calculation based on 5% of live births @ 45minutes per appointment.		3,712	1	2,784						

Cumulative audiological requirement on missed/not completed screens				2,784			2,784			2,784
Cumulative Total Hours of diagnostic audiological appointments				10,617			12,137			13,657
Indicative WTE – Indicative Working Hours Available										
No. of days per year	365									
Less shrinkage										
Less Weekends	104									
Less Bank Holidays	5									
Less Easter/Xmas Holidays	6									
Less Average Holidays	30									
Less Average Sick Days	3.5									
Working days available after shrinkage	216.5									
Standard Hours per Day	6.75									
Hours Available to Work per WTE in a Year	1,461									
WTE Requirement				7.26			8.31			9.35

7.1.20 Monitoring Children with Risk Factors for Permanent Hearing Loss

The purpose of Delayed-Onset Hearing Risk Monitoring is to identify infants who have passed newborn screening and have good hearing at birth, but who are at risk of developing hearing loss early in childhood. Based on the NHSP UK Annual Report 2006/7[46], 3% of children screened will be high risk. A strong surveillance component to newborn hearing screening is necessary to enable the early detection and intervention for these children. The US Joint Committee on Infant Hearing (JCIH 2007) states[31]:

"*Infants who pass the neonatal screening but have a risk factor should have at least one diagnostic audiological assessment by 24-36 months. Early and more frequent assessment maybe indicated for children with cytomegalovirus (CMV) infection, syndromes associated with progressive hearing loss, neurodegenerative disorders, trauma, or culture-positive postnatal infections associated with sensorineural hearing loss; for children who have received extracorporeal membrane oxygenation (ECMO) or chemotherapy; and where there is caregiver concern or a family history of hearing loss*".

The NARG recommends that a diagnostic audiology assessment be offered to these children no later than 24 months of age.

7.2 Infant Distraction Test Screen

Screening using the Infant Distraction Test (IDT) at around 8 months of age is carried out by PHNs/Community Health Doctor in the community as part of an overall child health surveillance programme. The UK Health Technology Assessment Report[12] highlighted the inadequacy of the Infant Distraction Test as a screening tool.

It is now recommended that, parallel to the introduction of the newborn hearing screening programme, the IDT screen should be phased out. Both screening programmes will run concurrently for a period of nine months, assuming that the IDT is being carried out at the recommended age of 7-9 months as recommended under Best Health for Children Revisited, 2005[41]. Following this, the IDT screen should be discontinued. For the nine month overlapping period Public Health Nurses will need extra vigilance to ensure comprehensive neonatal screening follow-up while the IDT screen is being phased out. During this period audiology services will likely experience an increase demand. The longer term should result in an improved and reduced referral rate.

PHNs will be involved in the targeted follow up of babies who missed/declined the newborn screen, do not complete the screen, and/or do not attend for audiological assessment following the screen in order to ensure that there is discussion with parents as soon as possible about hearing and appropriate arrangements/referrals made. Since parental concern is a major route to identification of PCHI not identified at birth, such concern should lead to timely specialist audiological assessment.

7.3 School Entry Hearing Screen

The aim of the school entry hearing screen (SES) is to detect children with PCHI that has not been detected to date. The screen uses sweep audiometry to establish if a child has satisfactory hearing or not. The prevalence of permanent childhood hearing impairment continues to increase through childhood. Of the 3.47 in 1000 children with a permanent hearing impairment at school screen age, half of these required identification after the newborn screen, and just under 20% of children with PCHI known to services as 6-year-olds or older, remained to be identified around the time of school entry[13]. The 2007 Health Technology Assessment report[13] concluded that there is a lack of good quality evidence upon which to base cost-effectiveness and policy decisions regarding the future of the SES. Nevertheless, it is a screen which is relatively easy to implement, with a captive population, at relatively low cost (estimated in the UK at £8 per screen test at 2007 prices), at an educationally and developmentally important point, and so the report recommended continuation of the screen with research and audit to establish a better evidence base. The NARG concurs with this, and furthermore recommends primary research be undertaken in Ireland to guide future policy decisions on the screen.

In the interim, we recommend a change to the current school entry hearing screen protocol in Best Health for Children such that the screen uses frequencies of 1000, 2000 and 4000Hz in each ear at intensity levels of 20dBHL. The child must hear all six stimuli at 20dBHL to pass the screen. A child with a screen not passed should be retested on a second occasion within 4-6 weeks unless there is particular concern. The rationale for removing 500Hz is that it is difficult to test in noisy school environments and creates additional unwarranted referrals. The training manual will need to be updated in line with the new protocol.

The Directors of Public Health Nursing are currently responsible for school entry screening in Ireland. The screen should be carried out on children in junior infants by dedicated PHNs with appropriate training. Currently SES is not done in all areas. All pre-school referrals from Public Health Nurses or Community Health Doctors, and referrals from school entry screening, should be directly referred to the audiology department for triage and follow up as required, as set out in the care pathways.

CHAPTER 8: REALISING THE VISION: DISCUSSION and RECOMMENDATIONS

8.1 Vision for the Future: Better Services, Better Value for Money

'Hearing deficits impact directly on communication ability, constrain development in children, lead to limitations in everyday activities and restrict personal and social participation. They have demonstrable effects on health-related quality of life, though they rarely register as priorities with health planners and policy makers. Hearing services are a low-cost, high-volume intervention, whose cost-utility compares very favourably with other healthcare interventions'[1].

The vision for audiology services delivered by HSE in Ireland is of high quality, safe, effective and efficient services, meeting and responsive to the changing needs of those of any age, from birth onwards, with potential or suspected difficulties with their hearing, auditory function, or balance, or with tinnitus. The services should be accessed without undue or unnecessary delay, and as far as possible be geographically convenient. Services should offer clear and accurate information upon which clients (or carers) can exercise their rights to make informed choices and should result in a high level of client (or carer) satisfaction. The services should be staffed by a well-trained, dedicated, caring and competent workforce with good governance and accountability, excellent clinical leadership at both national and regional levels, and committed to an evidence-based and evaluative service. They should work cooperatively, efficiently and collaboratively with closely allied disciplines as a multidisciplinary team, especially Ear Nose and Throat Departments and with Speech and Language Therapy, and with other Government Departments and Agencies, such as Department of Education and Skills. They should use techniques, procedures, facilities and equipment that reflect best practice.

This vision is anchored firmly in the needs evidence base: reliable data on the prevalence of hearing disorders in the population, and evidence about the effects of these upon development, participation, socialisation, inclusion, employability and quality of life are clear.

The work of the National Audiology Review Group during 2009-2010, including an extensive public consultation confirms the view that many audiology services in Ireland are substandard. Key performance indicators such as the age at diagnosis of congenital permanent childhood hearing impairment (PCHI) are extremely poor in comparison with similar developed countries. The reasons are many, and include:

- Lack of understanding by planners and policy-makers of the population needs
- Historical carry over from a non-unified health system
- Lack of investment in facilities and staff
- Structural anomalies in service organisation
- Lack of national clinical leadership and structured clinical governance
- Lack of training and regulation of workforce
- Lack of an evaluative and improvement culture
- Structural inefficiencies.

The current service inadequacies represent poor value for taxpayer's money. Despite an estimated annual investment in services by HSE of some €11 million (excluding voluntary organisation funding):

- Median age of diagnosis of congenital permanent childhood hearing loss is very late: data from one Region show the median age of intervention for permanent congenital hearing loss to be 24 months for children with severe and profound hearing loss and 60 months for children with moderate hearing loss
- Access to good authoritative audiological assessment and intervention is patchy at best, and nonexistent in some areas
- Children requiring cochlear implants have to wait longer than is optimal for surgery
- Children's earmould services are often slow, inadequate or even nonexistent in some areas
- Waiting times for adults requiring audiological assessment or hearing aids are unacceptably long
- Modern digital signal processing hearing aids are not yet universal for HSE's clients
- Services user comments about the services are highly critical of a range of issues concerning services or the lack thereof.

Thus, key outcomes such as developmentally-appropriate communication and language skills at school entry for children with permanent hearing impairment in Ireland will be poor. This gives rise to consequent higher special education costs, higher social welfare costs, mental health challenges, and lower employability[2].

It is our strongly held view that better use of existing resources coupled with necessary additional funding and full service integration to support the recommendations of this review would represent a highly justifiable long term investment, giving far better value for money in providing the best possible care, with improved health and social outcomes for clients.

A fundamental step-change is required in order to fulfil the vision, and this will require a very substantial commitment from clinicians, policy-makers and patient representatives of a kind and degree not seen before in this clinical area. The potential health, societal, and cost gains are very significant and this review presents an unprecedented opportunity to address many of the shortfalls of the current services. Some of the changes required and recommended can be achieved through reconfiguration and without additional resources, for example:

- The shift from silo based services to an integrated service is commensurate with the overall HSE Transformation Programme
- The validation of existing waiting lists
- Value for money opportunities in the procurement of hearing aids, equipment and accessories.

However, the cost-neutral changes on their own will not deliver the vision. Additional resources will be required over time to augment the changes referred to above and to provide the leadership, workforce and infrastructure required for a modernised audiology service in Ireland. The total additional investment would be likely to amount to a doubling of the existing indicative annual investment of €11 million (excluding voluntary organisation funding).

The recommendations that are proposed as a result of the work of the NARG are directed at achieving the vision and making the required step change. This will be a process that will take time, and may be constrained by a number of factors including resource availability. This should not, however, deter policy-makers, planners and clinicians from making an immediate change in priorities such that the required improvements in audiology and hearing services become a very high priority. Largely resource-neutral changes can be made immediately, given good will and commitment—again by both policy makers and clinicians themselves. Nevertheless, audiology services in Ireland have undoubtedly suffered from low investment over many years, and increased resources will be required for the vision to be achieved. While all recommendations are necessary and urgent they are however prioritised on the basis of service need (three, two or one star) in order to assist the process.

There will be a need, if the recommendations are broadly acceptable to the HSE, policy-makers, professional groups and the public, for a mechanism to oversee the detailed operational implementation of the changes and recommendations. The process would be expected to span a number of years, and **we recommend** that with immediate effect HSE appoints a national lead with full accountability for the modernisation of audiology services in Ireland based on the phased implementation of our prioritised recommendations.

We have categorised the recommendations into four themes: patient focus; clinical services; workforce, service structure and governance; infrastructure and support services.

8.2 Patient Focus

The aim of this group of recommendations is to reinforce the vision for quality audiology services by emphasising the importance of configuring services around patients/users needs, rather than the needs of professionals or services. The recommendations seek to place the patient/user at the centre of planning, provision, development, and decision-making affecting the operation of services.

We have relied heavily on the feedback from the public consultation exercises, including the Focus Groups, and seek to address directly many of the issues of particular concern to users/patients. We believe that some of the proposals are cost-neutral and offer the potential to transform the experience of patients using audiology services.

8.2.1 Patient Information***

We recommend that services provide full and comprehensive information to patients/carers in a variety of accessible formats. Specifically:

- An information pack at diagnosis, including information on voluntary sector support (e.g. DeafHear)
- An explanation of the relevant care pathway(s), with expectations addressed
- Where a diagnosis is likely to engender a high level of concern in a patient/carer (e.g. children with PCHI), those clinicians sharing the news should have undergone appropriate training and be experienced in the process
- The use of modern communication methods to keep patients informed e.g. e-mail contacts/text contacts/social network sites/website updates
- All correspondence about a patient to be copied to patient/carers
- Audiology departments to carry a range of publications/leaflets in waiting areas

8.2.2 Individual Management Plans (IMPs)**

We recommend that all patients, adult and children, who have a permanent hearing loss, tinnitus, or balance disorder, and who are being treated by audiology services, should have an IMP to 'provide an organised framework for planning, provision and evaluation'[47]. In more complex cases, IMPs can help to ensure better coordination of services, an important issue for patients and carers. Arrangements should be made for training for audiologists in the use of IMPs.

8.2.3 Link Workers for Children/Families**

We recommend the introduction of the concept of a 'link worker' for the parents/carers of children with permanent hearing impairment. Such a person would act as a single point of contact for a child/family, to signpost parents to appropriate local services and help reduce the perception of fragmentation of services.

8.2.4 Patient/Family Networks or Groups*

We recommend that audiology services facilitate the creation of user-led support and information networks for parents of children with PCHI, for adult hearing aid wearers, and where appropriate for other groups (e.g. those with Meniere's disease, tinnitus or balance disorders). User-led groups can provide a most effective form of support if properly organised, but issues around consent/privacy/protocols/technological issues require services support.

8.2.5 Patient Charter**

We recommend that the patient charter "You and Your Health Service" be promoted from the audiological services perspective. This service charter would, *inter alia,* ensure that patients' concerns would be listened to, that they would be kept informed about their treatment and care, that Care Pathways would be explained and timelines adhered to, that facilities and accommodation would be appropriate (e.g. child friendly), that patients/carers would be informed of best practice/technological advances whether available or not, that patients/carers would be fully informed when things go wrong, and that unbiased information about private sector provision be made available.

8.2.6 Children's Hearing Services Working Groups (CHSWGs)**

We recommend that CHSWGs be set up in each Region/area (some are already in existence, e.g. in Donegal/Sligo). The CHSWG model in the UK would serve as a useful model. CHSWGs would have multidisciplinary and multiagency membership, and would include significant representation from parents of children with PCHI. The CHSWG role is to monitor service performance, encourage and support innovation and improvement, and to involve users in planning, provision and operational changes to services.

8.2.7 Flexible Access***

We recommend that audiology departments introduce flexible working hours such that the service does not stop at lunchtime, and so that weekend and/or out of hours appointment slots are available for the benefit of working patients or school age children.

8.3 Workforce, Service Structure and Governance

8.3.1 Integrated Audiology Departments: Community and Acute Services * * *

There are two splits in current service structure which work against patient need and patient care, and which introduce anomalies, delays and duplication into the system. The first is the split between 'community-based services' and 'hospital-based services' (or 'community' and 'acute'). Within audiology this can give rise, for historical reasons, to serious anomalies that work against patient need and continuity of care. As an example: newborn hearing screening has been running in the maternity unit of Galway Hospital for a number of years, due largely to the efforts of the local ENT consultants and the dedication of the audiologists in the hospital. Children with moderate or greater PCHI are thus identified within a few weeks of birth. Hearing aid fitting is currently the responsibility of community services; the audiological scientist post in the Galway community service has been vacant for seven years. Audiologists in Galway community services, similar to most other areas, do not work with children, and therefore the service is unable to fit a child newly-identified by newborn screening with hearing aids—the starting point of early intervention. Integration across community and acute (alongside recommendations below) would lead to more efficient use of staff resources to the benefit of patients (in this case children with PCHI). Many further examples are to be found within the parental submissions to the Review.

In line with the HSE's strategic Transformation Programme, and in order to ensure effective critical mass, good clinical governance, efficient skill mix, efficient use of facilities and equipment, and opportunities for staff support, peer review and continuing professional development, and to minimize duplication and service complexity detrimental to the patient journey, **we recommend** that community and acute audiology services in each of the four HSE Regions should be merged and reorganised into a single managerial and clinical structure with identified high quality clinical leadership. The clinical leadership to the integrated all-age department of audiology should be provided from a fulltime consultant-equivalent audiology post occupied by a suitably qualified and skilled person whose primary speciality is audiology[XIX].

The integrated and autonomous department of audiology should have a main base location with adequate accommodation and equipment commensurate with good quality evidence-based audiology practice; justifiable outreach arrangements and/or satellite sub-departments should be made as and where appropriate. However, as the Scottish needs assessment[1] noted: 'Audiology services are inherently multi-disciplinary in nature, both within the NHS and with external agencies. Audiology services for adults and children are effective only when functioning links with child health, speech and language therapy, ENT surgery, other medical specialties and allied health professionals are in place'. For children's services, links with the Visiting Teacher of the deaf service are crucial. Initially after diagnosis there is a period of time when the child will be seen by a variety of medical specialties (ophthalmology, ENT, genetics, paediatrics) but since some 70% of children with PCHI have no additional disabilities the majority of these will not require ongoing medical assessment or intervention. Very often an appropriate location for the autonomous audiology department base would be adjacent to ENT, but other arrangements can work well and should not be excluded.

We recommend that the regional audiology clinical lead should report for operational matters to the RDO (or appropriate delegate), and should be the budget-holder for the audiology services in that Region. Budgets would be formed initially on a historical basis from community and acute audiology spends. Thereafter justified budgetary cases would be made by the clinical lead to the RDO, but the clinical lead would retain the flexibility to use the budget in order best to meet the needs of the population for hearing services. This post holder should report clinically to the national clinical lead for audiology.

[XIX] Consultant-equivalent means the equivalent of a Band 8c audiologist in the UK career structure. See also recommendation 8.3.2. It should not be taken to imply consultant in medical or surgical specialities.

8.3.2 Integrated Audiology Departments: 'Audiologists', 'Audiological Scientists' and a Unified Grading Structure * * *

In the UK in the 1970s, non-graduate audiology technicians who formed the bulk of the workforce were supplemented by postgraduate-trained audiologists; the latter coined the term 'audiological scientist' to emphasise the distinction. Shortly afterwards the audiology technicians adopted the title 'audiologist'. In the 1990s both these titles became protected prior to formal statutory registration with two separate registration routes. In 2002 the non-graduate training route for audiologists was closed in favour of a new BSc in Audiology.

This simplified outline of UK developments in the audiology profession has resulted in two titles (audiologist, and 'clinical scientist in audiology' or audiological scientist) with two registration routes, all within the generic title 'health care scientist' and its parallel (for e.g. Speech and Language Therapists and Occupational Therapists) of 'allied health professional'. It is highly likely that this confusing system of professional categorisation and associated titles is not understood by the UK general public (one of the criteria for registration).

The relevance of this UK context to Ireland is that the HSE as employer, and professionals themselves, have adopted the two titles of 'audiologist' and 'audiological scientist' with an over-interpretation of the implications of the basic qualification which in the case of an MSc from the UK did not on its own confer clinical competence. The pay scales for audiologists (see table 4.2 , Chapter 4) are different from (and lower than) the ad hoc pay scale for 'audiological scientists' (based upon the physicist scale; there is no explicit pay scale for Audiological Scientist). This is inefficient, and leads to serious anomalies which undermine the development of a competent workforce with good recruitment, retention, and career and personal development opportunities.

We recommend a root and branch restructuring of audiology careers in Ireland into a unified career structure and pay scale spanning audiological assistants (non-graduate), audiologists (graduate qualifications) and senior and consultant audiologists (postgraduate MSc or above qualifications, the latter with at least five years' additional experience), with training opportunities for those willing and able enough to progress from lower bands to higher bands, and with direct entry routes possible with additional appropriate conversion programmes. Suggested Scopes of Practice (SoPs) for these three broad levels are detailed in Appendix B; these would introduce more flexible working practices with regard to audiologists providing care to both children and adults without unnecessary demarcations. **We recommend** the usual procedures in such situations of the 'grandparenting' of existing staff to appropriate grades based upon competencies and tasks being practiced (rather than qualifications), with the usual protection for individuals' terms and conditions of employment.

8.3.3 Registration***

Statutory registration of a profession is an accepted route towards protecting the public from possible harm caused by poor or dangerous practice, and to ensuring high standards of training and practice within a profession. **We recommend** that the title 'audiologist' become a protected title, registered under the Health and Social Care Professionals Council, with graduate level (BSc in Audiology) as the point of entry as a registered practitioner, and with the title ('audiologist') covering both graduate level and postgraduate level practitioners. The procedures for registering a new profession takes time (see section 4.8) but efforts should be made to move to statutory registration of the unified audiology profession as a matter of urgency, with the usual safeguards for the existing workforce.

It would make for further rationalisation and increase public understanding and public protection if registration of private sector Hearing Aid Audiologists (HAAs) were to be incorporated within this regulatory scheme. Hearing Aid Audiologists deal with a restricted area of audiology, namely the assessments, procedures and rehabilitation associated specifically with the provision of hearing aids for adults. At present there is no regulation other than that provided by membership of the ISHAA; and anyone can set up as a hearing aid dispenser in private practice outside of ISHAA. The level of qualification recommended by ISHAA for HAAs is a two year work-based degree level course (a 'Foundation' degree), in line with recent developments in the UK. **We support** the ISHAA proposal for registration of HAAs, based upon the two year training programme, and linked in with the registration and training of audiologists, such that there is reciprocity and an integrated career structure with 'stepping on and stepping off' training opportunities.

8.3.4 Workforce Numbers, Training and Recruitment* * *

Workforce Numbers

Reorganisation of the existing workforce into integrated departments of audiology will realise some efficiencies. But there is no doubt that the extent of hearing healthcare need in the population (see for example the waiting list data in Chapter 4) requires an expanded workforce. Detailed work on workforce needs has been carried out in the last decade in the UK following a modernisation programme there. Green[48] has used benchmarks from existing good practice centres and the recommended appointment durations for most of the procedures employed by audiologists (based on published Good Practices Guidelines) to estimate required numbers of audiologists and assistants audiologists for an all-age NHS service covering a population of 400,000 (Table 8.1).

Table 8.1: Numbers of WTE audiologists and skill-mix for a good quality all-age UK NHS service covering a population of 400,000. This estimate is based on benchmarking against good quality sites, audiology appointment times and suggested Scopes of Practice (see Appendix B), and with calculations of staff ratios by banding (Green R. Personal communication, August 2010).

Assistant audiologists (non-graduate)	Audiologists (graduate/mid level)	Audiologists (postgraduate) [one at 'consultant' level]
3	9	7

If the figures in Table 8.1, based on 400,000 population, are extrapolated to the 2006 Irish population, and the adult hearing aid work component, which represents 40% of audiology staff time in the universal UK NHS service (Davis A. Personal communication, August 2010) is then reduced by 64% (because only 34.5% of the adult population have medical cards), the resulting estimated required audiology staff numbers for Ireland are as shown in Table 8.2.

Table 8.2: Estimated numbers of WTE audiologists and skill-mix required to provide good quality all-age HSE audiology services for the Irish based on current service entitlement and Green's (2010) figures.

	Assistant audiologists (non-graduate)	Audiologists (graduate/mid level)	Audiologists (postgraduate) [five at 'consultant' level]	**Total workforce WTEs**
Current reported approximate WTE:	0.5	49.9	16.1	66.5
Additional WTE required	23.5	21.1	38.9	83.5
Total Workforce	24.0	71.0	55.0	150.00

In order to move to the estimated required WTEs detailed in Table 8.2, approximately 83 additional WTEs would be required but with a different, more effective, skill mix than is found at present:

- The introduction of an additional 23.5 assistant audiologists
- An increase of 21.1 WTE graduate level audiology staff,
- An increase of 38.9 WTE postgraduate-level audiology staff.

*****We recommend** that HSE carry out an urgent workforce planning exercise of audiology clinical staff in order to confirm numbers for the necessary workforce uplift.

*****We recommend** that this uplift is undertaken within the proposed integrated audiology departments in the 4 HSE Regions, and **we recommend** the prior appointment, in 2011, of four Regional Clinical Audiology Leads and one National Clinical Lead to drive this forward. The first task of these 'consultant' level leads would be to oversee the implementation of integrated audiology services and to prepare fully justified cases for the numbers and deployment of additional staff and equipment needs (see below) in their region. Conditional upon the validation of these staffing numbers **we recommend** the recruitment of the estimated 21.1 graduate-level audiologists, alongside the estimated 23.5 assistant audiologists, in 2012, followed by the remaining 33.9 postgraduate audiologist (i.e. 38.9 less the five Clinical Audiology Leads) in 2013.

Training and Recruitment

Recruitment and retention has always been a major difficulty for audiology in Ireland (e.g. the audiological scientist post in Galway, vacant for seven years); a major reason for this is the lack of initial training programmes for audiology in the country, coupled with many poor services which are unlikely to attract overseas audiologists. Sponsoring nationals to one or more training programmes overseas (e.g. in the UK) carries the risk that some will choose not to return despite financial penalties, as well as the problem of clinical competence which at postgraduate level in the UK is not included within the degree award. This is a vicious cycle, because the best new graduates or postgraduates, those from whom tomorrow's leaders will emerge, tend to seek posts in dynamic, forward-looking, well-led departments of audiology.

Thus, a fundamental reason for the current state of audiology services in Ireland is the lack of training opportunities within the country. It is our strongly-held view that the underlying systemic problem for Irish audiology services of recruitment, retention and, most importantly, good effective clinical leadership will not be solved until a School of Audiology based within the country is established.

*****We recommend** that a suitable Higher Education institution be commissioned by HSE as a matter of urgency to develop integrated training programmes (based on the draft SoPs) for BSc and MSc level training in audiology, and for non-graduate audiology assistants, with stepping on and stepping off points that allow those able and willing to progress according to their personal needs and the needs of the service.

An Irish School of Audiology would ensure a steady supply of competent practitioners for the service; it would provide a focus for initiatives in service improvement and service development, underpinned by evaluative, evidence-based practitioners; it would help develop a research-led reflective culture in audiology; it would help meet the ongoing needs for CPD; and above all it would be the nursery for the future leaders of the service. All of these would help to ensure that the needs of people with hearing loss in Ireland are very significantly better met than they are at present.

Fail and attrition rates, changing-career rates, and retirement rates would suggest that training programmes need to provide new practitioners at an annual rate of approximately 20 per cent of the total workforce in order to refresh and sustain that workforce. Thus a School of Audiology might expect, based on the numbers in Table 8.2, to graduate 14 BSc graduates per year and 11 MSc graduates per year, as well as providing CPD courses, and contributing to the training of a small number of assistants each year. Additionally, the training of private sector Hearing Aid Audiologists could contribute to the training centre's development and realise economies of scale. Since there is currently no audiology training programme in Northern Ireland, there may also be opportunities for an all Ireland initiatives.

However, in order to address the immediate workforce needs,
*****We recommend:**

- That HSE negotiate a formal arrangement with a suitable University/Universities in the UK to provide MSc-level training in audiology for five suitable graduate recruits per year for six years starting academic year 2011/12. Since the clinical competence required to practice independently is outwith the one-year MSc in Audiology in the UK, arrangements would have to be made for the MSc Audiology graduates to secure competencies under a system of clinical education to be developed in Ireland using centres of excellence, drawing upon best practice elsewhere, and assured for quality. Development and coordination of such practical training and assessment of competency should be the responsibility of the new national and regional clinical audiology leads in collaboration with the ISA/IAA (Irish Society of Audiology/Irish Academy of Audiology).
- That HSE ensure that any students currently being sponsored are recruited into the service as soon as possible as part of the workforce uplift.
- That a coherent forward-looking national recruitment drive be developed to recruit the required graduate audiologists from the UK BSc Audiology programmes in 2012.
- That a training programme to train 23 assistant audiologists during the year 2012 be developed in a suitable venue or network of venues during 2011.
- That each Region be allocated dedicated once off CPD funding of €10,000, to be managed by the Regional Clinical Leads in collaboration with the National Clinical Lead, in order to address immediate needs for skills uplifts for existing staff, particularly in paediatric audiology and the requirements around newborn hearing screening.

8.4 Clinical Services

8.4.1 Universal Newborn Hearing Screening (UNHS) * * *

(See Chapter 7 for a fuller account of this, and associated, recommendations).

Age at identification of moderate, severe and profound congenital permanent childhood hearing loss is unacceptably late in Ireland. This compromises development, communication, literacy, educational attainment, and employment prospects, causes undue parental distress, increases later costs in health, education and social care. ***We recommend that a national programme of newborn hearing screening be introduced such that all babies have their hearing screened shortly after birth according to Care Pathway in Chapter 6 and the recommendations in Chapter 7. Implementation should be top-down, aimed at covering the whole population including home and private births. HSE has funded an initial phase in the South Region with effect from late 2010, and full national implementation should be achieved as quickly as possible and no later than the end of 2012. Information on costs per screen will emerge from the first phase implementation.

Some 10% of children identified by the newborn screen as having a permanent hearing impairment will have Auditory Neuropathy Spectrum Disorder (ANSD). This complex and challenging condition has a high level of prognostic uncertainty and cases of ANSD require careful and specialised ongoing assessment, support and intervention. With such small numbers of cases, around seven per year, ***we recommend the designation of one audiology department as a national specialist centre for those with suspected ANSD.

The significant potential for outcome benefit that follows the implementation of newborn hearing screening is not achieved without appropriate follow up and intervention. Thus newborn screening has implications for paediatric audiology (requiring high quality family-centered diagnostic assessments and fitting and management of hearing aids), and for the number and training of Visiting Teachers (VT) of the deaf, who are managed through the Department of Education and Skills. ***We recommend that within the constraints of the Visiting Teacher service, very early pre-school support for parents of children with permanent hearing impairment identified via newborn hearing screening is recognised as a major priority and that continuous availability of the service is ensured. The current VT service (delivered by 29 WTE Teachers of the deaf) supporting deaf children up to 18 years of age and their families is overstretched and is not all year round; thus an increase in staff resources is urgently required to support the newborn hearing screening initiative.

8.4.2 Other Childhood Hearing Screens ** (see also Chapter 7).

In the interim, efforts should be made to improve the performance of the 8-month Infant Distraction Test (IDT) screen; once UNHS has been implemented, ****we recommend** that the IDT screen should be abandoned and consequent savings made. The IDT screen tends to over-refer (high false positive rate) so efficiencies should be gained that will benefit those audiology services that take referrals from the IDT screen.

****We recommend** that school entry hearing screening should be implemented nationally as a back-stop for indentifying late onset or mild PCHI (not identified through the newborn screen or through responsive services) and any other hearing disorders at this important point in a child's education. The screen protocol, equipment, and training of screeners should comply with nationally-agreed uniform standards, and screen performance should be monitored regionally and nationally in order that any future policy decisions on the screen can be evidence-based. In order to achieve this, ****we recommend** that a national group draw up guidance on protocols and training, and initiate mechanisms for performance monitoring of the screen. This group should sit as appropriate within the emerging structures proposed for governance of all national screening programmes.

8.4.3 Validation and Clearance of Current Waiting Lists ***

We recommend that each Region should, as matter of urgency, validate their existing audiology waiting lists in order to establish the extent of ongoing need, and to prioritise patients according to level of urgency. Services should put measures in place to reduce waiting lists. As part of this exercise, there should be a common waiting list and referrals should be placed on that list by reference to the agreed criteria which cannot include the fact that the referral is arising as a consequence of the patient's attendance at a private ENT clinic[XX]. We have been advised by clinicians that the numbers of patients from private ENT consultations are likely to have a significant effect on waiting times for non-private patients; this could lead, for example, to further delays in the diagnosis of permanent childhood hearing impairment.

8.4.4 Care Pathways and Good Practice Guidelines * * *

We recommend that audiology services should immediately put into practice the Care Pathways (CPs) outlined in Chapter 6 of this report. To support the CPs, by the end of 2011 all services should be using the Good Practice Guidelines (GPGs) listed in Appendix C of this Report. **We recommend** that the HSE should convene, with appropriate representation, a national audiology standards group with responsibility for updating and monitoring the use of these and subsequent evidence-based GPGs. Key Performance Indicators (KPIs) should be monitored and made available in the public domain. The CPs should be made widely available, to PCTs, GPs, other professional groups and the public in order to foster a shared understanding of referral routes and pathways, and so that the public can know what to expect once a referral is made.

8.4.5 Hearing Aids, FM Systems and Earmoulds * * *(See also section 8.5)

*****We recommend**

- An increase in the overall budget for hearing aids and earmoulds to match 2009 expenditure
- The necessary additional financial accommodations to support the fitting of modern, good quality DSP hearing aids
- A review of the budget to ensure its allocation nationally is based on principles of equity and need.

There is the opportunity to realise savings through more strategic procurement, starting with new supply contracts in 2011/12 (see 8.5).

*****We recommend** that all hearing aids issued by HSE services to children and adults should be modern good quality Digital Signal Processing (DSP) hearing aids, fitted and verified by Real Ear Measures (REMs) according to the DSL i/o methodology (children) and the DSL i/o or NAL N/L methodology (adults). Manufacturers' click-and-fit rules should not be used. Where replacement hearing aids are provided to adults with old analogue aids (e.g. following irreparable malfunction) it is permissible to replace with the same analogue hearing aids while such remain available on contract, but all new aids should be DSP and patients should be encouraged to change to DSP aids as soon as possible. Open fits and RIC (receiver in the canal) technology should be encouraged and used where appropriate. ITE aids are individually matched to the shape of the patient's ears, and

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[XX] Advice National Contracts Office 2010 cannot therefore be replaced from stock. In view of this, and the relatively lower reliability of DSP ITE aids, the limited functionality of DSP ITE aids compared with DSP postaurals, and the recent cosmetic advances made with postaural aids, ***we recommend** that HSE services cease issuing ITE aids and phase out their use. In order that patients and clinicians understand the reasons for this, especially the acoustic benefit reasons for postaural aids, there will need to be a coherent information campaign to explain the change.

These recommendations should ensure that devices and the associated rehabilitative support meet patient needs; and should additionally reduce or remove the inefficient use of public monies which occurs when those with medical card entitlement also use the PRSI grant refund of €760 towards privately purchased hearing aids.

*****We recommend** that the Department of Health and Children and Department of Education and Skills liaise to develop a robust and comprehensive candidacy strategy for personal FM systems, to include pre-school provision. The optimal integration of high quality DSP hearing aids and personal FM systems for infants and children is complex and challenging, and is often compromised by poor liaison between Education and Health Services, the former being responsible for personal FM provision and the latter for DSP hearing aid provision. ***We recommend** that the two Departments review the system for procurement, provision, repair and maintenance of personal and soundfield FM systems in order to ensure the needs of children are fully and effectively met in the most efficient way.

Currently the Front Row Pro-Digital infrared classroom amplication system with a 940R Receiver is issued nationally to schools where there are children with hearing loss who meet the criteria for such a system. There is no formal system in place whereby an individual from the distributor or the supplier is responsible for overseeing the timely and correct installation of such systems. ***We recommend** that the DES discuss terms with both in order to ensure that all children who qualify for a soundfield system return to school or begin school in September with the appropriate technology in situ. Currently Visiting Teachers of the deaf are overseeing the installation with advice from the distributor. Dedicated staff for such a task would be preferable, so that teething problems and trouble shooting could be dealt with by an appropriate technician with expertise in this area.

The provision of good quality well-fitting earmoulds remains a serious challenge for services, especially for children. Parent submissions include some disappointing accounts of poor service. The value of modern DSP hearing aids is lost if good earmoulds are not forthcoming, and without unnecessary delay. ***We recommend** that clinical leads for services should ensure that paediatric audiology staff are fully trained to take impressions from babies, infants and children, and that the time from impression-taking to fit of the new earmoulds is no more than five working days. This target may require re-examination of the administrative and clerical systems supporting the process; direct mailing to the contracted earmould manufacturer and direct mailing of the earmoulds to parents or Visiting Teacher of the deaf for fitting are options to be explored in order to meet the target. For pre-school children in rural areas, consideration should be given to the home-visiting Visiting Teacher of the deaf being trained to take impressions and enabled to send direct to the manufacturer.

The current system for hearing aid repairs does not always meet the needs of patients; often they are left without amplification for a number of days despite the excellent work carried out by the national repair service in Dublin. ***We recommend** that the administrative and postal systems supporting the national repair service's activities be reviewed and improved to remove unnecessary delays. ***We recommend** in addition that all audiology departments should have a walk-in service for repairs staffed by assistant or graduate audiologists. Often the apparent repair problem will be the result of earmould or tubing problems (instantly remedied), or with the patient (e.g. unrealistic expectations, change in hearing) in which case an audiology review appointment should be arranged if the issues cannot be dealt with immediately.

There is no decontamination process in place as part of the national repair service, so aids once repaired have to be returned to that particular user. ***We recommend** that future hearing aid contracts with manufacturers should include a repair guarantee and decontamination clause in order to provide another repair option. This would allow the repaired aids to be returned to 'new' stock; in such cases patients can be provided with a replacement aid at the time their aid was sent for repair, thus avoiding downtime for the patient. This option could and should be used for those for whom downtime would represent a severe challenge to daily living (e.g. severely or profoundly deaf patients; deaf-blind patients).

8.4.6 Cochlear Implants (CI) and Bone-Anchored Hearing Aids (BAHA) * *

Both cochlear implants and BAHAs provide very significant benefit for suitable patients, adult and child. The public consultation provided considerable evidence of patient and parent satisfaction with the national cochlear implant centre, based at Beaumont Hospital. This is a good example in hearing services of a multidisciplinary team, with good skill mix, critical mass, and appropriate leadership. Outcomes and data monitoring are exemplary within an evaluative culture. **We recommend** continued ring-fenced financial support for the cochlear implant programme but at levels which allow for simultaneous bilateral implantation for children. We support the proposal to locate the national paediatric cochlear implant service within the new children's hospital, and **we recommend** that in order to take better advantage of the interactions and synergies between the clinical decisions, processes, and equipment, and to provide parents and children with a more seamless service, the paediatric cochlear implant team be integrated with the paediatric audiology service at the national paediatric hospital.

There is, on the other hand, no ring-fenced Bone Anchored Hearing Aid (BAHA) budget, nor a system for procurement, concentration of skills, or repairs. The proposed Care Pathway for BAHAs, and the notes therewith (Chapter 6), suggest significant gains in efficiency and patient care with a new system. **We recommend** ring-fenced financial support for a national BAHA service, based upon data on predicted national numbers of 25-35 per year, and located in three ENT departments (e.g. Dublin, Cork and Galway), where expertise can be concentrated. **We recommend** in addition that BAHA devices and repairs be subject to national procurement to ensure value for money.

8.4.7 External Services and Service Level Agreements (SLAs)*

***We recommend** that in the context of audiology and hearing-related services HSE reviews all SLAs currently in place to ensure;

- That there exists for each agency receiving funding one SLA only with a supporting accountability framework
- That allocation of monies satisfies the priorities set out
- That the SLA is scripted and standardised to support quality, transparency and accountability
- That robust and regular performance monitoring occurs

- That all SLAs supporting audiology and hearing-related services are reviewed in the context of the whole audiology service to ensure best value for money in the context of finite resources.

8.4.8 Children's Continuing Entitlement to Services into Adulthood **

****We recommend** that, in order to ensure ongoing continuity of care, for those who have a permanent hearing impairment requiring hearing aids during childhood, the HSE makes a policy decision with the Department of Health and Children with a view to providing hearing aids for life.

8.5 Infrastructure and Support Services

8.5.1 Information Systems * * *

To support good quality efficient clinical service, and also to enable performance monitoring and to support clinical governance, *****we recommend** that a single unified audiology Patient Management System (PMS) should be introduced to cover the activity of each Region's audiology department, with the necessary support training. The effective use of these systems will require additional IT support from the HSE. *****We recommend** that HSE urgently develop a national strategy to introduce PMSs throughout the proposed integrated HSE audiology services.

8.5.2 Equipment and Facilities * * *

We recommend that an equipment audit be carried out for integrated audiology services in each Region by a specially-appointed HSE group led by the new National Audiology Clinical Lead. This should be undertaken in collaboration with each of the four newly-appointed Regional Clinical Leads as a first and necessary planning step in the effective functioning of the modernised services. An audit of facilities should similarly be undertaken to assess current strengths and additional requirements.

8.5.3 Procurement and Supply * **

*****We recommend** that national procurement be instigated (or in some cases confirmed) to take advantage of efficiencies, consistency and economies of scale for:

- Postaural DSP hearing aids (separately for children's and adult's needs)
- DSP hearing aid fitting systems
- Audiological assessment equipment (e.g. equipment for ABR, OAE, tympanometers)
- An efficient and effective earmould manufacturing service
- Audiology Patient Management Systems and other IT requirements for the service

To support national procurement, *****we recommend** the establishment of an efficient national advisory group whose brief would include audiological and related equipment including hearing aids. The responsibilities of this group would be to work with procurement and supply services and advise on specifications for these national contracts, and to oversee and advise on evaluation exercises run by the national technical support service. The group should take advantage of links established (by NARG).

8.5.4 National Hearing Aid Repair Service *

Members of the NARG met with members of the technical support service based at North Great George's St in Dublin (and the Technical Manager for the team was a member of the NARG). The NARG members were impressed by the commitment and skills of the technical support team.

The skills and knowledge available to HSE's audiology services from the technical support service are considerable. There are further ways in which these could be used to benefit the service. ***We recommend** that plans be developed for the technical service to provide:

- A national calibration service for all audiological equipment
- A repair service for BAHAs, subject to negotiation with manufacturers (as part of procurement process)
- A technical evaluation service for potential contract aids and audiological equipment during procurement processes.

ABBREVIATIONS

NARG	National Audiology Review Group
CHI	Conductive hearing impairment
CP	Care Pathways
SNHL	Sensorineural hearing loss
GMS	General Medical Services
PCHI	Permanent childhood hearing impairment
DSP	Digital signal processing
DES	Department of Education and Skills
NICU	Neo-natal Intensive Care Unit
ANSD	Auditory Neuropathy Spectrum Disorder
OME	Otitis Media with Effusion
GPs	General Practitioners
PCTs	Primary Care Teams
HL	Hearing loss
IMP	Individual Management Plan
BTE	Behind the Ear
ITE	In the Ear
ACS	Association of Clinical Scientists
HAA	Hearing Aid Audiologist
BAAT	British Association of Audiology Technicians (now defunct)
BAA	British Academy of Audiology
ISA	Irish Society of Audiology
IAA	Irish Academy of Audiology

REFERENCES

1. Public Health Institute of Scotland. Needs Assessment Report on Audiology Services for Scotland, 2003.

2. Grosse S. Newborn hearing evidence-statement: screening. In: Campbell KP, Lanza A, Dixon R, Chattopadhyay S, Molinari N, Finch RA, editors. A Purchaser's Guide to Clinical Preventive Services: Moving Science into Coverage. Washington, DC: National Business Group on Health; 2006

3. Schroeder L, Petros S, Kennedy C, McCann D, Law C, Watkin PM, et al. The Economic Costs of Congenital Bilateral Permanent Childhood Hearing Impairment. Pediatrics 2006; 117:1101-12.

4. Neuhauser HK, Von Brevern M, Radtke A, Lezius F, Feldmann M, Ziese T and Lempert T. Epidemiology of vestibular vertigo. A neurotologic survey of the general population. Neurology 2005; 65: 898-904.

5. Coles RR. Epidemiology of tinnitus: (1) Prevalence and (2) Demographic and clinical features. J Laryngol Otol Suppl. 1984; 9 (1) 7-15, (2) 195-202.

6. Yoshinaga-Itano C. Benefits of early intervention for children with hearing loss. Otolaryngology Clinics of North America 1999 Dec;32(6):1089-102.

7. Moeller MP. Early Intervention and Language Development in Children Who are Deaf and Hard of Hearing. Pediatrics 2000 Sept; 106(3):1-9.

8. Sharma A, Dorma AF. Central auditory development in children with cochlear implants: clinical implications. Adv Otorhinolaryngol 2006;64:66-88.

9. Audiology Services Advisory Group. Quality Standards for Paediatric Audiology Services. Edinburgh: Scottish Government, 2009.[cited 20/10/2010]; Available from: http://www.scotland.gov.uk/Resource/Doc/270506/0080556.pdf

10. Fortnum HM, Summerfield AQ, Marshall DH, Davis AC, Bamford JM. Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire-based ascertainment study. British Medical Journal 2001; 323: 536-540.

11. Bamford JM, Ankjell H, Crockett R, Marteau T, McCracken W, Parker D, Tattersall H, Taylor R, Uus K and Young A. (2005). *Evaluation of the Newborn Hearing Screening Programme in England: Studies, Results and Recommendations*.

12. Davis A, Bamford JM, Wilson I, Ramkalawan T, Forshaw M, Wright S. A critical review of the role of neonatal hearing screening in the detection of congenital hearing mpairment. Health Technology Assessment 1997;1(10): 1-177.

13. Bamford J, Fortnum H, Bristow K, Smith J,Vamvakas G, Davies L, et al. Current practice, accuracy, effectiveness and cost-effectiveness of the school entry hearing screen. Health Technology Assessment 2007;11(32).

14. Bess FH. Tharpe AM. An introduction to unilateral sensorineural hearing loss in children. Ear Hear 1986 Feb;7(1):3-13.

15. Bess FH, Dodd-Murphy J, Parker RA. Children with minimal sensorineural hearing loss:prevalence,educational performance, and functional status. Ear Hear 1998 Oct;19(5):339-54.

16. Tharpe AM, Bess FH. Minimal, progressive, and fluctuating hearing losses in children. Characteristics, identification and management. Paediatric Clinics North America 1999; 46(1):65-78

17. Moore DR, Ferguson MA, Edmondson-Jones AM, Ratib S, Riley A. Nature of auditory processing disorder in children. Pediatrics 2010 Aug;126(2):e382-90. Epub 2010 Jul 26.

18. Ferguson MA, Hall RL, Riley A, Moore DR. Communication, listening, cognitive and speech perception skills in children with auditory processing disorder (APD) or specific language impairment (SLI).J Speech Lang Hear Res 2010 Aug 5[Epub ahead of print].

19. Young AM, Ackerman J, Kyle JG. On creating a workable signing environment: deaf and hearing perspectives. J Deaf Stud Deaf Educ 2000 Spring;5(2):186-95.

20. Seewald RC. Universal Habilitation. American Journal of Audiology 1995; 4(3):5

21. Seewald RC, Editor. A Sound Foundation Through Early Amplification: Proceedings of an International Conference, 2000. Stafa, Switzerland: Phonak AG.

22. Haggard MP. Hearing screening in children-state of the art(s). Arch Dis Child 1990 Nov;65(11):1193-5.

23. Haggard MP. Surgical intervention policy for OME:interpreting available indirect evidence in the absence of direct evidence. Clin Otolaryngol 2009 Jun;34(3):270-4.

24. Davis, AC. Hearing disorders in the Population: First Phase Findings of the MRC National Study of Hearing. In: M.E. Lutman and M.P. Haggard, Hearing Science and Hearing Disorders.1983, London: Academic Press.

25. Davis, AC, Smith P, Ferguson M, Stephens D, and Gianopoulos I. Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models. Health Technology Assessment 2007, 11 (42), 1-294.

26. Torrance G, Furlong W, Feeney D, Boyle M. Multi-attribute preference functions: Health Utilities Index. Pharmaco Economics 2005; 7(6), 503-520

27. Department of Health. Provision of Adult Balance Services: A Good Practice Guide. London: Department of Health, 2009.

28. Health Services Executive. Strategy to prevent falls and fractures in Ireland's aging population, June 2008.

29. Wilson JMG, Junger G. The principles and Practice of Screening for Disease. World Health Organisation, Geneva 1968. Public Health Press, 34: 26-39.

30. Grandori F. European Consensus Statement on Neonatal Hearing Screening. Journal of laryngology and otology 1998; 112(12):1219.

31. US Joint committee on Infant Hearing. Year 2007 Position Statement: Principles and guidelines for early hearing detection and intervention programs. Paediatrics 2007 Oct; 120(4):898-921.

32. Adelola OA, Papanikolaou V, Gormley P, Lang J, Keogh IJ. Newborn screening: A Regional Example for National Care. Irish Medical Journal 2010 May; 103(5):146-9

33. DeafHear. Making a Difference - Service Impact Report 2008/2009. DearHear;2010.[cited 01/10/2010]; Available from: https://www.deafhear.ie/DHFiles/docs/DeafHearImpactReport.pdf

34. DeafHear. Services for Deaf and Hard of Hearing People Annual Report 2009. DearHear;2010. [cited 01/10/2010];Available from: https://www.deafhear.ie/DHFiles/docs/DHAnnualReport2009Web.pdf

35. Department of Education and Skills. Visiting Teacher Service for Children and Young People who are Deaf/Hard of Hearing or Blind/Visually Impaired. [cited 01/09/2010]; Available from: http://www.education.ie/servlet/blobservlet/visiting_teacher_service_info_leaflet.pdf?language=EN

36. Pitt T, Fortnum H, Davis A. The Case for Change in Early Infant Hearing Screening in Ireland. Irish Medical Journal 1999; 92 (3): 292-294.

37. National Institute for Health and Clinical Excellence. Cochlear implants for children and adults with severe to profound deafness. NICE Technology appraisal guidance 166, 2009.

38. Programme of Action for Children. Report of the Universal Neonatal Hearing Screening Working Group. Health Services Executive, 2004.

39. Health Services Executive. An Integrated Approach to Neonatal Screening in Ireland. Health Services Executive: Unpublished;2008.

40. Greater Manchester Newborn Hearing Screening Collaborative Commissioning Sub-group. Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services. NHS; February 2007

41. Programme of Action for Children. Best Health for Children Revisited: Report from the National Core Child Health Programme Review Group to the Health Services Executive. Health Services Executive; October 2005.

42. Fortnum H, Davis A. Epidemiology of Permanent Childhood Hearing Impairment in the Trent Region: 1985-1993. British Journal of Audiology 1997;31(6): 409-466.

43. Health Technical Memorandum 08-01 Acoustic Performance. SLR Healthcare, 2006.

44. Department of Health. Transforming Services for Children with Hearing Difficulty and their Families: A Good Practice Guide. London: Department of Health, 2008.

45. The Early Detection and Intervention – BC Steering Committee. Hearing Screening for every baby – A Sound Start: A British Colombia Initiative for Early Hearing Detection and Intervention. Draft Document: July 30, 2004.

46. NHS Newborn Hearing Screening Programme. NHS Newborn Hearing Screening Programme Centre Annual Report 2006/7. NHS; 2007. [cited 01/06/2010]; Available from: http://hearing.screening.nhs.uk/publications#fileid16534

47. Karshmer J.F. Expert nursing diagnoses: the link between nursing care plans and patient classification systems. Journal of Nursing Administration 1991; 21(1), 31 39.

48. Green R. Confidential Report to Epsom and St Helier NHS Trust. Unpublished 2010.

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

HSE NATIONAL AUDIOLOGY REVIEW

FINAL REPORT APPENDICES APRIL 2011

HSE National Audiology Review - Appendices

Appendix A – Extracts from parental submissions (with permission) from public invite consultation
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Appendix A – Extracts from parental submissions (with permission) from public invite consultation

"The countless questions that I have asked myself on what could I have done differently are endless, but the one that keeps recurring is, why did it take so long for this diagnosis to be made? My child has a 'hidden disability', and is at a constant disadvantage because of her 'hearing age' is over two years less than her 'chrolological age', her speech intelligibility is inferior to her piers which leads to frustration and isolation and she is not even six years old yet! We are continuously trying to catch-up for the missing hearing years with speech therapy, special needs assistants, resource teaching hours, and I have reduced my working hours to the bear minimum in a bid to do extra curricular work to ensure that she doesn't regress because of the late diagnosis".

"When (name deleted) was born in 2006 and she spent about 1 week in neonatal undergoing tests for suspected genetic disorders such as Down's syndrome and Prader Willi syndrome, as she had poor muscle strength. She had also suspected meningitis and had jaundice. Thankfully, all came back negative, she was released home and continued to be seen by a consultant paediatrician for approx one year. At no time was her deafness suspected. Note: during her stay in neo, she had extensive testing including MRI, ECG, EEG, lumber puncture, but no newborn hearing screening. This should be the first step taken as early diagnosis is vital.
We were told after the ABR that she was profoundly deaf (bilaterally) and our world fell apart, as we were not expecting this news (April 08 she was 17 months old). To make matters worse, we were released home with no supporting/contact information. I remember the next day vividly, sitting in my office wondering who to contact, not having anyone to contact in a very emotional frame of mind. No one should ever be left in this situation, yet unfortunately as we meet parents of newly diagnosed deaf kids the story is only too familiar.
As you can imagine in this difficult time in our lives this situation was extremely upsetting and caused us a great deal of unnecessary stress. To cut a long story short, since then we have been sourcing (name deleted) moulds privately. They cost €95, are replaced every month and are turned around within a week. During this period we have continued to get the approved HSE version, they never fit and can take up to 7 weeks to turn around".

"The waiting periods for the delivery of hearing moulds is unacceptable. I had to purchase my sons moulds at (name deleted) at a cost of €160 and they can turn the order around within a couple of days of the appointment. My last mould clinic with the HSE in October 2009 resulted in the moulds not arriving until January 2010. This is just totally unacceptable – my son is constantly growing and we are now ringing again to make another appointment for a mould fitting.
The office hours of the clinic are ridiculous in this day and age. They do not open until 9:30, the close for lunch between 12:30 and 2pm and then are only open until 4pm. This was fine back in the 'good old days' but is totally unacceptable in 2010. Most parents are now both working and there should be more flexibility with appointment hours with at least one late night a week made available for appointments and the offices should be open through lunch".

"In a nutshell, (name deleted) attended the Southern Health Board/HSE for six years before receiving a correct diagnosis and hearing aids!
During this time he had six sets of grommets under general anaesthetic, some or all of which could have been avoided had he received hearing aids earlier. He missed out on the most vital years for the

development of speech and language and social skills and still has ongoing speech and language issues. He experienced high levels of frustration and missed out on so much during those years in social situations, playschool and primary school because he simply could not hear what was going on.
Even as I write, I feel a sense of futility that this review will simply end up as a dust collecting report that will never be acted upon. In due course, I would like you to let me know the result of the review".

""She was profoundly deaf in her left and severely deaf in her right ear … She is now 6 years of age and wasn't diagnosed till she was 5, she lost out on so much in those years. We need all the services of the HSE and extra as waiting times for hearing tests and moulds is crazy with only one person covering a huge area. We need to see a lot of changes in these areas it is just not good enough that children should have to pay the price".

"We were never giving any information about the hearing aids e.g. left/right cleaning them, batteries or how to put them in. We were left to learn all this for ourselves. Over the last 2 years we have been seen by the North Main Street service for hearing tests and new moulds. At present we are waiting for moulds since the 4th December 2009 almost 2 months. This is a disgrace. We would like a more and acceptable service with detailed information for parents and shorter waiting lists and a speedier return on replacement moulds".

"No child with a hearing loss should have their future compromised by losing out on invaluable time – time for Speech and Language development or learning Sign Language, time to get used to wearing hearing aids if they work well, time for being assessed for Cochlear Implant if this is an option.
"If anything at all is to come out of you, in your official capacity, reading letters from parents of a deaf child, then please please think about the positives to be gained from newborn hearing screening. This system is difficult to traverse at the best of times, and its things like early intervention and a formal support mechanism that would make the world of difference to both the child involved and their family.
Thank you for taking the time to read my memory of a terrible time, but know we are very proud of our son and very happy that we made the decision for him to have a Cochlear Implant. I am involved in forums and charities now, to help lend support to parents of newly diagnosed children as this really is a hard experience to go through and hope and support are vital".

"She was fitted with just one hearing aid one and half weeks later the mould was to small, we had a second set done 3 months ago and we are still waiting for these, which when we receive will be too small again".

"Being young parents of young children with a hearing loss is very frightening and one feels very vulnerable and it is a time when you really want the best for your child and the supports from the service are vital to help one cope".

"That was when my daughter was 4yrs of age. We have never since got another audiologist as the places advertised were temporary positions or as we were lead to believe not offering enough money for the position. It really does not matter the reason, all I do know is my daughter has no services now. There are no kids clinics, she never gets any appointments, she received digital hearing aids three years ago after I rang every TD I knew. They have not been checked since. Each summer I have to start ringing around fighting for an appointment just to get moulds. If any break she has to go without for up to a month or more. Try living without being able to hear at school and her friends, sports it is extremely hard for her. Once I was sent to Waterford, the next year Castlebar to be seen by a man from the North. It is just horrendous the way our children are being treated".

"My son has a progressive, terminal disease, his hearing is only part of his disability. It is a shock the audiology department here in Galway, it is desperate, something has to be done. My child depends on his hearing aids, one was broke and I left it with the department. We got it back 4 months later, meanwhile my son couldn't hear anything, his behaviour got worse and he began to un-learn some of his language skills as he could not hear us speaking, so I ask you, if this was your child would you be happy with this 'service'?"

"As parents of a 3 ½ year old girl with a profound hearing loss living in Co Limerick, the following are the issues we would like to see addressed by the National Review of Audiology.
Lack of Neonatal screening
This resulted in her not being diagnosed until she was1 ½ years old. The process of diagnosis we found slow and very frustrating. We suspected possible hearing loss at 10 months and it took 8 months to get her diagnosed. The pathway was as follows,
PHN to repeat assessment with PHN,
To Audiologist where she was suspected to have a possible mild hearing loss
Back to Audiologist where she tested as having a possible moderate loss but the testing was not conclusive as she was inconsistent in her responses.
Referral to ENT Consultant, where, we awaited 6 weeks to see him privately.
ENT Consultant decided to examine her ears under anesthetic again we waited five weeks for same. The ears were dry so he referred her back to Audiologist.
Reassessment by Audiologist to be told that a date needed to be organized for Brain Stem test.
Waited another 4 weeks for same to be organized.
Surely there must be a better way!".

"Beaumont seems very different when we attend appointments there we meet a whole team and it is much easier for us to make decisions regarding our son's needs. We meet everyone from surgeon to audiologist to visiting teacher to speech therapist under one appointment and the service is very efficient with no time lost. This is easier on our son and on us as his parents".

"At no stage in all of this had anyone explained the plan of care my son should get or what I should expect. No one explained the management of hearing aids, the planned follow up, the assessments, the time frame,

nothing. My greatest source of information was the Deaf Hear society, which incidentally I heard about by chance. I felt I was totally alone with the care of my son and had no idea what the future would hold.

To sum up my experience as a parent of a child with hearing impairment would be to say that I am frustrated and have met with incredible challenges. Including delay in accurate diagnosis, delay or gaps in appointments for hearing tests, very limited access to speech therapy, and generally no proper information for parents on what to expect. No one in the hearing services explained to me the implication of hearing loss at the level my son has, no one explained to me what I should expect in the management, or what I should aim for. I thank the Deaf Hear society they have helped me tremendously as has the internet".

"Dear Sirs,

We are the parents of a seven year old profoundly deaf child, the youngest of three children in our family. There is no history of hearing impairment in our respective families, so we came to this world with a complete lack of knowledge. Since our son's (name deleted) diagnosis in February 2005, we have ridden a virtual rollercoaster – moving through phases of frustration, joy, despair, and anger in equal measure throughout. In the hope that something may be gained from our story, we would be obliged for your consideration of our submission as part of the Audiology Review.

By and large it is too late for the major changes which we hope to come from this review, to benefit our son. We have to acknowledge that it is very easy for parents who have passed through the vital stages of a deaf child's life, not to be concerned with trying to make changes now. We hope that something may be learned from what (name deleted) could not avail of, which will benefit children to come.

Our son was not diagnosed until he was 2 years and 4 months old. No infant screening was offered, or was available to him. Why would we even have asked for it, as we had no reason to think our child might possibly be deaf? The lack of availability of infant screening, as a matter of course, is an absolute disgrace and a failing on the part of our health services, which could be interpreted as negligence. This screening is widely recognised as a matter of best practise. Early diagnosis permits early intervention. It allows children access to resources and services, and key access to sound in the provision of hearing aids from infancy, which in turn reduces language and social developmental delay, and ultimately avoids higher expenditure over the years in the provision of support. Early diagnosis in some cases practically negates the effect of hearing impairment.

We are constantly playing catch up in the area of language development with our son. Those vital early years cannot be bought back. We do not yet know the long term implications that late diagnosis will have upon his life. We see daily, the immediate implications, in comparing his language with his peers, in looking at the additional requirements for Speech & Language Therapy which will continue for some time, and in the extra school resources that meet his needs.

Infant screening is key.

As stated, (name deleted) did not have access to infant screening, and therefore his initial hearing tests were carried out by the local visiting health nurse, during the normal stages of developmental checks. (Name deleted) passed all his hearing tests. It is essential that responsibility for developmental stage hearing tests is removed from the health nurse and passed to trained audiologists. Audiology services should be available in each county, the audiologists in sufficient numbers to cater for the specific population sizes.

(Name deleted) first proper hearing test was conducted by Crumlin Hospital, after much pressure being exerted by us to be given the appointment. We were then advised that they did not have the specific skill, given the apparent loss which (Name deleted) had, to proceed further, and we were referred to Enable Ireland Sandymount, for assessment.

At aged 2 years and 4 months, this was the first time (name deleted) was to undergo a professional hearing test conducted by an audiologist, and the first time that we were informed that he had a profound hearing loss. Whilst there can be no doubt that there is a relief in the certainty of diagnosis, the manner in which the *diagnosis was conveyed, was in our view, entirely inappropriate. We were told that "yes, it does appear that he is deaf". This was the first time we were exposed to the word deaf, and even now, almost 5 years later, it's not an easy word to use.*

The gaps that appear in this part of (name deleted) story, centre around the manner in which staff convey diagnosis, and the information and support provided to parents at that time. We were given no information beyond the fact that our son was deaf. We were neither offered the possibility of counselling or other parent support, nor were we pointed in any direction to obtain this for ourselves. We were given no information about the implications for (name deleted) of a profound hearing loss.

We remember clearly leaving that building to sit and cry in our car, with no sense of direction, only a sense of loss. We floundered about using online internet information, and spent days on the telephone reaching out for contacts which could be of help and support. We were at sea.

It is essential that support information and support services are made available to parents at the time of diagnosis. A room should be made available and a specially trained member of staff be at hand to provide emotional support and direction to parents, immediately after diagnosis. Ideally a liason person should be available continually to parents while a child grows. Most importantly parents should be provided with a full information pack, setting out details of services available to them nationally, and within their own area, details of groups and associations who may be of help to them either at that time or in the future. There should be some life stories included, to give and maintain hope. Parents may not necessarily want to, or be ready to, access all these resources immediately, but the information should be given to them.

Through our own efforts, we have come in contact with agencies in the UK such as the CICS (Cochlear Implanted Children Support group) and the National Deaf Childrens Society. These groups have been an invaluable source of information and support to us. Through them, we have met with other parents and families in similar situations, are provided with up to date information on technological advances, tips to help in education and language stimulation, and most importantly have been given a forum for voicing opinion and asking questions. This should be available to us in our own country.

Further, full information should be given at diagnosis also, about the various options available to children in the areas of device aids (from hearing aids to cochlear implants), and the areas of language choice available (sign to verbal and various stages in between). Parents should be educated in the fact that from the point of view of language development and auditory memory, any language is a language. We found that we were not provided with all the information at the same time, information was rather provided to us as we discovered the right questions to ask, and that does not necessarily provide the correct information at the very time it is needed. We arrived at certain realisations too late and our son would have benefited from the information being fully available to us from the beginning.

Parents cannot make informed choices without full information.

One thing we have discovered, is that there is little or no communication between all the various bodies involved with deaf children. There is no cohesive approach in either the provision of services, or the dissemination of information. This must change as no needs are being served in the manner in which agencies "hold close" their information, resources and skills.

Following from Sandymount, (name deleted) was provided with analog hearing aids, April 2005. A referral was made for a Visiting Teacher to be assigned and we met his first visiting teacher quite quickly after that. This may be an appropriate time to mention the Visiting Teacher who can only be described as a jack of all trades, providing essential support to the child in the education system, and invaluable emotional support to the parents, often carrying them on their back to maintain and encourage progress. We could not have managed without this support, but the Visiting Teachers are themselves being let down, in the sense that they are overworked and spread too thinly on the ground. They are an invaluable link in the communication chain between the child/parents and the school, hospital, speech therapist, audiologist etc. They should be provided with greater resources and support and given a greater voice in making change.

In the area of education, regard should be had on a more formal basis to the pre-school system, and support services provided within the pre-school classroom. The provision of sound field systems as a basic *requirement would greatly assist the child in development of social interaction skills, language development, and ease the transition into education.*

The guidelines for the allocation of Special Needs Assistants should be reviewed to provide for assistance in the classroom for hearing impaired children in their own right.

After approximately 1 year of using hearing aids, it became apparent that (name deleted) language development had "plateaued" and something more was needed. We had come into contact with Beaumont hospital within the previous year, through contact we ourselves made at the initial diagnosis stage. We were advised by a telephone contact to seek out an ABR test and contacted Beaumont to enquire about this and seek to have this definitive test carried out. We came to the decision that (name deleted) should be implanted with a cochlear implant and this surgery was performed in September 2006, (name deleted) being officially "switched on " in October 2006, 2 months shy of his 4th Birthday. This was the first time at which our son gained what we would perceive as being sufficient access to sound to give him a fair chance at speech development.

It is our belief that (name deleted) was an ideal candidate for the implant from diagnosis, but the full information about the surgery, and the benefits thereof were not conveyed to us until we insisted upon taking that route. This reinforces our point that parents should be given full information about all options from the very beginning. Professionals should advise parents as to the best option available for the child, and not wait until the parents make the decision. This is not informed decision making. Whether the reason behind this is a lack of funding, people or will, we do not know, but it is our belief that parents are not being given full choice until a time of the service providers choosing. Early intervention, early information.

Hand in hand with every hearing impaired child is the issue and requirement of Speech Therapy, which is a sadly lacking resource. We have experienced a constant fight in obtaining speech and language therapy for our son, which has been hampered by ever changing staff, restrictive budgets and internal politics. There is no question but that Speech Therapy should be available as a constant for all hearing impaired children should they require it. Agencies need to communicate with each other to establish the best method of referral of children, to ensure continuity of service, and ongoing consistent assessment and monitoring. A clearly defined referral system, and responsibility route needs to be established, which filters down to the local level, to ensure provision of Speech Therapy for each child. Hearing Impaired children should be established as a "priority" category in this area.

Further, additional education and training is required to ensure that Speech Therapists have a sufficient knowledge and understanding of communication with deaf children, and of the impact of hearing impairment upon speech development.

(Name deleted) is a wonderful, intelligent and bright little boy, who is gradually overcoming his disability. We thankfully are in a position to be able to articulate our child's needs, and fight his fight for him when necessary. We despair of the children who do not have parents to go to battle for them, and who are continuing to slip through the cracks. It is our belief that the central element is Infant Screening, as this early intervention with the correct supports in place, will circumvent the developmental and language delays which are so crippling to these children. These children deserve to be given a fair chance. Early intervention will ultimately cost the exchequer less, as it will reduce the long term requirements for services.

With thanks for your consideration of the above.

Yours faithfully
Parents"

"To whom it may concern,

I just wanted share with you our experiences, annoyance and dissatisfaction with the Audiology and ENT services and support in Ireland. I truly have to question how professionals are forced to work with such incompetence and frustration in what is suppose to be a modern healthcare system and families struggle to get appropriate advice, guidance and support in this area.

Our Story:

Our daughter has being diagnosed with a very rare disease called Rhizomelic Chondrodysplasia Punctata Dysplasia (RCPD). From our research and what we have been told this impacts 1/100K babies born worldwide each year and we have learned lately that these figures are more likely to be 2 children every 2-3 years across the whole EU. There is very little known about the disorder and very little ongoing research into it with the exception of John Hopkins Medical Institute, Baltimore, USA.

The primary prognosis for most children is death at birth or within two years primarily as a result of respiratory failure although there are cases of children who have survived for up to 10 years and over but not beyond 12. In basic terms children with RCPD have what they call a Rhizomelic condition or a shortening of the entire major long bones i.e. Chest, Upper arm and upper leg and general abnormalities in the joint areas specifically the wrists and feet. In certain cases you also find kids suffer with Scoliosis or Kyphosis of the back (our daughter has got Thoracic Kyphosis and Lumbar Lordosis). Severe mental retardation, cataracts, dermatology etc are also very common as well as other physical features. Thankfully our daughter has excellent mental health, eye site and skin but this needs constant monitoring on a regular basis usually every 12 months.

We have had months of exhaustive consultation programs and Genetic testing in an effort to get a definitive answer on her underlying condition and the consequences as well as the management and treatment for it going forward. All the results gave us a definitive diagnosis which is referred to as RCPD Type 2 (Conradi-Hünermann http://en.wikipedia.org/wiki/Conradi-H%C3%BCnermann_syndrome). We, her parents both come from perfectly healthy families and genetic testing has determined this is a new genetic event with our daughter so our chances of a repeat case are less then 1%.

Our daughter's condition poses significant challenges and risks to her up to and inclusive of a much shortened life expectancy. There are very serious implications if medical intervention and treatment are not timely and proactive all of which are outlined extensively by the various medical professionals and supporting documents that we have on file. There is limited if any knowledge and experience in this country and in Europe amongst the medical profession irrespective of the discipline (Paediatrics, Orthopaedics, ENT, Genetics etc) in dealing with children who are born with Conradi–Hünermann syndrome and the associated challenges.

Our daughter has 80%+ hearing loss in both ears and needed to have her ears drained of fluid, assessed for grommets and an Auditory brainstem response (ABR) test conducted to understand how poor her hearing actually is so we could better understand her management, schooling and needs going forward. The only way we could achieve this was through OLCH Crumlin. We knew this in November 2008 but it took us and many of our local medical/social team 14 months of exhaustive letter writing, phone calls, and referrals to finally get this routine procedure conducted in Crumlin. What is more annoying is the stupidity and bureaucracy we observed during this period where we had 3 consultants under the one roof writing numerous letters to each other debating the case and loosing (forgetting at times) correspondents forcing us back to the start on more then 3 occasions. How in a day of modern communication can this be allowed to happen? Can simply a conference call or meeting be called for 15 minutes where the case is discussed, recorded and decision made. How much money is wasted like this everyday?

What is crazier still is that this is compulsory procedure for all new born babies in the UK and USA which makes a whole lot of sense considering a child is sleeping in excess of 16 hours a day in the early days of birth and this can be conducted without putting them under the strain stresses and risks of an anaesthetic or taking up valuable OR time for what should be a routine procedure.

Our daughter's most recent hearing assessment shows significant deterioration in her right ear and she had moved from severe hearing loss to profound as a result of not getting fluid removed in a timely manner prior to treatment in Crumlin. In addition the Audiology team have gone from telling to screaming that she really needs top be on an urgent referral to Beaumont as the cochlea route maybe a real necessity. I am at a point where if we don't get anywhere in the next couple of weeks I am going to start looking overseas which in my mind is a sad and disgraceful state of affairs. That is certainly through no fault of the efforts of our daughter's medical team locally which have been great. It is simply a reflection of the service or lack of that we work with.

In the past two years we been continuously frustrated and delayed in getting her hearing aids fitted not as a result of poor hearing aids but incredibly poor molds. At times she has had 5 sets of molds fitted in an 8-10 week period others have been lost or would not fit correctly. I believe that over the past year to 18 months the HSE made a decision to outsource there molds to a UK vendor as a cost reduction initiative moving them from a local source in Ireland. I would really like to see the payback analysis on this decision as it must be negative and adding further costs to an already strained poor quality service reducing much needed expenditure in other areas. The net result of all of this is wasted time, money and more importantly further damage to the health of a child who is already facing many future battles in her life.

Our final chapter in this sorry tale is with the general services available in supporting parents and families with children whom have severe hearing difficulties. This service is not let down by the front line doctors, teachers, nurses, social workers, audiologists etc who strive to give the best service possible but are stifled by a very poor infrastructure that lacks appropriate funding, has outdated equipment and is caught up in red tape and bureaucracy.

We have spent the past 18 months chasing and fighting for key services essential to our daughter's care and needs such as Audiology, Learning and Development, Sign Language etc. The simple fact is if you don't scream you do not get heard and therefore do not get responses or guidance about what direction or steps you should take that are in the best interests of your child. This coming September our daughter needs a full time PA for crèche and school and over the past months we are running around with different forms and being pushed from department to department to try and get her the support she so desperately needs. It should not be like this!! Over the past 12 months we have had classes and forums on sign language training, meetings with parents of children with hearing disabilities cancelled with no explanation or rescheduling on the horizon.

In summary it is a draining process and exhausting experience working with the Audiology and ENT services in this country on top of trying to deal with all the other complexities of raising a child with severe disabilities. Form after form, referral after referral, department after department, person after person until you eventually get to where you should have been sent first day.

On numerous occasions in clinics, waiting areas and talking to people at various forums you see how confused people are in terms of clarity, direction and entitlement and what is worse is there is an acceptance of this poor quality and lack of service. It is indicative of the how bad a service actually is when it's only the 10% that scream are heard and the other 90% go unnoticed. All we ask for is simple advice; direction and support that will help us make the right decisions for our daughter and ensure some level of independence and standard of living for our daughter in the future. These are such critical years in terms of her learning

and education and we run the risk of missing opportunities that will limit her down the line which I believe responsibility rests lays solely with this service.
As parents we strive and remain determined to try and do what is best and what we can for our daughter. This is what keeps us going thru the exhaustive appointment and consultation schedule that comes with a child with her condition and complexities. As a family we try to lead as normal a life as is possible and have come to terms that our daughter is ultimately fighting for her survival and future.
Basic things privileged and normal to many of us such as the ability to walk, talk, hear, see, learn etc are not normal and will never be for our daughter. She faces serious respiratory issues, significant challenges with posture, bone formation and ultimately a much shortened life expectancy if medical intervention and treatment are not timely and proactive. She is a little fighter like many of the brave children and families you meet with sick or disabled children. These kids know no other way and what may seem abnormal to many of us is very normal to them. They have unique personalities and through their eyes the world is full of mystery and surprises waiting to be explored.

Our health system & services should play a critical role in helping these children begin this adventure full of hope and with a positive attitude knowing that we have the systems and structures to support their needs. Society and our Government should continue to work side by side with these children and their families throughout the journey not knowing how the story ends but with the knowledge they are together on the one road ahead. Only through a properly supported & funded Audiology service and infrastructure can we continue to ensure the highest standards of patient care for every child that is born in this land with such challenges and disabilities.

I think it would be irresponsible of us to not to speak up on our daughter's behalf and other families with children in similar situations with significant hearing challenges. If there is anything that can be done to correct this diabolical and senseless waste and what will it take to get it right first time so ultimately kids such as our daughter can get on with their lives with the support they deserve and should expect from a first world economy with a third world service. If we can help in any small way to achieve this objective and get the Audiology service and support this profession deserves and stop the wasting of tax payer's money please let us know.

Thank you".

Appendix B – Suggested draft for Scopes of Practice for non-graduate assistants, and graduate and postgraduate audiologists

SUGGESTED SCOPE OF PRACTICE - AUDIOLOGY ASSISTANT

WARNING: THIS SoP IS DRAFT AND SHOULD NOT BE USED FOR HR PURPOSES

General

- Performs a range of tasks and protocol-based roles
- Performs protocol-limited tasks under the supervision and direction of more senior staff or with reference to professional advice.

Specific

- Work independently with clearly defined populations with routine / non-specialist needs following pre-determined guidelines, protocols, standard operating procedures
- Undertake client centered assessments following agreed protocols and procedures
- Recognise the limits of competence and levels of responsibility/ autonomy at all times and refer to other colleagues and services as indicated
- Perform assessments, following recommended procedures / protocols, for an individual client
- Develop, deliver & maintain, with agreement from client, carers and families, all, or part of, a care plan within agreed protocols, referring onto other colleagues and services as indicated
- Provide education to enable the client, carers and families to engage with the agreed care plan and outcomes
- Take responsibility for the client journey to achieve agreed, pre-determined outcomes
- Participate in audits and service evaluations to improve services.

Professional Competence/Clinical Governance

These practitioners will work within a defined governance and supervision structure providing specific parameters for freedom of action and autonomy.

Communication

Be responsible for effective communication with a range of people using appropriate communication skills

- Be responsible for accurate and complete record keeping following legislation, policies and procedures
- Be responsible for the supervision of others within the limits of competence and responsibility.

Examples of Assistant Level Activities

Independently working with Adults

- Triage: Assessment of suitability of adults for direct referral to Audiology or ENT using agreed criteria
- Determining not masked air conduction and bone conduction thresholds for adults
- Impressions for adult hearing aid users following otoscopy by a graduate/post graduate level member of staff
- Counselling & instruction in hearing aid use for non-complex adults

- Routine hearing aid repairs
- Completion of the Glasgow Hearing Aid Benefit Profile for non-complex adults.

Working under supervision

- Assisting post graduate level staff with VRA assessments
- Assisting post graduate level staff with vestibular assessments
- Participating in audit, innovation and service improvement.

SUGGESTED SCOPE OF PRACTICE – GRADUATE LEVEL AUDIOLOGIST

WARNING: THIS SoP IS DRAFT AND SHOULD NOT BE USED FOR HR PURPOSES

General

A graduate audiologist will have the necessary expertise in applied scientific techniques within a discipline or related disciplines and will work in a range of healthcare settings:

- With a defined role in the delivery and reporting of quality assured tests, investigations and interventions on patients, samples or equipment
- Will provide therapeutic interventions, some of which may be specialist.

Specific

- As a regulated professional, take responsibility for the assessment and management of assigned patients/clients referred to the department within which he/she operates, within defined structures of governance
- Additionally, as a member of a team, perform investigations and contribute to management of patients/clients who are under the clinical responsibility of another member of the team
- Take responsibility for quality assurance and audit of outcomes of own work and work carried out under their supervision
- Take responsibility for maintenance and updating of own knowledge and skills
- Prioritise referrals and case work according to local departmental policy
- Develop individual care plans to include a range of investigations, procedures or processes in consultation with patients and relevant others, based on individual patient needs/wishes and accepted good practice
- Perform a range of scientific/clinical investigations, procedures or processes to deliver patient care according to agreed individual care plan, making contingent changes to the plan as appropriate
- Interpret and report results of investigations, procedures or processes to patient and others involved in care of the patient
- Monitor and report on progress of the patient according to care plan, reviewing the need for further intervention as appropriate
- Recognise the need for referral to other agencies or specialists, making appropriate referrals
- Apply, maintain and be capable of setting quality standards, control and assurance techniques, including restorative action
- Provide clinical or scientific advice and information to healthcare and other professionals, patients and their carers to support effective assessment, diagnosis, management and treatment of patients or patient services
- Communicate clinical and scientific knowledge to a range of audiences, including professionals and patients
- Plan, organise and prioritise own work activities, practices and tasks
- Be aware of relevant advances in scientific knowledge and practice, interpreting scientific research and applying to practice
- Using knowledge management techniques, including critical appraisal, undertake audits and service development to improve quality of service provided.

Examples of Graduate Level Activities, in addition to activities that may also be performed by an Assistant

Independent Activities

- Otoscopy
- Pure Tone Audiometry, including masking as required
- Tympanometry and Reflexes
- Loudness Discomfort Levels
- Transient Evoked Otoacoustic Emissions
- Adult hearing aid work, including selection and fitting, habilitation/IMPs
- Hearing aid work for children of 10 years of age or older (following a period of post qualification training), including selection and fitting, habilitation/IMPs
- Developing and delivering care plans for adults and children with non-routine hearing loss or related disorders e.g. providing a rehabilitation package to adults and children and to others involved in their care, including fitting hearing aids to children of 10 years of age or older, according to agreed good practice
- Non-routine hearing aid repairs
- Impressions for cooperative children over 3 years of age (following a period of post qualification training)
- Behavioural assessments (e.g. Performance/Play Audiometry, Automated Toy Test) for children that are developmentally over 3 years of age (following a period of post qualification training)
- Other than when VRA is required, behavioral assessment of adults with disabilities
- Supervising audiology assistants
- Participating in teaching and learning of health and social care staff
- Participating in research, audit, innovation and service improvement.

Working under supervision *(Direct or indirect)*

- Children with complex needs
- Impressions for children under 3 years of age
- VRA assessments
- Vestibular assessments
- ABR assessments
- Hearing aid work under supervision for children under 10 years of age, including selection and fitting, habilitation/IMPs; assisting with hearing aid work for children under three years of age.

SUGGESTED SCOPE OF PRACTICE – POSTGRADUATE-LEVEL (MSC OR ABOVE) AUDIOLOGIST

WARNING: THIS SoP IS DRAFT AND SHOULD NOT BE USED FOR HR PURPOSES

Note: where there is a significant management or leadership role, at least five years post MSc-level experience would be expected.

General

- Provides clinical, managerial and scientific expertise and makes complex or highly complex judgments. Able to act as an expert in one or more specialties
- Provides specialist or highly specialist clinical, technical or scientific services and/or advice.

Specific

- May be responsible for work area, accredited specialty or clinical pathways and/or management of staff. May be accountable for direct delivery of part of service and may direct and influence commissioning and/or service provision. May be accountable for direct delivery of part or all of an Audiology Service
- Proposes changes to practices or procedures which impact beyond own work area. May plan and/or organise a broad range of complex activities or programmes with formulation of strategies. In addition to above may plan, develop and implement policy and service developments which impact beyond own area of responsibility beyond organisation
- May hold delegated budget for accredited specialty area or for part or whole of service. May be responsible for purchasing and/or maintenance of assets. May undertake supervision and/or teaching and training as major job role. May devise training or development programmes. May manage staff and services ranging in size and complexity
- May evaluate equipment, techniques and procedures. May undertake straightforward or complex audit or assist with clinical trials or research projects. In addition may carry out R&D as a major activity. May regularly undertake clinical trials or research projects
- May initiate and develop R&D programmes. May coordinate and implement R&D programmes and/or initiate and develop programmes with external impact.

Leadership

Post Graduate Audiologists should possess the following leadership qualities:

- Self awareness, self management, flexibility, a drive for service- and self-improvement, and personal integrity
- Leading change through people, holding to account, empowering others, effective and strategic influencing, collaborative working, service improvement skills.

Examples of Post Graduate Level Clinical activities, in addition to activities that may also be independently preformed by a Graduate

Independent Activities

- Impressions for children under 3 years of age
- VRA assessments
- Vestibular assessments
- Diagnostic ABR assessments
- Hearing aid work for children under 10 years of age, including selection and fitting, habilitation/IMPs

Appendix C – List of and links to recommended Good Practice Guidelines

- NHS Newborn Hearing Screening Programme website (http://hearing.screening.nhs.uk), in particular:

- http://hearing.screening.nhs.uk/standardsandprotocols
  Aetiological investigation
  Audiological calibration
  Screening equipment
  ASSR
  AN/AD
  Surveillance
  Audiological assessment
  Care pathways

- http://hearing.screening.nhs.uk/TandC in particular: Children's Hearing Services Working Groups (CHSWGs) http://hearing.screening.nhs.uk/chswg

- US Joint Committee on Infant Hearing (2007 Position Statement): http://www.jcih.org/posstatemts.htm

- Modernisation of Children's hearing Aid Services (England) guidelines: http://www.psych-sci.manchester.ac.uk/mchas/guidelines/
  Guidelines for the Taking of Impressions and Provision of Ear Moulds within a Children's Hearing Aid Service (Word 40 KB)
  Guidelines for Professional Links between Audiology and Education Services within a Children's Hearing Aid Service (Word 52 KB)
  Guidelines for testing Digital Signal Processing Hearing Aids 'In the Field' within an integrated Children's Hearing Aid Service (Word 56 KB)
  Transition from paediatric to adult audiology services: Guidelines for professionals working with deaf children and young people (PDF 1.48 MB)
  Procedures for the setting up of fm radio systems for use with hearing aids (PDF 400 KB)

- British Society of Audiology and British Academy of Audiology joint documents:

  Guidance on the use of real ear measurement to verify the fitting of digital signal processing hearing aids (2007).
  BSA Recommended procedures: http://www.thebsa.org.uk
  British Academy of Audiology: Guidelines for Referral to Audiology of Adults with Hearing Difficulty (2009) [updated TTSA guidelines]

- Quality standards for adult cochlear implantation (June 2009, BCIG):
  http://www.bcig.org.uk/downloads/pdfs/BCIG%20Adult%20Quality%20Standards%20Final%20Draft%20June%202009.pdf
  NICE Guidance of Cochlear Implants (Jan 2009): http://www.nice.org.uk/Guidance/TA166

ENT and Audiology Specialist Collection Update available at http://www.library.nhs.uk/ENT/ViewResource.aspx?resID=344858

- NHS, Antenatal & Newborn Screening Programme - Guidelines for fitting hearing aids to young infants, December 2009

- Guidance for ABR in babies. 1st April 2010 www.hearing.screening.nhs.uk/audiologicalassessment

- Informing Families of their child's disability – National Best Practice Guidelines – National Federation of Voluntary Bodies, Ireland. www.fedvol.ie

- Guidance for auditory brainstem response testing in babies, NHS Newborn Hearing Screening Programme, 1st April 2010 http://www.library.nhs.uk/ENT/ViewResource.aspx?resID=375190&tabID=288&catID=9005

- Publication – Pushing the boundaries: Evidence to support the delivery of good practice in audiology. www.improvement.nhs.uk/audiology

Appendix D – Major diagnostic & therapeutic activity by audiologists: summary of procedures, suggested times and skill level of staff required

Key to the tables :
Procedure –D: Diagnostic; T: Therapeutic; OP: Outpatient; DV: Domiciliary Visit; DC: Day case; IP: Inpatient.
Test Time – A: 10 mins: B: 10-15 mins C: 15-30 mins; D: 30-45 mins; E: 45-60 mins; F: 1-1.5hrs; G: 1.5-3 hrs; H: 3-4 hrs; I: >4 hrs.
Level of staff: 1=non-graduate, 2=graduate, 3=postgraduate
Standards and Guidelines: British Academy of Audiology (BAA) and British Society of Audiology (BSA) guidelines; Modernising Hearing Aid Services (MHAS) guidelines; Do Once and Share (DOAS) care pathways; Technicians, Therapists and Scientists in Audiology (TTSA) criteria for direct referral; RNID best practice guidelines for adult audiology; The Newborn Hearing Screening Programme (England) guidelines.

Referral for hearing aid assessment (new adult patients)/Re-referral for hearing aid assessment (existing adult patients)

Test/Procedure	Procedure category and location		Time requ'd/min. level of staff	Description of procedure	Purpose of procedure
Triage: Technicians, Therapists and Scientists in Audiology (TTSA) criteria (or locally developed referral criteria)	n/a	OP/DV	A/1	Assessment of suitability for direct referral to audiology or to ENT using agreed criteria.	To ensure that patients will be seen by the health professional most appropriate for their care.
Otoscopy	D	OP/DV	A/2	Clinical examination of external auditory meatus, ear drum and gross structures of middle ear.	To detect outer / middle ear abnormalities/pathologies.
Pure Tone Audiometry	D	OP/DV	C/2	Behavioural assessment of frequency specific hearing thresholds; requires active cooperation from the patient. Sound may be applied monaurally by	To determine hearing sensitivity and if there is a hearing loss, whether conductive, sensorineural or mixed.

				means of an earphone (air conduction audiometry), or vibrations may be applied to the skull by a bone vibrator (bone-conduction audiometry).	
Tympanometry & Reflexes	D	OP	B/2	Functional analysis of outer ear, eardrum and middle ear.	To aid in the diagnosis of middle ear and VII & VIII cranial nerve pathologies.
Loudness Discomfort Level test	D	OP/DV	A/2	Behavioural assessment for sound levels at which patients experience discomfort as a function of frequency.	In combination with pure tone audiometry thresholds, enables calculation of the effective Dynamic Range of hearing
Glasgow Hearing Aid Benefit Profile (GHABP) – part I	T	OP/DV	B/1	Assessment of initial disability & handicap of hearing impairment.	Needs assessment – disability & handicap.
Impression taking	T	OP/DV	B/1	Taking impressions for manufacture of patient specific ear mould.	To ensure well fitting ear moulds.

Referral for complex needs hearing assessment, adult

Test/ Procedure	Procedure category and location		Time requ'd/min. level of staff	Description of procedure	Purpose of procedure
Threshold Auditory Brainstem Response – tone pip ABR (air conduction)	D	OP/DV	F/3	Sounds are applied through supra-aural earphones or insert earphones. Changes in electrophysiological activity are detected by electrodes/sensors which are attached to the patient's head.	To determine if there is adequate frequency specific hearing.
Threshold Auditory Brainstem Response – bone conduction ABR	D	OP/DV	F/3	Sounds are applied by means of a bone vibrator. Changes in electrophysiological activity are detected by electrodes/sensors which are attached to the patient's head.	Bone Conduction testing is carried out when Air Conduction testing indicates that hearing is not adequate, in order to determine if there is a conductive, sensorineural or mixed hearing loss.
Transient Evoked Oto-acoustic Emissions	D	OP/DV	D/2	Functional assessment of the auditory system up to and including the outer hair cells of the cochlea.	To aid in the diagnosis of SNHL, ANSD and NOHL.

Hearing aid fitting and follow up, adult

Test/ Procedure	Procedure category and location		Time requ'd/min. level of staff	Description of procedure	Purpose of procedure
Real ear measurements	D/T	OP/DV	C/2	Objective measurement of sound-pressure level in patient's ear once hearing aid has been fitted to enable accurate programming of hearing aid to a target.	Fitting and evaluation of hearing aids.
Counselling & instruction	T	OP/DV	D/1 if routine, 2 if complex	Counselling and instructing the patient in the use of the hearing aid.	Hearing difficulty.
Glasgow Hearing Aid Benefit Profile (GHABP) – part II	D/T	OP/DV	C/1 if routine, 2 if complex	Outcome measure to assess use, benefit & satisfaction and residual disability with device.	Outcome measure – use disability & handicap, benefit & satisfaction.
Hearing aid repairs	T	OP/DV	B I if routine, 2 if complex	Hearing aid repair service. Wide ranging chronic and transitory faults in hearing aids diagnosed & rectified.	Maintenance of existing hearing aid systems.

Referral for paediatric hearing assessment

(In addition to the tests/procedures listed below, Otoscopy, Tympanometry & Reflexes, Pure Tone Audiometry and Transient Evoked Otoacoustic Emissions may also be performed, as described in previous sections).

Test/ Procedure	**Procedure category and location**		**Time requ'd/min. level of lead staff** (other where required may be level 1)	**Description of procedure**	**Purpose of procedure**
Patient History	D	OP	B/2	Parents/guardians provide information on risk factors for hearing loss, which the clinician documents.	To aid in the child's management.
Soundfield Visual Reinforcement Audiometry	D	OP	C/3 2nd tester requ'd	Behavioural assessment of frequency specific hearing thresholds. Binaural responses are obtained by applying sounds through a loudspeaker. One tester controls the child's attention; the other tester presents the stimuli.	To determine if there is a hearing impairment in the better ear.
Insert Earphone Visual Reinforcement Audiometry	D	OP	D/3 2nd tester requ'd	Behavioural assessment of frequency specific hearing thresholds. Ear-specific responses are obtained by applying sounds by means of insert earphones. One tester controls the child's attention; the other tester presents the stimuli.	To determine if there is a hearing impairment in one or both ears.
Bone Conduction	D	OP	C/3	Behavioural assessment of	To determine if there is a conductive,

Visual Reinforcement Audiometry			2nd tester requ'd	frequency specific hearing thresholds. Bone conduction responses are obtained by applying sounds by means of a bone vibrator. One tester controls the child's attention; the other tester presents the stimuli.	sensorineural or mixed hearing loss.
Performance Testing (play audiometry)	D	OP	C/2	Behavioural assessment of frequency specific hearing thresholds. Binaural responses are obtained by applying sounds through a loudspeaker. The child is conditioned to perform a task (e.g. placing a hoop on a stick); every time he/she hears the stimulus.	To determine if there is a hearing impairment in the better ear.
McCormick Automated Toy Test (or other e.g. Consonant Confusion Test)	D	OP	C/2	Toy identification to words presented at progressively quieter levels through a loudspeaker or headphones, with or without background noise.	To determine how well speech discrimination thresholds correlate with Performance Test/Play Audiometry thresholds; To demonstrate to parents the effectiveness of hearing aid amplification through comparison of aided and unaided speech discrimination scores
Threshold Auditory Brainstem Response under natural	D	OP/ DV /IP	G/3	Sounds are applied through supra-aural earphones or insert earphones for air conduction and by	Air Conduction testing is carried out to determine if there is adequate hearing.

sleep : Click Stimulus Air Conduction and Bone Conduction, when indicated				means of a bone vibrator for bone conduction. Changes in electrophysiological activity are detected by electrodes/sensors which are attached to the child's head.	Bone Conduction testing is carried out when Air Conduction testing indicates that hearing is not adequate, in order to determine if there is a conductive, sensorineural or mixed hearing loss.
Threshold Auditory Brainstem Response under natural sleep : Tone Pip Air Conduction and Cochlear Microphonic testing, when indicated	D	OP/ DV /IP	G/3	Sounds are applied through supra-aural earphones or insert earphones for tone pip air conduction. Changes in electrophysiological activity are detected by electrodes/sensors which are attached to the child's head. Sounds are applied by means of insert earphones when testing for cochlear microphonic responses (supra-aural earphones are not appropriate).	Tone Pip testing is carried out when Click Stimulus thresholds are elevated, in order to determine frequency specific thresholds. Cochlear Microphonic testing is carried out to aid in the diagnosis of Auditory Neuropathy Spectrum Disorder.

Referral for paediatric hearing aid fitting and follow-up

Test/Procedure	**Procedure category and location**		**Time requ'd/min. level of lead staff** (other where required may be level 2)	**Description of procedure**	**Purpose of procedure**
Impression taking for earmould	T	OP/ DV	C/2 2nd tester requ'd if preschool	Taking impression for manufacture of earmoulds for child.	To ensure well fitting hearing aids
Selection, programming and verification of hearing aids using DSL methodology and REMs	T	OP	E/3 2nd tester requ'd	Selecting and verifying hearing aids for children to include real ear to coupler differences (RECD) measurement or real ear aided response (REAR) for older children.	To ensure child has access to long term average spectrum (LTASS), and that fitting is optimal.
Counselling parents on hearing loss, management of aids	T	OP/DV	E/3	Providing verbal and written information on hearing loss and aids Responding to parent needs/requests for information.	Empower parents to manage hearing aids and accept hearing loss.
Monitoring access to speech sounds and response to language inputs	T	OP/ DV	D/3 2nd tester requ'd	Review of early intervention materials and parental observations of child's responses. Automated toy test or other suitable speech-hearing test. Aided play audiometry as demonstration to parents.	To ensure child has access to LTASS. To determine effectiveness of hearing aid fitting.

Communication with other professionals/team members involved with family; development of an Individual Management Plan for child/family	T	OP	D/3	Providing verbal and written information to other professionals with parental consent on child's hearing loss and hearing aid fittings.	To ensure seamless holistic approach to child and family needs.

Vestibular assessment

Test/Procedure	**Procedure category and location**	**Time requ'd/min. level of lead staff**	**Description of procedure**	**Purpose of procedure**
Vestibular History Taking	D OP/IP	D/3	Detailed questioning of the dizzy patient to include information about the following: -aural history -defining dizziness (nature, timing, duration, triggers, -past medical history -medications -social history	Differential diagnosis of cause of dizziness; may guide types of vestibular assessments performed on patient
Dix-Hallpike Manoeurve	D OP/IP	A/3	Sitting on an examination couch the patients head is turned 45° and extended backwards by 20°. The patient is then quickly brought from the sitting position to supine with their head extended off the end of the couch. The clinician then observes the eyes for nystagmus to include latency of onset, duration fatiguability, direction of nystagmus and any direction change	Used in the differential diagnosis of positional vertigo, namely benign paroxysmal positional vertigo (BPPV)

Epley Maneouvre – also known as the particle repositioning procedure	T OP/I/P	A/3	Position patient sitting on an examination bed with their head slightly extended and turned 45° to the side of the suspected lesion. Then bring patient into the supine position with their head extended off the end of couch and maintaining the 45° angle – maintain position for 1 minute. Now turn the head 90° in the opposite direction and maintain this position for 1 minute	Used as a treatment upon positive diagnosis of benign paroxysmal positional vertigo
Caloric Testing	D OP/IP	D/3	Flushing warm (44°C) & cool (30°C) water down the ear canal for 30 seconds on both sides; alternatively directing warm (50°C) & cool (24°C) air down the ear canal for 60 seconds. Electro nystagmography (ENG) or video nystagmography (VNG) is then used in measure eye movement (nystagmus) in response to water/air	Means of determining nystagmus slow-phase velocity which is considered to be a sensitive indicator of vestibular end-organ activity

			stimulation. A comparison is then made between the different stimulus types using calculations of canal paresis and directional proponderance.	
Ocular Motility Testing -Spontaneous Nystagmus -Saccades -Smooth pursuit -Optokinetics	D OP/IP	D/3	ENG/VNG is used in conjunction with a calibrated lightbar which produces a moving target for measurement of spontaneous nystagmus, saccadic, smooth pursuit and optokinetic eye movements	Used in the differential diagnosis and to differentiate between peripheral and central vestibular lesions
CTSIB – clinical test of sensory integration and balance	D OP/IP	B/3	Patient is asked to stand with arms crossed over chest and feet together and they are monitored for 30 seconds in 6 different conditions -eyes open, solid floor -eyes closed, solid floor -wearing visual conflict dome, solid floor -eyes open on foam mat eyes closed on foam mat -wearing visual	Attempts to measure the way that vision, vestibular and somatosensory interaction allows us to maintain our balance against the forces of gravity

			conflict dome on foam mat	
Head Shaking Test	D OP/IP	A/3	The patient is outfitted with VNG googles or frenzel glasses. They are then asked to shake their head vigorously in the horizontal plane for ~20 seconds and then stop suddenly. The eyes are then observed for nystagmus and if present the nature of the nystasgmus is noted.	Differential diagnosis of severe unilateral peripheral vestibular lesions

Appendix E

An Integrated Care Approach to Childhood Hearing Screening in Ireland

National Audiology Review Group, 2010

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Chapter 1 – Introduction

The National Director of Integrated Services requested in 2009 that a National Review of Audiology Services be carried out. A key focus of this review is integration between PCCC, Acute Services and external agencies involved in the provision of audiology services. The National Audiology Review Group (NARG) is comprised of health care professionals for adults and children from within the community and hospital setting, as well as other key agencies and patient representation. A sub group of NARG was established to examine, *inter alia*, the hearing services currently being provided to children nationwide and has developed this report for an integrated childhood hearing screening and audiological service.

1.1 Overview of Report

This report outlines the evidence base, service specification, clinical care pathways and integrated service structure in relation to requirements for an integrated childhood hearing screening and audiological service in Ireland.
The key elements of this Service include:

- Universal Neonatal Hearing Screening
- Childhood Hearing Assessment (Pre-school/School)
- Childhood Hearing Assessment /Habilitation up to 18 years of age

The report addresses each of these areas systematically.

1.2 Universal Neonatal Hearing Screening

Chapter 2 of this report;

- Examines the background to Universal Neonatal Hearing Screening, the context, the current provision and status of hearing screening. It sets out the clinical care pathways representing the baby's journey from screening through to intervention informed by epidemiological data.
- Describes and compares the hospital/community service models with recommendations.
- Proposes a phased implementation of the programme.
- Sets out a national framework for service delivery based on the existing HSE structure.
- Outlines the follow-on diagnostic paediatric audiology commitment required, informed by epidemiological data.

1.3 Childhood Hearing Assessment /Habilitation – Pre-school/School

Chapter 3 of this report sets out the childhood hearing screening programme requirements in the context of an integrated audiology service and is aligned to the recommendations from Best Health for Children Revisited, 2005[1].

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[1] Best Health for Children Revisited, HSE, 2005

1.4 Childhood Hearing Assessment /Habilitation – Up to 18 years

Chapter 3 of this report sets out care pathways for access to paediatric audiology and paediatric habilitation services for children up to 18 years of age.

Chapter 2 Universal Neonatal Hearing Screening

2.1 Rationale

Congenital Permanent Childhood Hearing Impairment (PCHI) may disrupt the process of communication and normal language acquisition, leading to poor language, communication and literacy skills. The disruption is likely to be greater the later in the child's life that the hearing impairment is identified. This has long term consequences for child, family and society in terms of educational achievement, mental health and quality of life. Newborn screening involves screening all newborn infants. This results in the early identification of PCHI leading to early intervention and much improved outcomes for children. Neonatal screening needs to be complemented by a system of ongoing surveillance through infancy and early childhood to ensure that progressive, late onset and acquired hearing loss is also identified as early as possible.

The case for a national, sustainable, consistent, quality universal neonatal hearing screening programme is well made from:

- A child health perspective (national/international evidence), including data on relative cost effectiveness
- A best practice point of view
- The perspective of fulfilling the internationally established criteria for screening
- The experience of other countries (and the number of other countries) who have introduced universal neonatal hearing screening
- A political perspective
- A public who expects the best quality service in terms of health
- An increasing liability perspective
- Cost-benefit analysis

2.2 Background

The National Report on Universal Neonatal Hearing Screening[2] which was commissioned by the then Health Board CEOs examined the case for developing a national hearing screening service for babies born in Ireland. It states that more than 80 children are born in the Republic of Ireland each year with PCHI and stated that the average age of identification using the current "infant distraction test" screening programme (which was first introduced to Ireland in the 1950s) is approximately 30 months. This far exceeds internationally recognised targets of 4-6 months for confirmation of hearing loss in infants. The consequence of such late referrals is that the opportunity to benefit from early identification is lost. The report states that the introduction of a universal neonatal screening programme in the Republic of Ireland (already in existence in Northern Ireland), would enable the average time between detection of hearing loss and starting treatment to be cut by several months and in some cases years, at a crucial time in the development of hearing, language and communication in children.

The report identified four current neonatal hearing screening programmes operating in Ireland, one in Northern Ireland, and three programmes in the Republic of Ireland based at Tralee, Castlebar (extended to Galway in 2003) and Sligo (2001–operating a programme, targeted at high risk babies). The programmes in the Republic of Ireland are 'stand alone' and continue to operate

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[2] Report of the Universal Neonatal Hearing Screening Working Group, Programme of Action for Children, 2004

in this way in the absence of a National Programme for Newborn Hearing Screening. These programmes have not been centrally funded and were established as a result of the enthusiasm and commitment of the personnel involved.

In late 2007, Professor Drumm, CEO of the HSE, established a Universal Neonatal Hearing Screening Programme Steering Group to oversee the implementation of universal neonatal hearing screening in Ireland. The group met a number of times. Amongst the outputs from this group was the development of a sponsorship programme for four audiology students and the drafting of national protocols and guidelines. A report was developed titled 'An Integrated Approach to Neonatal Screening in Ireland'[3].This report was approved in principle by HSE Senior Management and has provided the core information and evidence base underpinning the recommendations for childhood hearing screening by NARG.

Despite the compelling case made by previous reports for the introduction of neonatal hearing screening; the enthusiasm of those working in this area, and the benefits to be gained for children with hearing loss, the present position is that there has been no significant progress towards a Universal Neonatal Hearing Screening Programme in Ireland.

In 2009 the former National Director of Primary Community and Continuing Care now the National Director for Integrated Services requested that a National Review of Audiology Services be carried out. This report is a key product of this overall review.

2.3 Aim of Newborn Hearing Screening Programme

The aim of a universal neonatal hearing screening programme is the early detection of unilateral or bilateral moderate to profound permanent childhood hearing impairment, to reduce the age of identification of such hearing loss to not more than three months and to undertake/commence amplification, fitting and enrolment in early intervention programmes by six months of age. Early identification is the springboard for the processes of diagnostic and habilitative audiological, medical and educational intervention. Comprehensive intervention and management programmes to meet the child's needs along with support to the family are seen as natural extensions of a universal screening programme.[4,5]

2.4 Objectives of implementing a Newborn Hearing Screening Programme[6]

The objectives of implementing a newborn hearing screening programme are as follows:

- To offer a hearing screen to all eligible newborn babies in Ireland using an agreed national protocol for screening.
- To screen all eligible babies using the agreed national protocol for screening within 4 weeks of birth, and by 44 weeks gestational age for babies who have been in a Special Care Baby Unit (SCBU) or Neonatal Intensive Care Unit (NICU) for more than 48 hours.

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[3] An Integrated Approach to Neonatal Screening in Ireland, HSE, 2008

[4] Seewald, R.C. (1995). Universal Habilitation. American Journal of Audiology, 4(3), 5

[5] Seewald, R.C. (2000). A Sound Foundation Through Early Amplification: Proceedings of an International Conference. Stafa, Switzerland: Phonak AG.

[6] Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services, February 2007

  - To undertake timely referral and assessment to integrated audiology services of babies identified as requiring assessment. This includes:
    - all babies referred from the newborn hearing screen
    - babies requiring targeted follow-up assessment at 7-9 months of age e.g. babies who did not start/complete their screen, or
    - babies who satisfactorily complete the screen but who require on-going surveillance due to the presence of specific high risk factors
- To ensure that all babies with PCHI receive effective and acceptable intervention, care and support that meets their individual needs, including appropriate referral to other services e.g. ENT and allied health professionals and other statutory bodies/ agencies such as Dept of Education & Skills.
- To provide all screening and paediatric audiology services in a seamless family-friendly way.
- To provide families with accurate, up-to-date and comprehensive information at every stage of the care pathway, enabling them to make informed decisions about their child's care. Such information should be offered in a range of formats and in such a way as to ensure that it is meaningful to, and comprehended by all, regardless of social, cultural or ethnic background.
- To provide timely and accurate information about the effectiveness and quality of the service as required.
- To ensure that there is a system of clinical governance in place, with clear and robust lines of responsibility and accountability, enabling the delivery of a quality and standards-driven service[7]

2.5 Limitations of a Newborn Hearing Screening Programme

Newborn hearing screening tests have high sensitivity and high specificity. However, it is acknowledged that a newborn hearing screening programme will miss a very small number of babies with a hearing loss, as no screening programme has perfect sensitivity. Moreover, there will be some children whose hearing deteriorates over time (late onset and progressive permanent childhood hearing impairment). Thus, ongoing monitoring of childhood hearing as part of the child health surveillance programme is critical as well as audiological monitoring of children with risk factors for hearing loss. Care Pathways for access to paediatric audiological assessment have been developed and will support this requirement, followed by appropriate management/habilitation.

If mild, temporary or fluctuating hearing impairment is identified following audiological assessment, the child's hearing impairment must be managed appropriately, in line with best practice.

2.6 Eligibility for newborn hearing screening

- The newborn hearing screen should be offered to all newborn babies born in Ireland, and to those babies under a certain age (3 months) who have missed the hospital screen or moved into the area without having completed a hearing screen elsewhere. Babies between 3 and 6 months who have missed the screen/moved into the area who have not had a screen should be offered an age appropriate audiological assessment.
- All babies are considered eligible for the screen unless there is unequivocal evidence of hearing impairment (e.g. meatal atresia) as per the agreed national protocol.

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[7] Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services, February 2007

2.7 Screening Process

Newborn hearing screening involves screening all eligible neonates. Testing may take place in either the hospital or the community setting. For well babies screened in hospital the screen can take place within hours of birth. Babies that have been cared for in SCBU or NICU for more than 48 hours should ideally be screened as close to discharge as possible in accordance with agreed national protocol. Screening care pathways are developed for SCBU /NICU and well babies (Chapter 6 HSE National Audiology Review Report).

2.8 Service Models – Hospital, Community & Recommendation

Hospital Model

Internationally the predominant model adopted in the implementation of Newborn Hearing Screening has been the hospital based model and has been shown in many studies to be effective. This model is used in 75% of local screening programmes in the UK. The hospital model is where the baby is screened from start to finish in the birthing hospital or if necessary the screen completed in a follow-up outpatient's clinic. In the UK, screening is performed by 'dedicated screeners'. Internationally, the majority of service models are hospital based as the captive population facilitates high coverage with easy access to infants.

Community Model

The community model is where the screen takes place in the community (except for SCBU/NICU babies who should begin and/or complete their screen in hospital) and it this model that is used in 25% of local screening programmes in the UK. Under this model, babies are screened at home by a Public Health Nurse/Screener/other health professional (e.g. health care assistant) during the primary visit. In the UK, this home visit takes place usually at 10 days of age. The scheduled visits of Public Health Nurses in Ireland provides for a recommended home visit within 48 hours post discharge.

Table 2.1 Hospital and Community Service Model – Benefits and Challenges

Hospital Model	Community Model	Combination Approach with use of both models
▪ Has been shown to have worked on a large scale ▪ Model most widely used internationally	▪ As a model tends to operate on a smaller scale alongside a pre-dominantly hospital based model	▪ Challenges of combined approach include consistency and coherence in planning, performance monitoring and quality assurance
▪ Greater efficiency ▪ Availability of significant cohort of babies on site 77%-93% of babies[8]	▪ Good coverage, but there may be travel and salary cost implications if the screen does not align with schedule of nursing visits	▪ Risk of not screening babies where two approaches in operation
▪ Dedicated screeners, helping to ensure greater level of competence/experience	▪ Throughput of babies screened per nurse may not be sufficient to ensure competence in	

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[8] HIPE Data, Health Atlas Ireland, 2009

	screening	
▪ Quality assurance is easier to ensure	▪ Quality assurance issues may pertain in terms of consistency	▪ Allows scope to test community based model in Irish context
▪ Easier management and monitoring of performance	▪ Management and monitoring of performance more difficult	
▪ Salary cost of screeners lower than PHNs	▪ Salary cost not an issue if screen is incorporated as part of 48 hour scheduled PHN visit	
▪ Equipment set up cost less	▪ Initial set up of equipment cost greater	
▪ Need for office accommodation/storage	▪ No accommodation requirement	
▪ Acceptable to parents	▪ Acceptable to parents.	
▪ Babies screened before 48 hours greater chance of test fail	▪ Has been shown to have lower referral rates as babies older at time of screen	
▪ Trend towards earlier discharge of mothers/babies which could be an issue		

Recent evidence from the London site of the UK screening programme[9] suggests a single model approach as the preferred option. It furthermore questions the effectiveness of the community model and states that "*most community type screening models do not work well and especially those that border hospital sites. Areas that operate community sites should reassess the workings of the site and examine the possibility of joining with a nearby hospital site to form a larger exclusively hospital site*".

Recommendation of Service Model – Hospital Model

Based on this evidence and the high percentage of babies born in the hospital setting, the National Audiology Review Group recommends the adoption of the hospital model as the single national model.

The success of this model, (whilst reliant on a range of factors, in particular a multidisciplinary effort) is dependant on an integrated approach between hospital and community with integrated discharge planning a key element. It is important however that arrangements for babies, born at home/private hospital and babies who miss screening, are put in place at local level to ensure comprehensive coverage in providing a population based approach.

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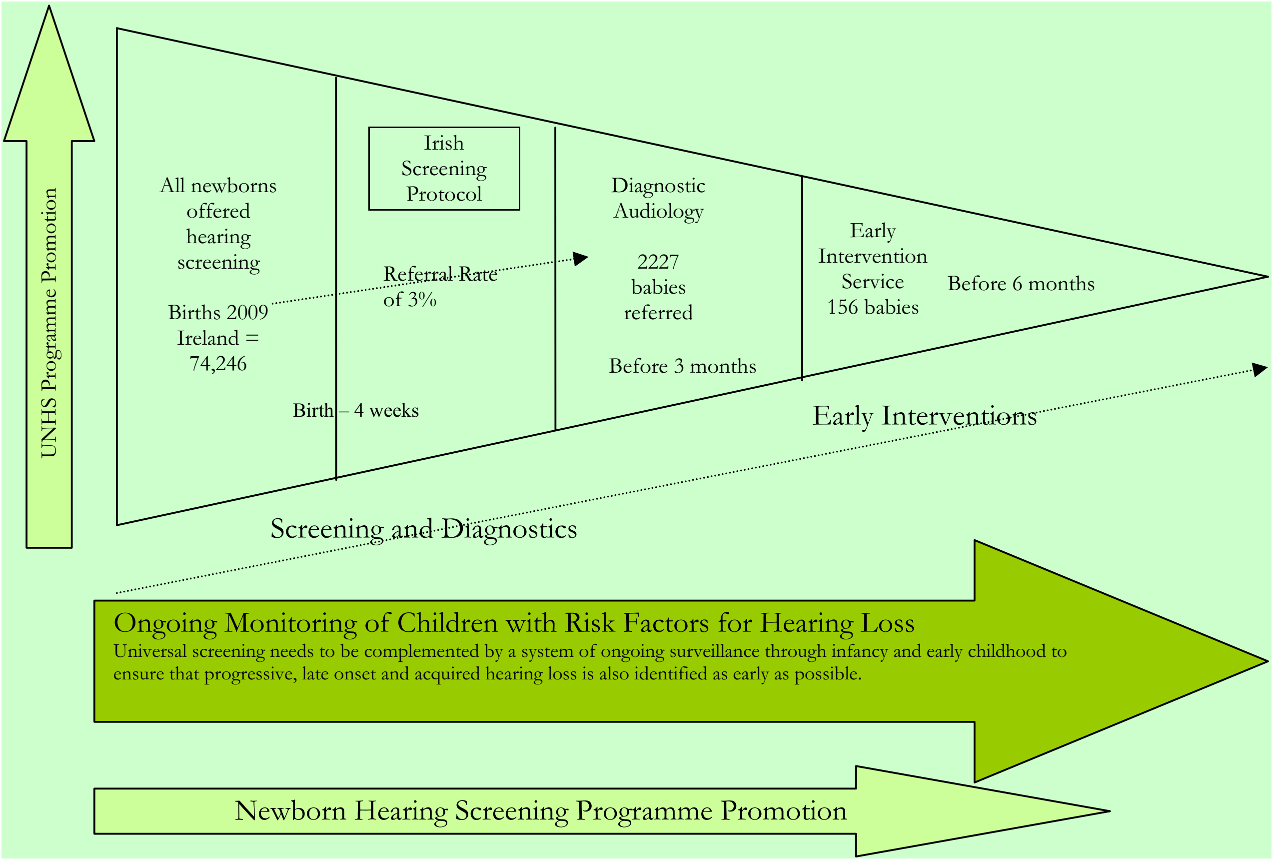
[9] Mapping of Newborn Hearing Screening Including Health, Education and Family Care Services in London, report to the Department of Health, July 2006

2.9 Baby's Journey from Screening through to Intervention

The diagram (Figure 2.1) below represents the baby's journey from screening through to intervention. Detailed care pathways supporting the well baby's journey and the SCBU/NICU baby's journey have been developed (Appendix A & B). Critical to the success of a screening programme is the smooth and timely journey of the baby from one stage of the process to the next. In addition there will be ongoing monitoring of childhood hearing as part of the child health surveillance programme as set out in Best Health for Children Revisited[10]. In terms of the number of births, the 2009 HSE maternity hospital live births are used i.e. 74,246 births and this remains constant for planning purposes for subsequent years.

The quality standard for most international screening programmes is a referral rate of less than 3%. At the start-up phase of the programme, evidence suggests a referral rate of 3% or higher. Experience from the UK suggests that this rate is lower for an established programme. The prevalence data used is based on international evidence and the experience of the UK screening programme.

Figure 2.1



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[10] HSE Best Health for Children Revisited October, 2005

2.10 Newborn Hearing Screening Programme Design

The establishment of newborn hearing screening is one of the key elements of an integrated childhood hearing screening and audiological service in Ireland and should ideally be set within an overarching HSE national childhood screening programme governance structure.

This design structure ensures that all elements of the Childhood Hearing Screening Programme and its associated pathways, function in an integrated way and is informed by best practice. Implementing a national screening programme is a major undertaking, the success of which will be dependent on the quality of the programme. Important elements of a programme include: central organisation, appropriate service configuration, a skilled workforce, high quality health promotion and education, robust supporting information systems, quality and policy standards, monitoring of performance, appropriate accountabilities and levers, the consumer voice, and audit. The balance between scope, cost, time and quality needs to be achieved to ensure effective and safe programme implementation, informed by screening ethics.

The proposed national integrated audiology service structure by NARG would encompass responsibility and support for the implementation of the newborn hearing screening programme:

1. The proposed National Integrated Audiology Lead role will have as part of its remit, responsibility for the national oversight, management and quality assurance of the Newborn Hearing Screening Programme along with all audiology service delivery.
2. The proposed Regional Audiology Leads will have as part of their remit, responsibility for the day to day management, audit and quality assurance of the Newborn Hearing Screening Programme within their geographic areas. This structure is designed to complement the current HSE design structure whilst ensuring that audiology is provided within an appropriate governance structure and integrated framework.
3. Work is underway within the HSE in the design of a national governance structure for childhood screening programmes. It will be important that these structures complement each other.

It is recommended that screening be undertaken by dedicated Screeners in each of the HSE Maternity Hospitals. The UNHS Scottish Implementation Report[11] describes the process of screening as one that "can be carried out by staff who have no special knowledge or skills in hearing science but who are good with babies and can assimilate the basic training required", as is the case in England and Wales. Screening programmes around the world employ a variety of personnel which include: audiologists, mid-wives, health visitors and volunteers. Experience and training in speaking to parents is essential. The level of resource and cost attaching to screening will depend on the staff group recruited to the task in specific settings. Spivak (2000)[12] states that performing screening tests is neither the best nor most cost-effective use of audiologists' 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 programme. In order to ensure efficient screening, screeners must also have a certain throughput to maintain their skills. Johnson et al.[13] observed that best screening outcomes were obtained when screeners

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[11] UNHS Scottish Implementation Report, 2001

[12] Ready, Set….Laying the groundwork. The Hearing Journal Special Issue: Universal Newborn Hearing Screening. Spivak, L, November 2000

[13] Implementing a Statewide System of Services for infants and toddlers with hearing disabilities, Johnson, 1993

worked a minimum of 20 hours per week or as the UK experience suggests a minimum of 20 babies screened per week. An initial intensive training programme is vital to equipping screeners with the required competencies with ongoing quality monitoring and support. The experience of other programmes suggests that the use of part-time screeners provides a greater level of flexibility enabling greater coverage than exclusively fulltime screeners. Additionally the incorporation of the administrative function into the screener's job (rather than distinct administration and screener posts) enables greater screening capacity/coverage as well as providing administrative support.

The experience of Ireland's audiology services has been that of operating within scare audiology resources. In this regard and recognising the management principle that tasks should in general be done by staff at the lowest level commensurate with the safe and effective practice of that task, thus freeing more highly trained staff deal with more specialist activities. This is in keeping with the international evidence available that supports the use of screeners.

It is recommended that the Regional Audiology Leads should be in post in advance of the screeners for planning and implementation purposes.

2.11 Roll-Out

The decision on whether to roll out the programme in a single stage or on a phased basis is influenced by a number of critical factors which include: risk, resources (staff and funding), project/service capacity, quality and the opportunity for lessons learned, amongst others. There are clearly greater risks to a single national rollout.

It is proposed that this programme should be rolled out on a phased basis by region with the initial phase evaluated. It will incorporate all HSE maternity hospitals, home births and arrangements with private maternity hospitals in that region, thus providing a population based approach. A rapid evaluation should follow prior to further roll out of the programme. In parallel preparatory work to enable full national roll out is ongoing. A national implementation team and supporting programme plan should guide implementation.

Table 2.2 below sets out the ratio of staff to births. The newborn hearing screening staffing requirements, within an integrated audiology service are for a National Audiology Lead role, 4 Regional Co-ordinators and 59.4 WTE Screeners. Key responsibilities are identified for each post. These are informed by the National Report on Universal Neonatal Hearing Screening (2004)[14] and the Manchester report recommendations[15].

Table 2.2 Newborn Hearing Screening Requirements within the National Childhood Hearing Screening Programme

Post	Ratio of staff to births	Responsibility
National integrated Audiology Lead	1 WTE	▪ Strategic oversight and responsibility for Childhood Hearing Screening Programme, within the Integrated National Audiology Service
Regional Audiology	1 WTE per	▪ Operational responsibility for Integrated

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[14] Programme of Action for Children, Report of The Universal Neonatal Hearing Screening Working Group, HSE, 2004

[15] Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services, February 2007

Lead	HSE Region	Audiology service in the Region encompassing Childhood Hearing Screening Programme.
Dedicated Screener	1 WTE screener per 1,250 births*	▪ Responsibility for screening process and for administrative work associated with screening.

* This ratio is as set out in UK screening programme – however Irish evidence following initial roll out in one region will assist in guiding practice.

The administrative requirement as has been suggested in some of the literature should be integrated within the screener post /job description (Appendix B).

2.12 Other Requirements for Newborn Hearing Screening Programme

Equipment

The UK experience recommends the following approximations in terms of equipment provision.

Table 2.3 Screening Equipment Indicative Cost

Screening Equipment	Detail	Indicative Cost per Unit*
1 OAE Screening Unit per 1,200 births	Birth Rate 74,246 = 62 OAE Screening Units	€3,600
1 AABR Screening Unit for each Maternity Hospital	19 Maternity Hospital	€8,800
1 AABR screening unit for each NICU and as contingency	19 NICU/SCBU	€8,800
Diagnostic ABR equipment	Estimated 2-4 diagnostic audiology departments per HSE region = 8-16 ABR kits	€12,000 - €24,000
Consumables Costs	e.g. disposable ear phones, electrodes, new calibrated leads, ear tapes etc	To be established by region

*The costing is indicative and will be revisited and informed by completed national needs equipment assessment.

A list of recommended equipment specifications for newborn hearing screening has been compiled (Appendix C). In addition a national needs assessment of equipment requirements in terms of diagnostic audiology has recently been undertaken. Funding has been provided for key diagnostic equipment for each of the regions in 2010.

Audiology facility standard specification /Accommodation

For babies who are screened in hospital, the screen may take place at the mother's bedside. Alternative suitable accommodation close to the maternity ward should be made available to the screening team to carry out screening if the level of ambient noise on the ward is too high. Office accommodation and storage will be needed for screening staff to perform tasks associated with screening such as data entry[16]. Patient confidentiality is maintained. Where babies complete their screen at an outpatient's clinic or community clinic, the accommodation used should be

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[16] Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services, February 2007

appropriate, preferably in rooms that minimise distraction or sound pollution from other activities. The environment needs to be as family-friendly as possible.

The facilities required for diagnostic audiology should include a sound proof room whose specification should be defined in accordance with recognised international standards of the Hospital Technical Memorandum (HTM) No. 2045, 1996. Good international practice also suggests the need for a family friendly environment. An assessment of requirements should be undertaken. Audiology facility standard specifications should be incorporated into the planning and design of new HSE facilities/centres being developed e.g. Primary Care Centres..

Information Management System

Fundamental to having a quality screening programme is a national information management system that identifies the cohort of babies requiring screening, enables effective monitoring of performance, and supports the tracking and follow-up of babies. This is crucial to the delivery of high quality continuous clinical care, and in the organisation of clinics and efficient record keeping17.Effective performance management at local and national level providing for programme evaluation and outcome measurement is an element to be incorporated in a National IT system.

It is accepted that there is a need for a single national system that is integrated, where data can be entered at local level. There currently exists no single integrated child health system in which to incorporate a national audiology hearing screening programme. The development of such a system should only be undertaken within a national framework and in the context of the broader HSE child health requirements. The development of a partnership approach with ICT is required.

The development of a core data set is an area of work that can be progressed in anticipation of a national IT system.

Training for Screeners

A formal training program for screeners should be developed/sourced, and/or tailored to the needs of the Irish setting. The content of the training program should:

- Be guided by the job specification requirements
- Address all aspects of screening responsibilities with clear definition of limits in the role and function of screeners
- Include specific competency-based training through formal instruction and supervised practice
- Include instruction in the operation of the screening equipment

Individual observation/assessment to determine the ability of the screener to perform duties associated with newborn hearing screening safely and competently should be completed with documentation or certification of proficiency. Personnel should complete a recertification of proficiency every two years, as a minimum, with ongoing assessment and re-training as needed.

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[17] Transforming Services for Children with Hearing Difficulty and their Families: A Good Practice Guide; NHS August 2008

Audiologists Upskilling/Training

There will be a specific need for training/upskilling of the paediatric audiologists who will provide paediatric ABR and VRA assessments, and for those paediatric audiologists who will be fitting and managing hearing aids for infants in each HSE region. In preparation of roll out in one RDO area, training courses have been organised for those involved in the diagnostic assessment of babies who will be referred from the screening programme and further national training is planned. In the longer term, an urgent priority is to secure a well-trained, competent, stable audiology workforce with much better recruitment and retention statistics than at present. In the context of newborn hearing screening, paediatric audiology services should be provided by a skill-mixed team led by postgraduate trained specialists and include practitioners and assistants as appropriate to defined tasks covering assessment and intervention from birth to 18 years of age.

Audiologists training (medium to long term)

The overall review report will address this issue in more detail. In brief, if Ireland is to maintain a workforce of sufficient skill and competence to provide a coherent, consistent audiology service, able to recruit and retain suitably qualified staff, then a national school of audiology should be considered.

Training needs of other professionals

Once babies, infants, children and young people have been identified with PCHI, a number of other professionals are crucially involved in supporting the child and family in home and school settings, according to individual need. Additional training will be required in working with very young babies and their families. Visiting Teachers of the Deaf and Speech and Language Therapists in particular, are a vital component in the delivery of services, and upskilling will be required as well as a review of the curricula of existing pre-registration training programmes for these professionals.

Public Awareness/ Information

Public and professional awareness of the benefits of the screening programme to infants/families is fundamental to the success of the programme. A campaign to heighten awareness of newborn hearing screening is an essential prerequisite to programme implementation and will be an ongoing requirement.

Appropriate information materials should be developed and available for the different stages of the screening process as follows:

- Before screening
- For the screening tests
- For the audiological assessment of those referred by the screen
- For those who are found to have a permanent hearing loss

These materials should be available in a range of languages and culturally appropriate. There is a comprehensive range of materials available in the UK and the National Audiology Review Group recommends sourcing and adapting these materials subject to copyright permission.

2.13 Newborn Hearing Screening Programme – Follow-up Paediatric Audiology Commitment

Diagnostic Assessment and Hearing Aid Evaluation

Babies who do not show clear responses to the screening tests will be referred on for audiological assessment. Audiologists with expertise in evaluating infants determine the presence, type and degree of hearing loss, if any. The purpose of audiological assessment is to provide sufficient audiometric information for subsequent audiological, educational, social and medical/surgical management, organised around an individual management plan. An individual management plan is a key tool and best practice requirement for an integrated multidisciplinary approach that has the client at the centre.

The objectives of audiological assessment are to obtain valid and accurate estimates of ear specific, frequency-specific thresholds and, in those infants with a hearing loss to determine its nature and type (temporary or permanent, conductive, sensorineural, mixed, auditory neuropathy spectrum disorder (ANSD). For infants, definitive quantification of hearing may require several test sessions, either to improve audiometric completeness, and/or to monitor possible changes in hearing. Audiological assessment needs to be completed by three months of age for early identification to occur and to allow intervention to begin before 6 months of age in accordance with nationally agreed protocols and best practice. Children who are identified with PCHI need aetiological investigation, which may include genetic testing, developmental assessment and opthalmological assessment. These needs require a medical input from suitably upskilled Paediatric Otologists, Paediatricians, or Audiovestibular Physicians.

Figure 2.2 outlines the expected number of babies to be present at various points of the baby's journey of the screening programme. The number of expected appointments at each stage of the follow up journey has been determined using service requirement data from the British Colombia[18] and in consultation with the NARG.

Number of expected appointments Year 1: (*2009 Hospital Birth Data applied i.e. 74,246)*

1. Based on a 3% referral rate of babies screened, 2227 babies will require diagnostic services. The other 72,019 will continue to undergo routine child health surveillance.
2. Of the 2,227 babies screened, 1,603 (72% using British Columbia calculation) will be found to have normal hearing and be discharged from the programme. These babies will continue to undergo routine child health surveillance. The 624 babies remaining will require further diagnostic assessment.
3. Based on a prevalence rate of 1 per 1,000 live births (Fortnum, 2001)[19], 74 of the 624 babies will have a bilateral moderate or worse hearing loss. These babies will need three more appointments/hearing aid assessments in Year 1 and a further 6 in Year 2. Based on the Greater Manchester Service Specification document (2007)[20] approx 50% of these babies will be assessed for cochlear implant. Assessment for cochlear implant is recommended for

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[18] Hearing Screening for every baby – A Sound Start: A British Colombia Initiative for Early Hearing Detection and Intervention Prepared by The Early Detection and Intervention - BC(EHDI-BC) Steering Committee Revised DRAFT Document July 30, 2004

[19] Fortnum HM, Summerfield AQ, Marshall DH, Davis AC, Bamford JM. Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire-based ascertainment study. BMJ 2001; 323: 536-540

[20] Greater Manchester Service Specification for Newborn Hearing Screening & Paediatric Audiology Services, February 2007.

those with a profound hearing impairment and in some cases with severe hearing impairment.

4. Based on a prevalence rate of 0.4 per 1,000 live births (UK annual report 2006/2007)[21], 30 of the 624 babies will have a unilateral moderate or worse hearing loss. These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.
5. 520 of the 624 will need a second (1 further additional) diagnostic appointment. Of that 520, 468 will be found to have normal hearing and be discharged from the programme. These 468 will continue to undergo routine child health surveillance. The remaining 52 will have either a mild hearing loss or are audiologically uncertain and require further monitoring (0.7 per 1000 live births) this prevalence rate is based on the UK Annual Report 2006/2007). These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.

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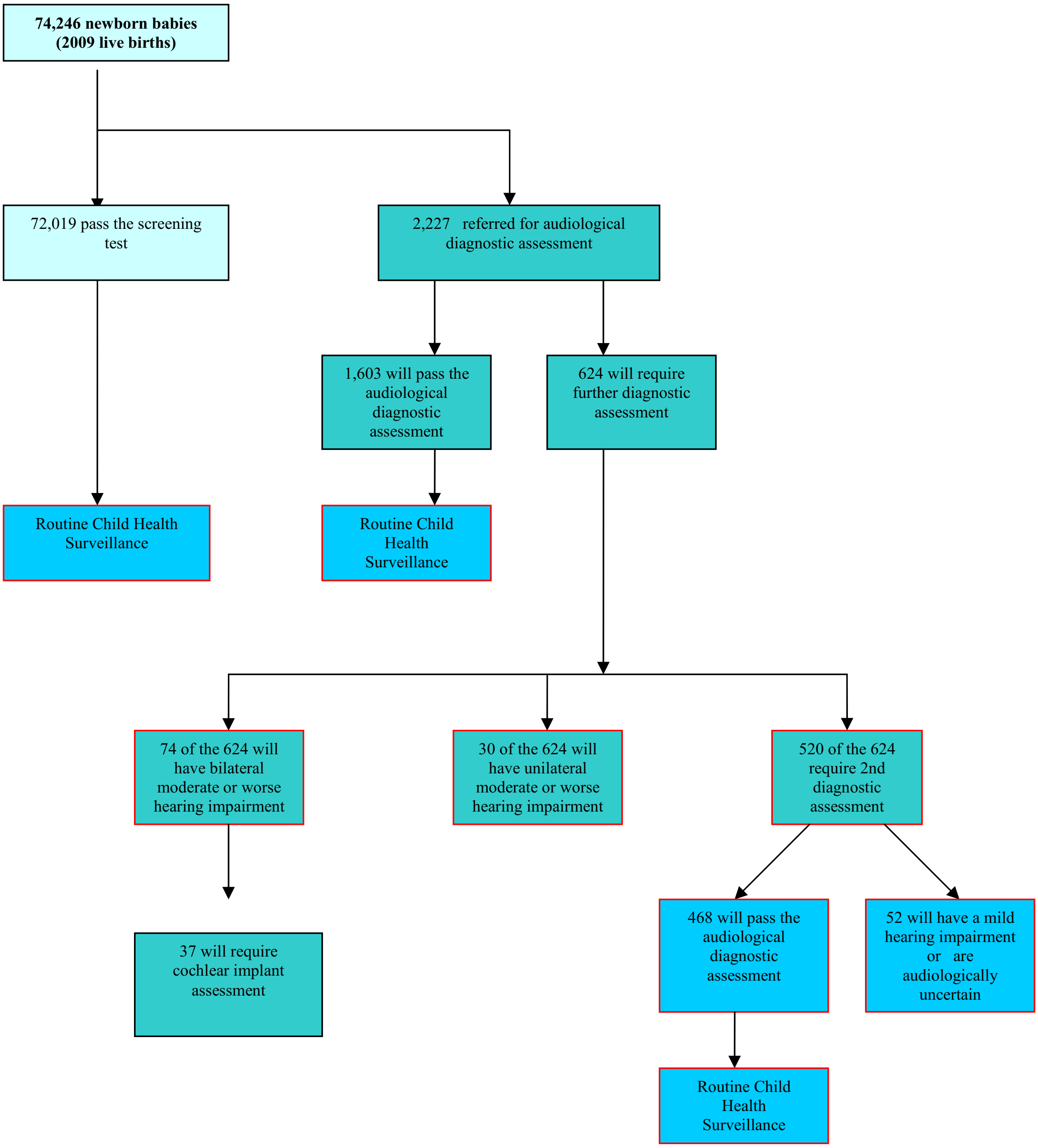
[21] NHS Newborn Hearing Screening Programme. NHS Newborn Hearing Screening Programme Centre Annual Report 2006/7

Figure 2.2 Expected numbers throughout journey of the screening/audiology programme



Number of Expected Appointments Year Two and Subsequent Years

1. Annual Year 1 numbers repeat as new children are identified in the screened population
2. Ongoing hours are required for children identified the previous two years. These are calculated as follows;
    - The 74 children with bilateral moderate or worse hearing loss will need 6 assessments/hearing aid appointments in Year 2 and Year 3.
    - The 30 children with unilateral, moderate or worse hearing loss and the 52 children with mild hearing loss or have audiological uncertainty hearing loss will need 2 assessments/hearing aid appointments in Year 2 and Year 3.

For clarity, these data are summarised in Table 2.3, along with estimated appointment times and consequent staffing needs. Note that none of the children identified with PCHI by screening are new cases for services - rather they are cases which are found earlier than would be the case if no screening were in place. Note also there are aspects of the audiological clinical work that are easier with younger babies and infants than with older infants, as well as long term outcome improvements associated with early intervention which will reduce later costs.

Table 2.3 Diagnostic Audiology – Calculation of hours of paediatric audiology service

Table 2.3		**Year 1**			**Year 2**			**Year 3**		
Diagnostic Audiological Assumptions		**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**	**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**	**No. of children**	**No. of Apts per child per year**	**Total Hours of Apts @ 2.5 hrs earned**
Hours per Appointment				2.5			2.5			2.5
2009 live births - 74,246 2009										
Number of babies referred from screen (3% of referral rate)		2,227	1	5,568						
Number of babies who require 1 additional diagnostic appointment		520	1	1,300						
Number of babies with bilateral moderate or greater hearing loss		74	3	555	74	6	1110	74	6	1,110
Number of babies who have either a mild hearing loss or are audiologically uncertain and require further monitoring These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.		52	2	260	52	2	260	52	2	260
Number of babies who have a unilateral moderate or worse hearing loss. These babies will need two more appointments/hearing aid assessments in Year 1 and two further appointments in Year 2 and 3.		30	2	150	30	2	150	30	2	150
Audiological Diagnostic Requirement from UNHS Programme				**7,833**			**1520**			**1,520**
Cumulative Audiological Diagnostic Requirement from				**7,833**			**9,353**			**10,873**

UNHS Programme										
Children who missed screen/did not complete screen (Calculation based on 5% of live births @ 45minutes per appt).		3,712	1	2,784						
Cumulative audiological requirement on missed/not completed screens				2,784			2,784			2,784
Cumulative Total Hours of diagnostic audiological appointments				10,617			12,137			13,657
Indicative WTE – Indicative Working Hours Available										
No. of Days per year	365									
Less shrinkage										
Less Weekends	104									
Less Bank Holidays	5									
Less Easter/Xmas Holidays	6									
Less Average Holidays	30									
Less Average Sick Days	3.5									
Working Days Available after shrinkage	216.5									
Standard Hours per Day	6.75									
Hours Available to Work per WTE in a Year	1,461									
WTE Requirement				7.26			8.31			9.35

2.15 Monitoring of Children with Risk Factors for Hearing Loss

The purpose of Delayed-Onset Hearing Risk Monitoring is to identify infants who have passed screening and have good hearing at birth, but who are at risk of developing hearing loss early in childhood. Based on the NHSP UK Annual Report 2006/7, 3% of children screened will be high risk. A strong surveillance component to newborn hearing screening is necessary to enable the early detection of and intervention for these children. The US Joint Committee on Infant Hearing (JCIH) states *"Infants who pass the neonatal screening but have a risk factor should have at least 1 diagnostic audiological assessment by 24-36 months. Early and more frequent assessment maybe indicated for children with cytomegalovirus (CMV) infection, syndromes associated with progressive hearing loss, neurodegenerative disorders, trauma, or culture-positive postnatal infections associated with sensorineural hearing loss; for children who have received extracorporeal membrane oxygenation (ECMO) or chemotherapy; and where there is caregiver concern or a family history of hearing loss*". The NARG recommends that a diagnostic audiology assessment be offered to these children no later than 24 months.

Chapter 3 Childhood Hearing Screening Pre-School and School and up to 18 years of age

3.1 Best Health for Children Revisited (2005)[22]

The Public Health Nursing (PHN) child health developmental assessments encompasses assessment for hearing as part of the overall assessment at various stages for the pre-school child i.e. 3 months, 18 -24 months and 3.25 – 3.5 years (Table 3.1).

Table 3.1 from Best Health for Children Revisited (2005) recommends the following Hearing Assessment Schedule, Equipment and Health Promotion information. This may need review in time in accordance with new evidence/developments.

Timing	**History**	**Examination**	**Equipment**	**Health Promotion**
Birth	Antenatal, birth and family history, risk factors for hearing loss, parental concerns	UNHS is gold standard (two stage screen as per UNHS report recommendations) Inspection of ears, facial morphology, associated physical findings or syndromes.	Otoscope	Encourage parental observation, 'Can your baby hear you?' leaflet
Postnatal visit	As above	As above		As above
6 to 8 weeks	As above	Observation of auditory behaviour	Otoscope	As above
3 months	As above	Observation of auditory behaviour		As above
7 to 9 months	As above	Distraction hearing test in the absence of UNHS	Sound treated/quiet room (ambient noise<35dB (A), carpets, curtains & low table, toys. Calibrated warbler, trained LF/HF voice, Manchester HF rattle. Access to sound level meter	As above
18 to 24 months	As above	Observation of speech and language behaviour		
3.25 to 3.5 years	As above	Observation of speech and language behaviour		As above
School entry (Junior	As above	In the absence of UNHS – pure tone audiometry (sweep test screen, 1st and	Quiet room <40dB (A) ambient noise, bricks, tapper or	

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[22] Best Health for Children Revisited, HSE, 2005

Infants)		2nd test stages)	hammer for child responses. Small screening audiometer Sound level meter	

Best Health for Children recommends:

- Early implementation of UNHS programme
- Retention of Infant Distraction Hearing Test and School Sweep Test as an interim measure, until implementation of UNHS
- Education of parents and professionals in using "Can your Baby Hear You"

3.2 Infant Distraction Test Recommendation

Screening using the Infant Distraction Test (IDT) continues and is carried out by Public Health Nurses/Area Medical Officers in the community as part of an overall child health surveillance programme. The UK Health Technology Assessment Report (1997)[23] highlighted the inadequacy of the Health Visitor Distraction Test as a screening tool. Children who do not pass the test are generally retested one month later, if they do not pass the test they are referred for diagnostic assessment to the HSE community audiology service. The UNHS Scottish Implementation Report (2001)[24] identified a referral rate of between 10% and 20% from the infant distraction test. Data from the UK Health Technology Assessment Report (1997) suggests a referral rate of nearly 10% from the IDT. While there is no published Irish data available, anecdotal evidence suggests similar referral rates.

It is now recommended that, parallel to the introduction of the newborn hearing screening programme the IDT should be phased out. Both screening programmes will run concurrently for a period of 9 months; assuming that the IDT is being carried out at the recommended age of 7-9 months as recommended under Best Health for Children Revisited, 2005. Following this period the IDT will cease and the Neonatal Screening Programme will run as the single screening programme.

As with the UK Health Visitors, PHNs will be involved in work relating to the targeted follow up of babies who miss/decline the screen, do not complete the screen, and/or do not attend for audiological assessment following the screen; to ensure that there is discussion with parents as soon as possible about hearing and appropriate arrangements made.

For the 9 month overlapping period of screening programme PHNs will need extra vigilance to ensure comprehensive neonatal screening follow up whilst the IDT is being phased out. The longer term should result in an improved and reduced referral rate.

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[23] Davis A, Bamford J, Wilson I, Ramkalawan T, Forshaw M, Wright S. 1997. A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. Health Technology Assessment,1.

[24] Universal Neonatal Hearing Screening Scottish Implementation, April 2001

3.3 Childhood Hearing Assessment /Habilitation Pre-School/School

The prevalence of PCHI continues to increase through infancy. Of the 3.47 in 1000 children with a permanent hearing impairment at school screen age, 1.89 in 1000 required identification after the newborn screen[25]. Just under 20% of permanent moderate or greater bilateral, mild bilateral and unilateral impairments, known to services as 6-year-olds or older, remained to be identified around the time of school entry[26].

A health technology assessment in the UK concluded that there is a lack of good quality evidence regarding the effectiveness of the school entry screen (SES) thus impeding any decisions to change the screen. The report found that a national screening programme for permanent hearing impairment at school entry meets all but three of the criteria for a screening programme. The report recommended national protocols, data monitoring systems, audit and studies comparing alternative approaches to the identification of PCHI post the newborn screen. The American Academy of Paediatrics also recommends hearing screening at school entry age[27].

The aim of the SES is to detect children with a PCHI that has gone undetected to date. The screen uses sweep audiometry to establish if a child has satisfactory hearing or not. The NARG recommends a change to the current Best Health for Children school screen protocol. The new protocol recommends for frequency levels (pitch) at 1000, 2000 and 4000 Hz in each ear at 20 dB/HL (loudness of the sound). The child has to correctly identify all 6 stimuli to pass the screen. A screen not passed should be retested on a different occasion within 4-6 weeks unless there is particular concern of marked hearing loss. All referrals from PHNs/SMOs from screening through pre-school or school screening should be directly referred to the Audiology Department for triage and follow up as required as set out in the Paediatric Assessment or Paediatric Habilitation Care Pathways.

The Directors of Public Health Nursing are currently responsible for school entry screening in Ireland. The screen should be carried out on children in junior infants by a dedicated PHN with appropriate training. Currently SES is not done in all areas. A training manual “Training Programme for Public Health Nurses and Doctors, Unit 3 Hearing Screening and Surveillance” by the Programme for Action for Children is available but will need to be updated in line with the new protocol.

The National Audiology Review Group recommends primary research be undertaken to guide continuance of the SES.

3.4 Childhood Hearing Assessment /Habilitation - Up to 18 years

At any stage up to 18 years of age where referral to audiology service is required access to integrated audiology service can be made via the Paediatric Assessment or Paediatric Habilitation Care Pathways. These care pathways acknowledge that referrals can be received from the following;

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[25] Bamford et al, 2007

[26] Bamford et al, 2007

[27] Allen et al. Clinical Report, Hearing Assessment in Infants and Children: Recommendations Beyond Neonatal Screening, Paediatrics 2009;124;1252-1263; originally published online Sep 28, 2009.

- Screening (refer from neonatal screening, those who missed, moved or did not complete screen)
- Surveillance
- Direct referral (by client and/or parent/guardian)
- Primary Care Team members

The Critical Review of Evidence for newborn hearing screening carried out by the Health Technology Assessment Programme in the UK[28] includes a detailed report on a comparison study of the costs of Newborn Hearing Screening (undertaken by three defined population districts) and the 8-month distraction test screen. Results indicated a cost ratio of 2:3 (Newborn Hearing Screening: 8-month screen) on a per-child-screened basis. The ratio favours Newborn Hearing Screening even more on a cost per case detected basis, due largely to the poorer coverage, higher referral rate, and poorer sensitivity of the 8-month screen. Absolute costs per child screened in 1996 prices were £14 for Newborn Hearing Screening and £21 for the 8-month screen; this includes screening and follow up to the point at which cases are confirmed as true positives or false positives. Current cost in England per child screened by the Newborn Hearing Screening programme there is of the order of £35[29] although there are aspects of the programme in England which are likely to make it towards the top end of the range of likely cost-per-child-screened estimates. Further detailed cost analyses of newborn screening are available in the report of the first phase of implementation of newborn screening in England[28]

Costs of audiological interventions for true cases (ongoing assessments, device fitting and management etc) during childhood may increase somewhat with newborn hearing screening, since they will take place over a longer period (say 18 years, birth to adulthood, rather than say the 16 years from late diagnosis to adulthood). Other possible sources of increased costs derive from the extra training and expertise needed to provide good quality early audiological management and for the support to families of very young deaf children from teachers of the deaf and social services.

There are a number of ways of assessing the benefits and cost-benefits of newborn hearing screening. The age of diagnosis of moderate or greater permanent congenital hearing loss in England reduced from a median of 22 months (with some cases very late) to a median of below three months of age following the implementation of Newborn Hearing Screening[30]. Assessment of parental judgements of benefit and possible harm of the newborn screen have been equally convincing[31] Intervention before six months of age results in significantly better language and communication skills[32].

An over-riding objective of early diagnosis and appropriate intervention is for deaf children to approach school entry with age-appropriate language and communication skills, so that the development of literacy, numeracy and knowledge acquisition is on a typically-developing trajectory, rather than the child, the family and educators having forever to endeavour to 'catch

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[28] Davis A, Bamford JM, Wilson I, Ramkalawan T, Forshaw M, Wright S. (1997). A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. Health Technol Assess, 1 (10), 1-177.

[29] Davis, personal communication to John Bamford May 2010

[30] Bamford JM, Ankjell H, Crockett R, Marteau T, McCracken W, Parker D, Tattersall H, Taylor R, Uus K and Young A. (2005). Evaluation of the Newborn Hearing Screening Programme in England: Studies, Results and Recommendations. Department of Health, http://www.library.nhs.uk/screening/ViewResource.aspx?resID=123519&tabID=288&catID=8205 pp 243.

[31] Watkin P, Beckman A, Baldwin M, The views of parents of hearing-impaired children on the need for neonatal screening. Br J Audiol 1995; 29:259-62.

[32] Moeller 2000; Moeller M. Early intervention and language development in children who are deaf and hard of hearing. Pediatrics 2000 Sept; 106(3):1-9. Yoshinaga-Itano C, Sedey A, Coulter B, Mehl A. Language of Early- and later-identified children with hearing loss. Pediatrics 1998; 102:1161-71. Yoshinaga-Itano C, Gravel JS. The evidence for universal newborn hearing screening. Am J Audiol 2001; 10:62-4.Yoshinaga-Itano et al 1998; Yoshinaga-Itano and Gravel 2001

up'. Late diagnosis and consequent delayed development have long term costs associated with special education and support, as well as personal, family and societal costs resulting from lower educational achievement, poor employment prospects, and potential mental health problems.

Grosse[33] (2006) produced an evidence-statement on newborn hearing screening. This statement concludes that 'To the extent that improved language leads to lower special education costs and to improved learning potential, the monetary benefits of screening are likely to exceed the costs[34]. The economic benefits of newborn hearing screening include reduced special education costs associated with improved hearing and language and also lower social and community services. A study from England[35] (Schroeder et al 2006) has reported that average education costs among 7 to 9 year-old children with bilateral hearing loss were lower by 22% among children born in districts with universal newborn hearing screening. The savings in special education costs are likely to exceed the costs of screening within five years.'

Briefing Paper John Bamford
Dated 02/05/2010

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[33] Grosse S (2006) Grosse S. Newborn hearing evidence-statement: screening. In: Campbell KP, Lanza A, Dixon R, Chattopadhyay S, Molinari N, Finch RA, editors. A Purchaser's Guide to Clinical Preventive Services:Moving Science into Coverage. Washington, DC: National Business Group on Health; 2006

[34] Mehl AL, Thomson V. Newborn hearing screening: the great omission. Pediatrics 1998 Jan;101(1):E4; Keren R, Helfand M, Homer C, McPhillips H, Lieu TA. Projected cost-effectiveness of statewide universal newborn hearing screening. Pediatrics 2002; 110:855-64.

[35] Schroeder L, Petros S, Kennedy C, McCann D, Law C, Watkin PM, et al. The economic costs of congenital bilateral permanent childhood hearing impairment. Pediatrics 2006; 117:1101-12.

SAMPLE JOB DESCRIPTION

JOB DETAILS

Job Title:	Newborn Hearing Screener
Pay Band:	Band 2
Pay Band Scale:	
Hours of Work:	
Department:	
Division:	
Base:	
Duration:	Permanent

ORGANISATIONAL ARRANGEMENTS

Accountable to:	1. Programme Manager (Managerially) 2. Programme Manager/Asst Programme Manager* (Reporting) ** Delete as appropriate* **3.** Divisional Co-ordinator and Associate Director (Professionally)
Responsible for:	Managing or Supervising

Job Summary:
Newborn Hearing Screening Wales (NBHSW) operates as a managed network across Wales providing a uniform service to high quality within an all Wales policy and to all Wales standards and protocols. The programme is managed by (insert name) with local arrangements in each area.

JOB PURPOSE

To work as an established member of the team participating in the hearing screening of new born babies, under the clinical supervision of the Divisional Co-ordinator. The post holder will undertake the full range of newborn hearing screening duties including gathering and accurately recording clinical and test data relevant to the screening process.

Main Duties and Responsibilities

- To operate administration and IT systems to co-ordinate information on all newborn babies.
- To identify which babies require screening and prioritise the daily work load
- To liaise effectively with parents, team member and other health care professionals.
- To carry out the hearing screening of newborns and accurately record results.
- To undertake screening tests in a hospital, home and clinic setting.
- To promote a professional, welcoming and caring environment endorsing a family friendly approach to care

- To competently use IT system for recording results and transferring information to other areas
- To identify when community appointments are required and undertake processes to arrange and book those appointments.
- To maintain up to date knowledge of procedures
- To maintain the confidentiality of the babies and their families at all times
- To ensure the safety and security of equipment at all times and report any problems

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1. Communication and Relationship Skills

- Provide and receive routine information requiring tact or persuasive skills or with barriers to understanding e.g. give information to new parents abut newborn hearing screening with sensitivity.
- Information provided may need to be conveyed via an interpreter if dealing with foreign languages or deaf parents using British Sign Language.
- Provide results to parents about the outcome of the hearing screen which may cause parents to become anxious and upset
- Ability to be empathetic when dealing with anxious parents e.g. babies in Special Care Baby Units (SCBU) or babies with special needs.
- Liaise with other health professions when conveying information both within the hospital and community setting.

2. Knowledge, Training and Experience

- Willingness and commitment to undertake further in house training
- Good interpersonal and communication skills for communication with parents at a sensitive time.
- Ability to liaise with health professions when conveying information both within the hospital and community setting
- Awareness of child protection issues and adhere to local procedures
- Awareness of infection control policies and procedures
- Ability to communicate with parent to elicit information
- Ability to organize and prioritise work
- Ability to work as a team and with a flexible approach to adapt to the constantly changing demands of the programme
- IT skills and competence in the use of the NBHSW IT package
- Organisational skills to arrange clinic appointments
- Ability to gather and accurately record clinical and test data relevant to the screening process.
- Ability to fault find on screening equipment
- Implementation of screening protocols
- Judge appropriate timing of screen e.g. to fit in with visitors and other procedures.
- Full driving license.

Experience:

- Experience of working with parents
- Experience of working with small babies
- Experience of working as part of a team
- Experience of working alongside health professions

3. **Analytical and Judgemental Skills**
    - Will be expected to make judgements around faults with screening equipment and when to use the fault reporting procedures.
    - Will make a judgement from a range of options within tightly defined SOPPS
    - When planning community visits screeners have to deciede the best route, to take account of time and mileage and working hours of the screeners involved.

4. **Planning and Organisational Skills**
    - Plan daily travel arrangements to attend community visits on time, with correct materials and records required.
    - Plan clinics - send out letters ensure room availability.
    - Plan visits for colleagues to mothers in community. Amendments may be required if mothers cancel or are not in on the day.

5. **Physical Skills**
    - Standard keyboard skills for entering data and producing appointment letters
    - Ability to drive to community visits on a daily basis
    - Use of small equipment requiring a level of manual dexterity on a daily basis

6. **Responsibility for Patient /Client Care**
    - Provide clinical technical newborn hearing screening service to newborn babies – the procedure is the initial screen in the diagnosis of hearing loss.
    - Direct communication to parents to provide information and answer questions about newborn hearing screening.
    - Provide hearing screening results to parents and advice about when further testing is required.
    - All employees have a duty to take reasonable care for their own health and safety, and that of others who may be affected by their activities; to cooperate with the Organisation by complying with all health and safety rules and safe systems of work; and to inform their line manager of any work situation, or practice which may be considered a danger to health and safety.
    - Ensure good practice is followed in line with the Organisation's policies and procedures, such as learning from complaints and concerns.

7. **Responsibility for Policy / Service Development Implementation**
    - Implement policies for own areas and contribute to changes in working practice
    - Follow local and All Wales protocols for implementing newborn hearing screening
    - Contribute to the development of the newborn hearing screening programme locally by providing comments on possible improvements to protocols in collaboration with local managers.

8. **Responsibility for Financial and Physical Resources**
    - Responsible for the safe use and security of expensive equipment. This includes dismantling and assembling equipment for use at outpatient clinics
    - Responsible for cleaning equipment to ensure control of infection polices are adhered to
    - Responsible for maintenance of equipment. This includes daily calibration, trouble shooting and reporting to manufacturers when a problem is discovered.
    - Maintain stock control for disposable ear tips, ear muffs and stationary supplies

- Risk Management – to deliver the quality standard and targets outlined in the Organisation's Risk Management Strategy and local operational policies.

9. Responsibility for Human Resources

- Provide advice on newborn hearing screening to other clinical staff working in the maternity unit
- Manage own workload

10. Responsibility for Information Resources

- Responsible for uploading results from screening equipment to NBHSW IT system.
- Responsible for data entry of screening results onto the NBHSW IT system. Data entry involves inputting numerous pieces of data, including screening results on a daily basis.
- Responsible for identifying all babies born in the area on a daily basis using a national identification system.
- Responsible for obtaining informed consent from parents for entering their baby's information on the system.
- Ensure security and confidentiality of patient information i.e. adherence to the data protection act.
- Regularly retrieve patient information to pass to other health professionals when required
- Regularly produce appointment letters for home and clinic visits.

11. Responsibility for Research and Development

- Contributes to gathering of data to be used in national evaluation of newborn hearing screening services
- Health and Safety requires attendance at appropriate health and safety training.

12. Freedom to Act

- Guided by clearly defined protocols and procedures at a local and All Wales level.
- The post holder is required to use their initiative and demonstrate an ability to work on their own both on maternity wards and in the community.
- Use initiative, based on training, when acting on test results
- Post is managed rather than supervised.

13. Physical Effort

- Use of screening equipment on a daily basis
- Moving equipment on trolleys, pushing trolleys to different parts of the hospital on a daily basis for more than 20 minutes in one shift.
- Mixture of sitting, standing and walking, bending, leaning over cots for prolonged periods
- Frequently carries heavy portable equipment with extreme care to outreach clinics and homes.
- Driving between base and community visits on a daily basis.

14. Mental Effort

- Required daily to concentrate for periods of time when inputting data onto the IT system
- Required to operate sensitive equipment with accuracy in what can be pressurised conditions
- Carry out screening tests daily on new born babies and repeating the test within designated time spans

- Prolonged concentration required when working with babies to ensure optimum test conditions and relaying screen results.

15. Emotional Effort

- Dealing with new parents everyday who can be in an anxious state
- Advising parents of the need to refer as a result of initial test
- Dealing with parents with care and empathy when referring a baby for future hearing assessment.

16. Working Conditions

- Use of VDU on a daily basis
- Exposure to dirty linen occasionally
- Close proximity to dirty nappies, vomit and birth debris found in babies ears (mucus, blood etc)
- Dealing with occasionally angry/rude parents or relatives.

COMPETENCE

You are responsible for limiting your actions to those which you feel competent to undertake. If you have any doubts about your competence during the course of your duties you should immediately speak to your line manager / supervisor.

REGISTERED HEALTH PROFESSIONAL

All employees of the Organisation who are required to register with a professional body, to enable them to practice within their profession, are required to comply with their code of conduct and requirements of their professional registration.

SUPERVISION

Where the appropriate professional organisation details a requirement in relation to supervision, it is the responsibility of the post holder to ensure compliance with this requirement. If you are in any doubt about the existence of such a requirement speak to your Manager.

RISK MANAGEMENT

It is a standard element of the role and responsibility of all staff of the Organisation that they fulfil a proactive role towards the management of risk in all of their actions. This entails the risk assessment of all situations, the taking of appropriate actions and reporting of all incidents, near misses and hazards.

RECORDS MANAGEMENT

As an employee of (insert name), you are legally responsible for all records that you gather, create or use as part of your work within the Organisation (including patient health, financial, personal and administrative), whether paper based or on computer. All such records are considered public records, and you have a legal duty of confidence to service users (even after an employee has left the Organisation). You should consult your manager if you have any doubt as to the correct management of records with which you work".

HEALTH AND SAFETY REQUIREMENTS

All employees of the Organisation have a statutory duty of care for their own personal safety and that of others who may be affected by their acts or omissions. Employees are required to co-operate with management to enable the Organisation to meet its own legal duties and to report any hazardous situations or defective equipment.

FLEXIBILITY STATEMENT

The content of this Job Description represents an outline of the post only and is therefore not a precise catalogue of duties and responsibilities. The Job Description is therefore intended to be flexible and is subject to review and amendment in the light of changing circumstances, following consultation with the post holder.

CONFIDENTIALITY

All employees of the Organisation are required to maintain the confidentiality of members of the public (patients, well women and service users etc.) and members of staff in accordance with Organisation policies.

PROBATIONARY PERIOD

Appointment to this post is subject to the satisfactory completion of a probationary period of 3 months (6 months in Welsh Blood and PSU within HSW to give them sufficient time to undertake appropriate training and to have their competencies signed off). During this time your Departmental Manager will have the opportunity to review and assess your suitability.

Date Prepared:
Prepared By:
Date Reviewed:
Reviewed By:
Agreed By: Date:
Employee's Name:
Signature:
Contact details:
Agreed By: Date:
Manager's Name:
Signature:
Contact details:

SAMPLE PERSON SPECIFICATION - SCREENER

Job Title: **Screener - NBHSW** **Band:** **2**

	ESSENTIAL	DESIRABLE	**METHOD OF ASSESSMENT**
QUALIFICATIONS	▪ Educated to GCSE standard or equivalent experience	▪ ECDL or other computer skill qualification ▪ Evidence of Continuing Personal Development	Application Form Certificate / Registration Check
EXPERIENCE	▪ Experience of using a computer	▪ Experience of working with children and families ▪ Experience of working in the NHS ▪ Experience of administration/clerical systems	Application Form Interview References

SKILLS	▪ Interpersonal and communication skills for communication with parents at sensitive times ▪ Ability to undertake routine equipment checks ▪ Ability to work within a team but ability to also screen independently in hospital and in the community ▪ Ability to understand screening result and management plans ▪ Good interpersonal skills ▪ Good organisational skills ▪ Accurate data entry ▪ Ability to keep accurate records	▪ An understanding of a clinical ward environment ▪ An awareness of deafness ▪ Ability to speak Welsh	Application Form Interview References
KNOWLEDGE	▪ Knowledge of team working ▪ Ability to develop understanding of equipment, results and administrative procedures ▪ Flexible ▪ Committed to quality ▪ Reliable ▪ Able to learn from experience	▪ Knowledge of hearing problems ▪ Knowledge of administration/clerical systems	Application Form Interview References
PERSONAL ATTRIBUTES (*Demonstrable*)	▪ Ability to work as part of a team ▪ Ability to organise and prioritise work	▪ Willingness to participate in ongoing in house training	Application Form Interview References

INTERESTS		▪ Varied	Application Form Interview References
OTHER (*Please Specify*)	▪ Full driving licence ▪ Able to travel to locations across a region on a regular basis ▪ Able to work some weekend and bank holidays on a rota basis		Application Form Interview Document Check
Date Prepared:		Prepared By:	
Date Reviewed: **Agreed By: Employee** **Date Agreed**		Reviewed By: Agreed By: Manager Date Agreed	

Appendix C
Listing of Recommended Newborn Hearing Screening Equipment Specification requirements

Newborn Hearing Screening Equipment – OAE Specification Essentials & Desirable Specification

	Essential Specification	Desirable Specification
1	Stimulus levels used to be within a tolerance of +/-3dB with respect to nominal set levels into a nominated test cavity. Please specify protocol used for factory calibration	Factory or screening programme settable parameters for varying and setting pass criteria; parameters must be described and evidence supporting these must be enclosed
2	Specify stimulus levels and duration of stimulus for recommended OAE test protocols and the range that can be factory or user set	Details of settable stimulus range and recording windows if they exceed the essential specification
3	Recording bandwidth at least 1000 to 4000Hz. If the decision algorithm uses a smaller bandwidth please specify	Specify ability to perform DPOAE and whether additional equipment is necessary to do this
4	Provide details of the recording response window	Tolerance in recording bandwidth better than (+/- 3dB)
5	Provides and stores summary measures on probe fit and test to operator; specify detail	Provides information on definition and value of amplitude of response; specify details
6	Able to store identifiable waveforms or equivalent data in a manner that they can be retrieved for further inspection and can be retrieved for further analysis by other software	Indication of test progress
7	Provide a range of probe tips to cover all neonatal ears; specify sizes available	Able to measure frequency response of stimulus and recording system; specify details
8	Demonstrates ability to reject artefactual responses by specifying a procedure by which this can be independently validated	Stimulus levels used to be within a tolerance of +/- 2dB with respect to nominal set levels into a nominated test cavity and within a tolerance of +/- 3dB within the ear canal
9	Can control progress of test (e.g. pause, stop); provide details. Ensures that all test attempts are saved	Settable parameters for varying and setting recording response window in the range of at least 3-12 ms
10	Readout of outcome immediately as a discrete display for tester only	Provide statements on outcome of 'no stimulus' tests in a cavity, i.e., with the stimulus channel acoustically blocked. The result should show that equipment and software version offered give a maximum of 1 test where a pass was recorded out of 120 tests, or better, that can be independently verified

11	Provide information that screening equipment has pass criteria greater than or equal to 6dB signal to noise ration in 2 half octave bands centred on 1.5, 2, 3 or 4kHz or equivalent	Facility to prompt user when instrument calibration or service is required.
12	Hygiene protocol for probe, equipment, probe tips and associated accessories to be described.	
13	Microphone noise floor ≤30dB ASPL for bandwidth 500Hz to 4000 Hz	
14	Number of tests that the machine can store without downloading (minimum of 100 required)	
15	Provide statements on 'specificity' from a minimum of 1000 real tests (i.e. 500 well babies with no suspected hearing loss on either ear) that can be independently verified	
16	Evidence of cavity trials at volumes close to 0.05; 0.1; and 0.2ml; showing a maximum of 1 pass on 120 repetitions. To be conducted with normal stimulus levels present in (a) quiet conditions and (b) with wide band-noise applied externally to such a level that the reject system is activated between 30% and 70% of the time. Such noise may be generated by the wide band masking of a clinical audiometer. For condition (b) if a method of data rejection is employed that does not enable this test to be performed, provide evidence of an equivalent test in noisy conditions	
17	Specify methods and/or procedures for the laboratory calibration of the stimulus level and recording microphone used by the equipment	
18	Specify protocols for routine checks of the equipment to be carried out by the user (daily/weekly user checks), including protocol for checking the stimulus level and TEOAE recording function	
19	Provide details on information that the equipment can provide on each test attempt concerning stimulus delivery, response measured and recording conditions	
20	Provide information on mean and variability of test times for neonatal hearing screening using recommended protocol on well-baby population	
21	Provide details of battery life, charging regimes, replacement cycles assuming:	

	Continuous testing; Number of tests
22	Machine portability; detail suitability for use as a portable screener, provide detail on carrying case, robustness, and needed accessories when away from main base. Statements regarding weight (grammes) and dimensions (in cm w x d x h) for each piece of equipment offered must be provided
23	If equipment can test when connected to the mains supply, it must meet the relevant safety regulations

Newborn Hearing Screening Equipment –AABR Specification Essentials & Desirable Specification

	Essential Specification	Desirable Specification
1	Provide detail on information that the equipment can provide on each test attempt concerning stimulus delivery, response measured and recording conditions – please indicate how that information could be provided	Ability to set stimulus within the range 30-60 dBnHL in 5 dB by user commands including protection against unauthorised changes being made
2	Provide information on intensity level and duration of stimulus and how stimulus intensity level is calibrated including details of coupler and reference data used. Confirm how the calibration relates to the reference values, as specified on the Newborn Hearing Screening Programme website, http://www.nhsp.info/	Ability to provide screening at two stimulus levels within a range of 30-60 dBnHL
3	Hygiene protocol for transducer, equipment, probe tips and associated accessories to be described	If a system does not record the ABR waveform, able to check accuracy of the system in recording the ABR response to include the ability to export the relevant data so can be read for example on Microsoft Excel
4	Provide information on test times for a normal hearing neonatal ear testing between term and 4 weeks corrected age giving the mean and variability	Provide a method for checking insensitivity of the system to artefact which are to be carried out by the user (daily/weekly user checks)
5	Equipment should provide measures on quality of electrode attachment; including details of methods used and test frequency	Provide evidence to demonstrate accuracy of statistical parameters used
6	Provides ability to reject data during periods of high muscle activity; specify detail	Provide evidence of sensitivity to permanent childhood hearing impairment (PCHI) greater than 40dBHS in one or both ears which can be independently verified
7	Provides ability to reject artefactual responses/results. Please provide details of types of artefacts i.e. mains interference, RF interference that can be rejected	Provides facility for screening programme to vary and set response window which can be password protected
8	Specify suitable electrodes, connecting leads, transducers and earphones including inserts and muffins etc suitable for testing all babies. If equipment is limited to specific manufacturer's accessories please detail and state the reasons why	Facility to prompt user when instrument calibration or service is required

9	Stimulus levels used to be within a tolerance of +/-3dB with respect to nominal set levels into a nominated test cavity. Please specify method used for factory calibration, including detail of coupler, coupling to coupler and reference values	
10	Provide statements on 'specificity' from a minimum of 1000 real tests (i.e. 500 well babies with no suspected hearing loss on either ear) that can be independently verified	
11	Provide written evidence of the outcome of 'no stimulus' trials i.e., with the device used for normal screening with stimulus acoustically blocked, on at least 120 neonatal ears, which can be independently verified. The results should show that the number of tests where a pass is recorded does not exceed 3 in every 120 tests or better. (Please detail exact protocol used)	
12	Specify methods and/or procedures for the laboratory calibration of the stimulus level used by the equipment	
13	Can control progress of test (e.g. pause, stop)	
14	Machine portability; detailing suitability for use as a portable screener, provide detail on carrying case, robustness, and needed accessories when away from main base. Statements regarding weight (grammes) and dimensions (in cm w x d x h) for each piece of equipment offered must be provided	
15	Able to calibrate accuracy of amplitude and time measures of recorded waveform. If the system does not record the amplitude and time directly please specify how the accuracy of the recording system is checked	
16	Specify protocols for routine checks of the equipment, including a subjective listening test	
17	Able to store response details or waveforms for further inspection and analysis by the NHS Newborn Hearing Screening Programme Centre	

Appendix D

Newborn Hearing Screening Programme – Suggested Key Performance Indicators

HSE 2010 Newborn Hearing Screening Sites –Required Data from Screening Programme to be provided on a quarterly/monthly basis			PI
BIRTHS & SCREENING			
	1	No. of babies born at the hospital during the month/quarter	
	2	Total number of eligible well babies	
	3	Total number of eligible NICU babies	
	4	No. & % of babies ineligible for hearing screening	
	5	No. & % of well babies whose parents were offered hearing screening	
	6	No. % of NICU babies whose parents were offered hearing screening	
	7	Total no & % of eligible babies whose parents were offered hearing screening	>99%
	8	No. & % of well babies whose parents were offered but declined hearing screening	
	9	No. & % of NICU babies whose parents were offered but declined hearing screening	
	10	Total & % number of babies whose parents were offered but declined hearing screening	<0.1%
	11	No. & % of babies to whom screen was offered but not started (do not include those who declined the screen)	
	12	No. & % of well babies who started hearing screening	
	13	No. & % of NICU babies who started hearing screening	
	14	Total No. of eligible babies who started hearing screening	98%
	15	No. & % of babies who started hearing screening but not completed	
	16	No. & % of babies who did not complete screening while an inpatient in the maternity hospital or who missed the screen scheduled for a screening apt within 7 working days of discharge	95%
	17	The no of babies offered screening appointments who do not attend (DNA or cancelled)	<4%
	18	No. & % of babies who completed well baby protocol screening	
	19	No. & % of babies who completed NICU protocol	
	20	No & % of eligible babies to have screen completed within 4 weeks of age for well babies or 4 weeks corrected age for NICU babies	95%
	21	No. & % of eligible babies to have screen completed by 3 months	95%

		Breakdown of Babies Screened	
	22	No. & % of well babies with a clear response	
	23	No. & % of NICU babies with a clear response	
	24	No. & % of well babies with NCR at AOAE 1	≤30%
	25	No. & % of well babies with NCR at AOAE 2	≤6%
	26	No. & % of well babies with unilateral NCR at AABR	≤2%
	27	No. & % of well babies with bilateral NCR at AABR	≤1%
	28	No. & % of NICU babies with unilateral NCR at AABR	≤6%
	29	No. & % of NICU babies with bilateral NCR at AABR	≤3%
	30	Total no. & % of unilateral referrals	≤2%
	31	Total no. & % of bilateral referrals	≤1%
	32	No. of well babies referred from screening programme for assessment	
	33	No. of NICU babies who were referred from screening programme for assessment	
	34	Total no. & % of babies referred from screening programme for assessment	≤3%
	35	Copy of all screening results for all babies retained for patient records	100%
	36	Copy of all screening results where baby did not pass screen forwarded to diagnostic audiology	100%
	37	No. of babies screened per screener	
COMMUNICATION	1	**COMMUNICATION PROTOCOL APPLIES**	
	2	No. clients to whom full information on hearing screening was provided	ALL
	3	No. of babies for whom informed verbal consent was received parents/guardian	ALL
	4	Informed verbal consent maintained with clinical notes for all babies screened? Y/N	ALL
	5	Comments / Suggestions box in place on site and comments/suggestions reviewed and acted on quarterly? Y/N	
	6	Quarterly patient / staff survey system in place and reviewed and acted on quarterly? Y/N	
	7	Complaints procedure in place & visible to clients? Y/N	
	8	No. of formal complaints received during the month and referred to XXX?	