National Screening Unit

Universal Newborn Hearing Screening for New Zealand 2005

A report of the Universal Newborn Hearing Screening Advisory Group to the National Screening Unit

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to the National Screening Unit, October 2005

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Foreword

This report contains the findings and recommendations of the Universal Newborn Hearing Screening Advisory Group (UNHSAG) to the National Screening Unit (NSU) regarding high-level policy and implementation issues for a potential future universal newborn hearing screening programme (UNHSP) for New Zealand. This report will contribute to the development of policy by the NSU and its advice to the Ministers of Health, Education and Social Development regarding a possible UNHSP for New Zealand.

The UNHSAG was convened by the NSU and represented a broad range of interests and experience in screening, audiology, neonatal and paediatric care and education as well as representing the interests and views of parents of deaf children, deaf consumers and Māori and Pacific views. The views expressed in this report developed over the course of meetings, which expanded the knowledge and deepened the understanding of the various representatives.

The views and recommendations in this report are those of the group, and do not necessarily represent the policy position of the Ministry of Health.

The NSU would like to thank the UNHSAG for their positive contribution and development of a new body of knowledge in the New Zealand context. The information given through the course of the meetings will be invaluable should the Ministers determine that a UNHSP should be implemented.

Thanks to:

Dr Ashley Bloomfield (Ministry of Health)
Dr Roland Broadbent (Paediatric Society of New Zealand)
Mr Colin Brown (New Zealand Society of Otolaryngology – Head and Neck Surgery, Starship Children's Hospital)
Mrs Margaret Cooper (Federation of Deaf Children, Project HIEDI)
Mrs Lorraine Fox (National Audiology Centre)
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Professor Peter Thorne (National Foundation for Deaf, Project HIEDI)
Dr Pat Tuohy (Ministry of Health) (Chair)
Ms Oriole Wilson (formerly National Audiology Centre, Project HIEDI)

The NSU would like especially to thank Dr Pat Tuohy for chairing the UNHSAG and Kathy Hassan and Shizue Sameshima for their tireless sign interpretation.

Executive summary

Background and process

Congenital hearing loss is a significant health and disability issue, affecting 135–170 newborns each year. Māori are disproportionately affected, accounting for 46 percent of all deafness notifications.

Two recent evidence-based reports have recommended the introduction of newborn hearing screening and early intervention. The National Screening Unit responded to this evidence, at the Minister of Health's request, with a project to consider newborn hearing screening. One component of that project was to establish an advisory group to identify issues and make high-level policy recommendations. This report presents the main findings and recommendations of that group.

Hearing screening, early identification of hearing loss in New Zealand and the objective of newborn hearing screening

Programmes intended to identify hearing loss in babies and children already exist in New Zealand but they have proven unsuccessful in lowering the age of detection of hearing loss to the recommended three months of age. From a national perspective these programmes are not sufficiently sensitive, do not reach enough newborns, and/or are applied too late to be effective. New Zealand's average age of identification of moderate to profound hearing loss was 45.3 months in 2004 (NAC, 2005). By this age many opportunities for early intervention have been lost.

The interface between screening and early intervention

The success of any screening programme is dependent on the success of intervention services. The UNHSAG identified a range of concerns relating to early intervention services for children who are deaf or have a hearing loss in New Zealand and makes some recommendations for their resolution.

Potential issues for a UNHSP

A range of issues were also identified across the screening pathway that will need to be addressed alongside the introduction of a UNHSP. These relate to operational policy, workforce, overall management, quality standards, monitoring and audit, research and development, evaluation and partnership and understanding.

The impact of the UNHSP and addressing inequalities

The introduction of a UNHSP would have an impact on existing services for detecting and providing interventions for hearing loss amongst babies, infants and children. However, the UNHSAG did not undertake a review of these services or consider what their future contribution should be.

Conclusion

The UNHSAG strongly endorses the introduction of a universal newborn hearing screening programme for New Zealand to address the late age of detection and delayed and poorly coordinated intervention services for children with significant hearing loss in New Zealand. This would align New Zealand with other developed countries and allow New Zealand infants and their families to maximise the benefits of early intervention choices. Sixteen recommendations are made by the UNHSAG covering the purpose, scope, implementation, operational aspects and infrastructural requirements of a universal newborn hearing screening programme for New Zealand.

1.0 Background

Hearing loss in New Zealand

Sensorineural hearing loss is a permanent condition that occurs when the inner ear, the auditory nerve and/or its connections to the brain are damaged. The effects of this hearing loss are significant particularly when it occurs before speech has developed (pre-lingual deafness). Sensorineural deafness cannot usually be prevented, but the effects can be mitigated if the condition is detected early and appropriate interventions provided.

Between 135 and 170 babies (2–3/1000) are identified each year in New Zealand with a significant permanent congenital hearing loss[1] making it a much more common condition than other conditions screened for among the newborn population. New Zealand has a poor record for identifying hearing loss at an early age. The average age of detection of moderate to profound hearing loss in 2004 was 45.3 months (NAC 2005).

Ethnic differences are apparent in hearing loss statistics. Māori infants and children are significantly more likely to have a hearing loss than other members of the community with 46 percent[2] of deafness notifications (>26dBHL) attributed to Māori infants and children despite Māori making up 27.9 percent[3] of the comparable population. However, Māori children tend to have a predominance of mild to moderate hearing loss. When mild hearing loss is excluded from the data, Māori infants remain over-represented in deafness notifications, accounting for 38 percent of moderate and greater degrees of hearing loss. Pacific infants are also somewhat over-represented in hearing loss statistics with 13.5 percent of notifications compared with 10.9% of the population. In addition, Māori and Pacific children are diagnosed later than non-Māori, non-Pacific children (NAC, 2005).

Hearing loss in infants, independent of degree, is not readily detectable or often suspected by parents or health professionals until speech and language milestones become significantly delayed. By this time the effects of such late identification are considerable. Lack of exposure to language during early critical periods of language development can lead to ongoing problems with cognitive development, communication, educational and vocational achievement and social functioning and well-being. Early detection, habilitation and early intervention have been shown to improve language development, but the long term impact is still unclear (Thabrew, 2003).

New Zealand deafness notifications data limitations

New Zealand deafness notification data is currently limited by its retrospective collection and by non-mandatory reporting. Slight hearing loss (<26dBHL), unilateral loss, acquired loss and overseas born infants are excluded from the reported data (NAC, 2005). While it is not possible to be certain of the aetiology of the reported hearing loss, the reported hearing losses are likely to be congenital. It is also not possible to be sure of the degree of hearing loss present at birth, as the degree may have altered between the time of birth and reporting, or indeed not have been present at all at birth. The only way to significantly improve the quality of New Zealand deafness data is by implementing a universal newborn hearing screening programme with associated data collection and monitoring systems.

[1] Significant hearing loss refers to mild and greater degrees of hearing loss (>26dBHL in the better ear).
[2] This figure is the average over the five years 2000–2004 inclusive for hearing loss >26dBHL calculated from raw data obtained from New Zealand Deafness Notification Reports 2001–2005.
[3] This ethnicity proportion is calculated from raw data supplied by NZHIS for live births from 2000–2004. Based on this data the proportion of the population by ethnicity for 2000–2004 is: European 51.65%, Māori 27.86 %, Pacific 10.87%, Asian 8.39% and other and not stated 1.25%)

Universal newborn hearing screening programmes

Universal newborn hearing screening programmes (UNHSPs) aim to mitigate the effects of hearing loss through early detection and provision of intervention services. A well designed UNHSP would be expected to reduce the age of identification of hearing impairment to within three months of age. Once identified, infants with hearing loss should be offered early interventions that result in improved outcomes. There is a range of options available to assist families and infants with hearing loss including resource materials and support groups for parents, hearing aids (including cochlear implants) and habilitation and early intervention in a range of communication modalities including sign language. With good early intervention approximately 80 percent of children with hearing loss could develop age appropriate language and communication (Yoshinaga-Itano, 2004).

Universal newborn hearing screening is becoming the standard of care internationally, with programmes being established or already implemented in the United Kingdom, most states of Australia and the United States as well as a number of other developed countries. These programmes use objective screening technologies that are safe and relatively easy to perform on newborns. They vary in some regards including the level or threshold of hearing loss screened for. Various screening technologies have standard settings at points from 25dBHL to 70dBHL (Davis et al,1997). The UK has set the threshold at 40dBHL although considers that the actual level being detected is higher than this (Davis 2005). New South Wales and a number of other Australian states have set a threshold within the mild range at 35dBHL (Radford, 2005). There are various technical limitations associated with practical application in screening settings as to where the threshold can be set but 35dBHL and 40dBHL appear to be commonly used thresholds.

Evidence in support of UNHS in New Zealand

In 2003 the Clinical Services Directorate of the Ministry of Health commissioned a review of vision and hearing screening in the context of the Well Child schedule. This review was undertaken by Dr Hiran Thabrew, and the report is available from the Ministry of Health. The report supports examining the introduction of universal newborn hearing screening.

In late 2004 a sector interest group, Project HIEDI, prepared an evidence-based report, with the assistance of the National Foundation for the Deaf. The report is titled *Improving Outcomes for Children with Permanent Congenital Hearing Impairment: the case for a national newborn hearing screening and early intervention programme for New Zealand.* Copies of the report are available online on http://www.nfd.org.nz or by phoning the National Foundation for the Deaf on 64 9 307 2922, or by emailing hiedi@nfd.org.nz. The report supports the introduction of a universal newborn hearing screening and early intervention programme.

Policy work undertaken to consider a UNHSP

In response to the HIEDI report the Minister of Health, the Hon. Annette King, requested that the NSU provide her with policy advice regarding the possibility of implementing a UNHSP in New Zealand. To this end the NSU established a project with four primary strands:

1. The establishment of a UNHSAG to advise the NSU on high level policy and key implementation issues.
2. Commissioning an independent evaluation of the newborn hearing screening service provided by Waikato DHB.
3. Commissioning an economic evaluation of universal newborn hearing screening.
4. Commissioning piloting of community outreach screening initiatives.

This report represents the findings and recommendations of the first strand, namely recommendations from the advisory group on high level policy and key implementation issues identified by the UNHSAG. This report is their recommendation to the NSU. The views and recommendations in this report are those of the group, and do not necessarily represent the policy position of the Ministry of Health.

Process and establishment of the UNHSAG

The NSU identified key stakeholders in universal newborn hearing screening taking an initial lead from the work of the advocacy group Project HIEDI, and following internal consultation. Due to the significant body of knowledge that had been built up through the development of an evidence-based report by Project HIEDI, it was determined that several of the steering group from Project HIEDI should be included on the UNHSAG. Three members were approached on this basis, namely Peter Thorne, Oriole Wilson and Margaret Cooper. Each brought a wide range of experience both professionally and personally. Other members were either directly nominated by their respective professional society at the request of the NSU or approached by the NSU due to their unique body of knowledge. Four additional representatives ultimately joined the UNHSAG – one Māori provider, one parent of a deaf child and two from Group Special Education at the Ministry of Education, at the invitation of the Chair.

The membership of the full Universal Newborn Hearing Screening Advisory Group is listed below along with their main affiliations. As indicated, several members joined the group after the first meeting. Their first meeting attendance date is listed, although they may have received meeting documentation prior to this date.

Dr Ashley Bloomfield (Ministry of Health)
Dr Roland Broadbent (Paediatric Society of New Zealand)
Mr Colin Brown (New Zealand Society of Otolaryngology – Head and Neck Surgery, Starship Children's Hospital)
Mrs Margaret Cooper (Federation of Deaf Children, Project HIEDI)
Mrs Lorraine Fox (National Audiology Centre)
Dr Aumea Herman (Pacific)
Mr Mark Hutton (Ministry of Education) 22 June 2005
Ms Trish Jackson-Potter (Royal New Zealand Plunket Society)
Ms Tracey Maule-Cooper (Auckland Parents of Deaf Children Inc.) 22 June 2005
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Ms Jean Smith (Ministry of Education) 22 June 2005
Mr Patrick Thompson (Consumer)
Professor Peter Thorne (National Foundation for Deaf, Project HIEDI)
Dr Pat Tuohy (Ministry of Health) (Chair)
Ms Oriole Wilson (formerly National Audiology Centre, Project HIEDI)

The group was chaired by Dr Pat Tuohy – Chief Advisor – Child and Youth Health, Ministry of Health. The advisory group was supported by Kathy Hassan and Shizue Sameshima as non-participatory sign interpreters and provided with secretariat support from the NSU by Ruth Bijl, consultant policy analyst and Bronwyn Petrie, policy analyst later replaced by Dr Simon Baker, public health physician.

The group met on nine occasions from 16 March 2005 to 3 August 2005.

This report presents an overview of their deliberations and key conclusions in the form of recommendations to the NSU.

2.0 Hearing screening, early identification of hearing loss in New Zealand and the objective of newborn hearing screening

Current approaches to the detection of hearing loss in New Zealand

Hearing screening already occurs in New Zealand, although there are regional differences in how it is conducted. Hearing screening and surveillance in New Zealand currently takes a variety of forms, including:

- Some regional newborn screening for permanent congenital hearing loss, as determined by individual District Health Boards. Currently this is undertaken at major hospitals in Waikato DHB and at Gisborne Hospital in Tairawhiti DHB. Neonatal intensive care (NICU) babies are also screened by Canterbury DHB. Previously, newborn hearing screening has been conducted in other DHBs or hospitals although these services have not been sustained due to changes in personnel or failure to secure sustainable funding.
- Identification and referral of high risk babies based on the American Speech-Language-Hearing Association (ASHA) risk criteria.
- Questionnaire based surveillance at specified intervals from six weeks to 24 months of age. The questionnaire is designed to determine whether an infant has developed age appropriate hearing behaviour and speech. This is provided as part of the Well Child programme and delivered through a range of community nursing services including the Royal New Zealand Plunket Society and the infant's general practitioner.
- Tympanometry testing as part of the Well Child programme at preschool age (three years) for Otitis Media with Effusion. This service is not a hearing test and thus is not able to identify permanent congenital hearing loss.
- Audiometry and tympanometry testing under the Well Child programme at school entry (five years).

With the exception of regional newborn hearing screening initiatives outlined in point one, the value of these programmes in detecting permanent hearing loss or improving outcomes is not supported by evidence, and fails to detect those infants at greatest risk of poor outcomes. Furthermore, the development of objective testing methods, which can be conducted on newborns (newborn hearing screening), along with improved and earlier intervention options mean that there are now better screening alternatives than those methods currently offered through the Well Child programme (Thabrew, 2003).

Universal newborn hearing screening and its limitations

Following the development of safe and objective screening equipment a number of countries have implemented partial (hospital only) or universal newborn hearing screening programmes. This has brought both the age of detection for permanent congenital hearing loss down to the recommended three months of age with interventions commenced by six months of age. New South Wales, for example, diagnosed hearing loss by, on average, 1.6 months of age after the introduction of UNHS. Prior to the introduction of universal newborn hearing screening the average age of diagnosis was 18 months of age (NSW Health, 2004).

New Zealand is now far behind these countries. The average age of detection of moderate and greater degrees of congenital hearing loss in 2004 was 45.3 months (NAC, 2005). The average age of identification for Māori and Pacific children was even later. As a consequence New Zealand children are not able to obtain the full benefits of early intervention. Approximately 80 percent of children with hearing loss who receive good *early* intervention will develop age appropriate language and communication (Yoshinaga-Itano, 2004).

Not all forms of childhood hearing loss will be detected by a universal newborn hearing screening programme. Only permanent congenital hearing loss present at birth is detected by newborn screening. As with any screening programme there is a possibility that some cases will be missed because the baby is not screened or due to technical errors, for example, malfunction of testing equipment or inaccurate data entry. In addition, a proportion of infants will either acquire deafness or become progressively deaf after birth. Infants at risk of progressive loss need to be identified and monitored, and the management of specific conditions, including meningitis, needs to include appropriate referral to audiology in each case. Cases of moderate and greater degrees of hearing loss would be expected to be identified through newborn hearing screening, but some cases of mild and lesser degrees of hearing loss would not be detected, due to the technical limitations of screening equipment. A newborn screening programme may, however, enhance the identification of these cases by raising awareness and promoting improved referral pathways. Temporary conductive hearing losses are not the focus of newborn hearing screening programmes but will inevitably be identified through the screening process and will need to be managed appropriately. This area was outside the Terms of Reference of the UNHSAG. The UNHSAG did not consider how best conductive loss should be screened for and/or managed.

Based on the evidence presented in the Project HIEDI report, the current late age of detection and intervention for permanent congenital hearing loss, the significant inequalities apparent amongst various groups and the potential to make available effective and affordable early intervention, the UNHSAG makes the following recommendation.

Recommendation 1: New Zealand should implement a universal newborn hearing screening programme to reduce the age of detection and intervention for infants with permanent congenital hearing loss.

The objective of a New Zealand UNHSP

The UNHSAG considered the purpose of a UNHSP and agreed that the reason for identifying children with permanent congenital hearing loss was to ensure that appropriate interventions were offered early so that the benefits for the child and their family can be maximised. Hence the reason for a UNSHP in New Zealand should be to improve outcomes for infants and children with hearing loss and their families.

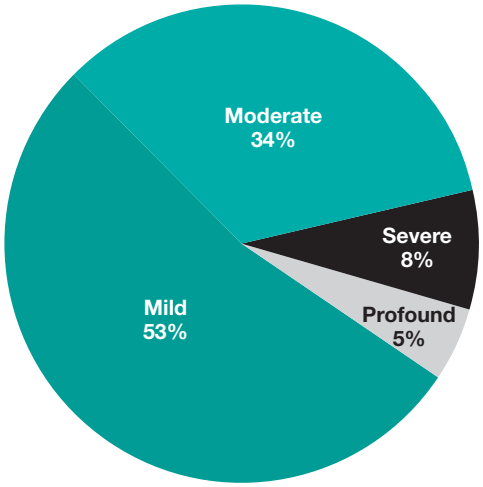
It was recognised that:

1. The child should not be seen in isolation from their family/whanau unit. A New Zealand UNHSP should therefore provide information to inform families about their child's hearing loss so that the family can make better decisions in relation to their child.
2. Hearing loss inhibits the development of both receptive and expressive communication. Communication is the gateway to effective educational and social interaction.
3. Hearing loss and its potential sequelae are not time limited but impact throughout the life course. Consequently a UNHSP should seek to enhance developmental outcomes for the child with hearing loss over the life course by maximising communication and language opportunities.
4. A family's informed choice regarding intervention and habilitation services must be a central philosophy.

It was also considered appropriate to define the nature of the hearing loss being screened for. Hearing loss has traditionally been defined by the degree of hearing loss in the better ear. In New Zealand the following degrees and definitions have been applied by the Deafness Notifications Database, with hearing loss presenting in the proportions as shown in figure 1.

FIGURE 1: PROPORTION OF HEARING LOSS BY DEGREE

Mid hearing loss	**26–40 dBHL**
Moderate hearing loss	**41–65 dBHL**
Severe hearing loss	**66–95 dBHL**
Profound hearing loss	**>95 dBHL**



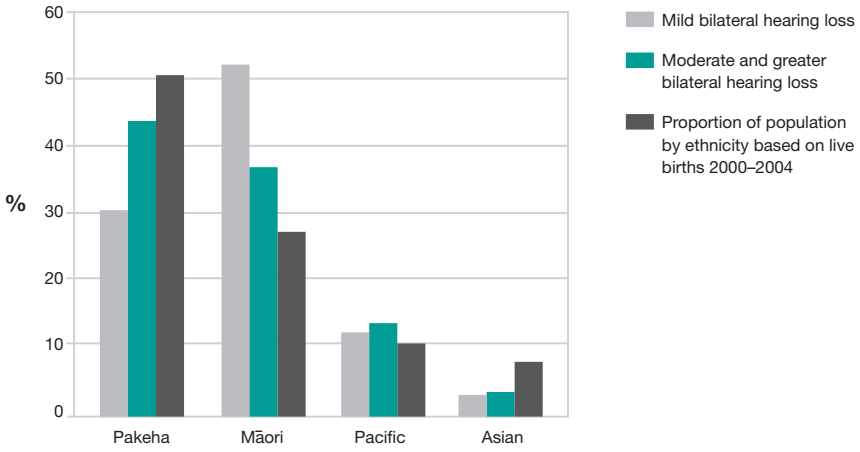
Importantly, the distribution of degree of hearing loss varies by ethnicity as shown in figure 2 and figure 3, although it is as yet unclear how much of this loss and/or the degree is present at birth. As discussed in previous sections, retrospectively reported hearing loss is more common among Māori children, with the distribution of degree of hearing loss suggesting that Māori children are more likely to be affected by mild to moderate hearing loss. This may have implications for deciding the level of hearing loss that should be screened for in New Zealand.

FIGURE 2: BREAKDOWN OF DEGREE OF HEARING LOSS BY ETHNICITY

DEGREE OF HEARING LOSS	PAKEHA	MĀORI	PACIFIC	ASIAN	TOTAL
Mild	30.90%	52.81%	12.92%	3.37%	100.00%
Moderate	40.53%	41.41%	14.98%	3.08%	100.00%
Severe	57.41%	25.93%	12.96%	3.70%	100.00%
Profound	48.57%	31.43%	11.43%	8.57%	100.00%
Population proportion	51.65%	27.86%	10.87%	8.38%	98.75%*

*1.25% of the population breakdown is unstated or not known.

FIGURE 3: MILD, MODERATE AND GREATER DEGREES OF HEARING LOSS AND POPULATION PROPORTION, BY ETHNICITY 2000–2004



Retrospectively reported data for bilateral hearing loss 25–40 dBHL and for bilateral hearing loss >40 dBHL for the five years from 2000–2004. Annual mean n=134.4 (Mild n = 71.2, Moderate and greater n = 63.2).

In addition, hearing loss may be unilateral or bilateral. Bilateral hearing loss is regarded as more disabling than unilateral hearing loss, even when less severe, but the impact of unilateral loss is also concerning and a UNHS programme would identify unilateral losses.

It is necessary for a screening programme to specify a case definition in order to determine how it will go about case finding. This requires an understanding of the effect, prevalence and distribution of a condition and a practical understanding of the capability of various technologies to identify and affect benefits by identifying the condition.

There is no debate about the effect of moderate, severe or profound hearing loss. Mild hearing loss also has a significant effect, particularly if it is diagnosed late. However, the potential to mitigate the effects of mild loss is the topic of international debate. In New Zealand many children with mild permanent hearing loss are provided with good quality hearing aids, which are considered by audiologists to be beneficial. This is not always the case in the United Kingdom and this is reflected in both the screening threshold for the UK programme, which is set at greater than 40dBHL or moderate loss, and the services offered to infants with mild hearing losses. By comparison, the New South Wales programme has set a lower threshold of 35dBHL or mild to moderate loss. Both programmes will identify some cases of mild loss and refer these infants appropriately. They may, however, not measure the detection rates of these cases in their programme monitoring.

Similarly, some programmes have determined that they will only screen for bilateral hearing loss, as the effects of unilateral loss are less marked. However, UNSHP's should aim to detect cases of unilateral loss and then take steps to refer these infants appropriately.

The UNHSAG considered a range of screening thresholds. The Group determined that further research was required in the case of mild loss but acknowledged the importance of mild loss particularly for Māori children. Accordingly, the UNHSAG recommended that New Zealand set its threshold at an achievable level of 35dBHL (decibel hearing level) to identify mild to moderate and greater degrees of hearing loss as has the New South Wales Programme but that specific research be undertaken to establish if a lower threshold is feasible in a practice setting. A UNHSP should, however, focus its efforts on detecting levels of hearing loss that are likely to impact on the development of speech and language and work towards improved outcomes for these children and their families.

The UNHSAG therefore recommends that the following statement be adopted as the primary objective for a UNHSP in New Zealand.

Recommendation 2: The UNHSP should identify permanent congenital hearing loss present at birth that is likely to impact on the development of speech and language and maximise communication and language opportunities through early intervention/s.

Further policy work will need to be undertaken to define other secondary objectives and targets including;

– age of identification

– age of first intervention

– ensuring a family centred approach.

3.0 The interface between screening and intervention services and models for a UNHSP

Screening and early intervention

A critical issue for any screening programme is its effect on existing treatment or intervention services and the ability of those services to manage the increased workload created by screening. If those infants identified through screening cannot access effective intervention services then the value of screening is at best doubtful and at worst could result in harm for infants and their families.

Both consumer and service provider participants within the advisory group expressed significant concern about the current state of intervention services for children who are deaf or who have a hearing loss. In analysing the effect of earlier identification following newborn hearing screening it was identified that:

– There was a perception that early intervention services currently are under-resourced, especially those provided within education through Group Special Education (GSE) and additional resourcing would be required if newborn hearing screening was introduced, particularly for the newborn to three-year age group.

– Increased funding has recently been made available for early intervention services within GSE. There will be an additional funding requirement for early intervention services to cover the cohort of children who are diagnosed earlier. This temporary increase will be required for a number of years.

– The interface between the health and education sectors, despite willingness on the part of practitioners, is extremely variable and cooperation at all levels from providers to ministerial needs to be fostered.

– There is significant regional variation in the quality and accessibility of services.

Recommendation 3: The UNHSP should be implemented in conjunction with efforts to ensure that early intervention services are available to infants who are deaf or have a hearing loss and their families as a nationally consistent, co-ordinated programme.

Recommendation 4: Irrespective of the implementation of a UNHSP, an early intervention working group should be convened between the Ministries of Health and Education to ensure that nationally consistent, co-ordinated early intervention services are provided.

Recommendation: 5: Given the inter-agency nature of early intervention services and the need for commitment, inter-agency co-operation and co-ordination, the NSU needs to ensure that the relevant Ministers are informed of the likely impact of a UNHSP on a range of services.

Proposed model for a New Zealand NBHS and EI Programme

A range of models for the UNHSP were considered by the UNHSAG against the principles listed in Appendix 1. The factor that most concerned the UNHSAG in determining an appropriate model was the interface between screening and intervention services. To obtain the best outcomes for the child and family, the quality of an early intervention services was a primary concern. Consequently, the UNHSAG considered models which incorporated early intervention services into the screening programme and ranged from a screening programme which was confined to the identification of a hearing loss through to a programme that took responsibility for all children identified with hearing loss throughout the screening pathway and through into adulthood. These are outlined in Appendix 2. Finally the UNHSAG developed a model that clearly identified the screening programme and, separately, an early intervention programme. Outcomes from the early intervention programme would however be monitored by the screening programme as the success of the screening programme is dependent on the success of early intervention services. The model would take account of the Disability Strategy. This model for the UNHSP in New Zealand was approved unanimously by the UNHSAG.

Components of the Proposed Model

The proposed model for a New Zealand NBHS and EI Programme has three primary components:

1. The screening programme. This would incorporate the following;

   – antenatal health promotion;

   – invitation and informed consent;

   – universal offer of the screening test with opt off;

   – audiological confirmation of a positive screening result, and;

   – multi-disciplinary development of an initial action plan with the family.

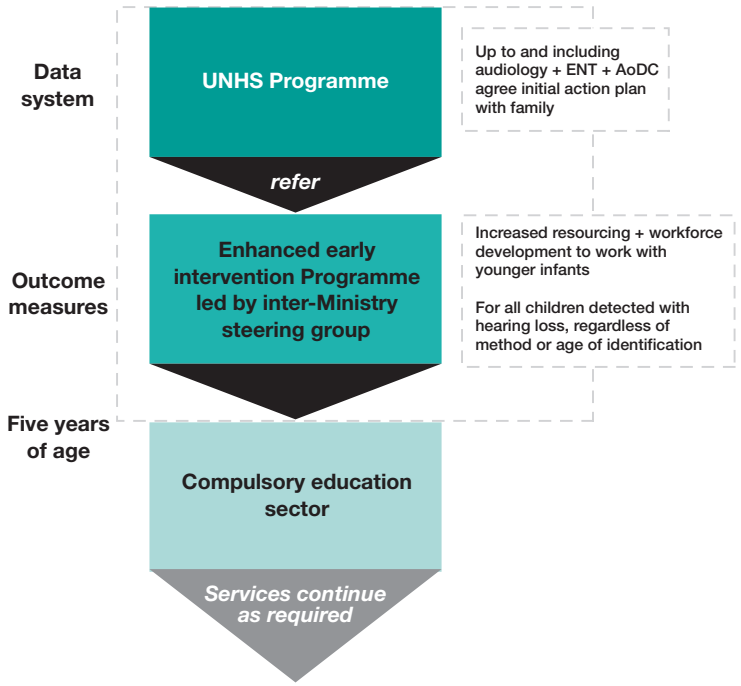
   The plan would be developed with the family by the Advisor on Deaf Children (or their equivalent), the audiologist and the Ear, Nose and Throat surgeon/otolaryngologist. The elements of the initial action plan would include, but may not be limited to, referral to a range of services, provision of information, assessments and initiation on the intervention pathway. Following this the infant would be referred to the early intervention programme (EIP).

2. The early intervention programme. This would be separate from the UNHSP and be led by an inter-Ministry (Health and Education) steering group. The steering group would focus efforts on ensuring that nationally consistent, seamless, coordinated and appropriately resourced early intervention services are provided to children aged from birth to five years with hearing loss and their families. The primary objective of the EIP would be to ensure optimal communication and language outcomes for pre-school children. Health, education and social services would be included in the EIP, as may a variety of non-governmental and/or voluntary providers. The EIP would build on existing services.

3. Outcome measurement. Monitoring of key screening metrics and outcome measures which would be developed by the UNHSP in conjunction with the EIP. The UNHSP would routinely monitor outcomes across the screening pathway including those achieved under the EIP.

THE MODEL IS SHOWN DIAGRAMMATICALLY BELOW.

Proposed model for UNHS and EI Programmes



Implications of the proposed model

AoDCs are currently funded through Vote: Education. The UNHSP would need to enter into an agreement whereby the contribution of GSE towards the initial action plan was included via a formalised arrangement. All the other UNHSP services currently reside within the Health Portfolio. However, additional services would need to be created in a range of areas such as data management and monitoring of outcomes across the screening pathway.

Early intervention services currently exist but their co-ordination in a more programmatic approach would be a new feature introduced under this model. The resourcing of these services would also need to be considered. This point is discussed further in the next section.

The UNHSAG was of the view that this model would ensure the range, quality and consistency of intervention services would be achieved and that the management task of both the screening programme and EIP was achievable within existing policy and organisational contexts. Most importantly, the UNHSAG considered that this model would best ensure that optimal outcomes were achieved for infants and their families. Responsibility for detection, intervention and outcome measurement was also clear under this model.

Conclusion

Having considered each of the models, the UNHSAG determined that the proposed model would best meet the principles for a UNHSP. In particular a seamless interface between screening and early intervention services could be assured and outcome measurements across the screening pathway obtained.

Recommendation 6: Establish a UNHSP, which screens, diagnoses and prepares an initial action plan with the family and then refers to and monitors the outcomes of a clearly defined and appropriately resourced early intervention programme.

Recommendation 7: Early Intervention services should be enhanced through the introduction of an organised early intervention programme for children aged from birth to five years of age. This programme would be available to infants with hearing loss regardless of the method of identification of their hearing loss.

4.0 Potential issues for a UNHSP

The UNHSAG defined and considered a range of issues that may impact on the implementation or conduct of a UNHSP in New Zealand. They did so by considering the screening pathway against key deliverables identified by the NSU in its strategic plan (NSU, 2004). The screening pathway includes five elements: health promotion, invitation, the screening test, diagnosis and (if required) intervention. Failures at any point on the pathway can result in the failure of a screening programme. The NSU strategic plan identifies six key deliverables for managing screening programmes. These are:

1. Service Development through Operational Policy
2. Workforce Development through a Workforce Strategy and Action Plan
3. Overall Management through Funding Agreements, Legislation and National Data Systems
4. Quality Improvement, Evaluation and Monitoring through the establishment of Quality Standards and a Monitoring and Audit Plan
5. Research and Development through a Research and Development Plan and an Evaluation Framework
6. Partnership and Understanding through Stakeholder inclusion and Communication planning (NSU, 2004).

The elements of the pathway and deliverables were matrixed and issues identified for each segment. This matrix is provided in Appendix 3. These issues will need to be managed during planning and implementation phases. Some of the major issues identified are outlined briefly below.

Operational policy

As for any screening programme quality must be ensured though the appropriate definition and specification of services. The UNHSAG was of the view that screening should be universal and that a high quality service, based on best practice and national consistency, should be developed through the clear specification of protocols. Service providers must be accredited to the programme and must work to specified standards. Policy should be child and family centred. Provider competencies will need to be developed to facilitate working with very young babies and infants and understand the psychological impact of screening on families. Cultural competencies including developing an understanding of deafness as well as ethnic differences will need to be developed.

The programme's ultimate aim should be to provide the best outcome for the child/tamaiti and family/whanau. To ensure the best outcome for the child, intervention providers need to work in multi-disciplinary teams and support the child and family to make informed choices about intervention options.

Recommendation 8: Develop nationally coordinated, consistent strategic and operational policy which is child/tamaiti and family/whanau centred, ensures informed choices and endeavours to ensure the best outcome for the child/tamaiti and family/whanau.

Workforce

All those providing services to a UNHSP and EIP will need to develop skills and competencies to work with younger babies and infants. This includes audiologists, ENTs, paediatricians, Advisors on Deaf Children, early intervention teachers, speech language therapists, kaitakawaenga, educational

psychologists, other providers along the screening pathway and other allied professionals, including general practitioners. Clear referral guidelines to accredited providers will ensure that services are provided by clinicians and practitioners with appropriate skill sets and competencies.

There is currently only a very small neonatal hearing screening workforce which has been created to staff the services in Waikato, Gisborne and Christchurch. A national workforce would need to be developed either from other workforces or newly established. In either case the workforce development needs are relatively straightforward, as an otherwise unqualified screener can be trained to use the screening equipment in as little as two weeks. An approved training programme should be developed and consideration given to obtaining a New Zealand Qualification Authority standard for the screening workforce. This may also assist the development of a Māori screening workforce. Māori providers across the screening pathway are under-represented and opportunities to develop a larger Māori workforce need to be taken.

Recommendation 9: Develop a nationally recognised qualification for newborn hearing screener training.

Overall management

The UNHSAG agreed that one lead agency should be responsible for the screening programme as defined in the preferred model in the previous section and its oversight should include policy, monitoring and national funding. Services should be provided by a range of existing or newly developed providers who can meet the programme's standards in either DHB or private settings. Links with a range of programmes and allied providers will need to be developed.

In the case of intervention services there are a number of identified issues that would need to be resolved. The UNHSAG recommends that the NSU ensures that the Ministers' responsible for these services are informed of the likely impact of UNHSP on these services including on:

1. Service interconnection: different funding streams and providers currently impact on children and their families who consequently experience service fragmentation. There is the potential for increased fragmentation if a UNHSP is implemented. Steps should be taken to ensure that intervention services, in particular those provided through both health and education funding streams are reviewed and steps taken to improve service integration, should this be feasible. As suggested by the preferred model described in the previous section, and in recommendation 7, a specific early intervention programme should be set up to, amongst other objectives, improve service interconnection for infants and their families.
2. Early intervention services, currently provided by Advisors on Deaf Children through Group Special Education in the Ministry of Education: it is anticipated that there will be an ongoing increase in the workload of AoDCs (or their equivalent) as younger infants will require more intensive interventions for a longer period of time. Services will need to be further developed to cater for very young infants and should be provided on the basis of evidence-based best practice.
3. Diagnostic services will be provided by accredited providers.
4. Hearing aids and paediatric fitting: it is anticipated that there will be a temporary increase in the number of hearing aids fitted as infants will be detected earlier through the NBHSP. Children with hearing loss will also require more intensive audiological services in the early years. Paediatric hearing aid fitting will be undertaken by accredited providers. Training and resourcing will need to be considered to ensure appropriate services are provided to young infants. Agreement regarding acceptable quality and timeliness of services may need to be forged between the providers to ensure the best outcome for infants and their families. Timeliness and a range of other outcome indicators would be monitored by the UNHSP.

5. Cochlear Implant Programmes (CIPs): There are two CIPs (Southern and Northern) funded by the Ministries of Health and Education and managed through two independent trusts. It is anticipated that there will be a temporary increase in the numbers of children being referred to the CIPs as children are identified earlier. Depending on the staging of roll out this temporary increase in referrals may last for a number of years. Over this period of time an increase in funding to these services will be necessary to ensure that services are provided in a timely manner. The early intervention services would need to work closely with the CIPs to ensure appropriate alignment. Agreement regarding acceptable quality and timeliness of services may need to be forged between the providers to ensure the best outcome for infants and their families. Timeliness and a range of other outcome indicators would be monitored by the UNHSP.
6. A UNHSP is likely to impact on the existing VHT and Well Child questionnaire approaches to hearing screening and surveillance funded by the Ministry of Health. The precise nature of the impact has not been considered by the UNHSAG. The Ministry of Health will need to assess this impact and consider what if any changes are required to these services.

Effective management would also require the development of a single national information system and hearing screening database. It would be appropriate to establish links to other information systems, for example the Kidslink – National Immunisation Register (NIR).

Recommendation 10: A single lead agency should take the role of the screening programme's management, policy development and service monitoring under a single funding stream.

Recommendation 11: Appropriate resourcing of early intervention services will need to be reviewed along with the implementation of an early intervention programme for the screen detected cohort of children.

Recommendation 12: A single national information system for the UNHSP should be developed.

Quality standards, monitoring and audit

Quality standards and a monitoring and audit plan should be developed. Their development should involve key stakeholders including consumers and providers and include each component along the screening pathway including health and education providers of intervention services. It is anticipated that minimum standards may need to specify qualifications as well as volume of work undertaken. In particular monitoring should focus on outcomes and whether these are being optimised. Measurable outcomes would need to be defined and standardised through the development of programme indicators and targets.

Recommendation 13: Quality standards for the screening programme that reach across the entire screening pathway and include both health and education services need to be developed and monitored against an agreed set of national indicators and targets. Standards and indicators need to be developed with consumers, service providers and stakeholders.

Recommendation 14: UNHS Programme monitoring must measure programme outcomes across the screening pathway until children are five years of age and include both health and education services.

Research, development and evaluation

The UNHSAG considered there were some issues for which additional research was required, although it was not able to identify all of these. However, some areas for new research were identified in the course of the UNHSAG meetings. These included:

- Whether rates of permanent congenital hearing loss (PCHL) at birth are indeed higher for Māori and Pacific babies. If so, why, and what steps can be taken to address this, for example through environmental change and tackling determinants of health. If the rates at birth are not significantly different, then what factors are contributing to later onset of hearing loss and how could these be managed to reduce hearing loss in Māori and Pacific communities?
- Whether it is feasible to reduce the screening threshold to 30dBHL and if improved outcomes would be obtained for infants and children with this degree of mild hearing loss, if their hearing loss were identified at birth.
- Which interventions provide the best outcomes for the child and their family?

Efforts would need to be made to keep current with changing technology and best practice, as technology, knowledge and understanding in this field is continuing to make rapid advances. A plan for reviewing technology and maintaining currency of best practice should be developed.

Recommendation 15: An appropriately resourced research and development plan for the UNHSP should be developed at the establishment phase of the UNSHP.

Partnership and understanding

Relationships with the communities associated with hearing screening and hearing loss would need to be developed by the lead agency including service providers, community groups including the deaf community and, especially, parent groups. Opportunities for strengthening the voluntary support groups that exist for families with children with hearing loss should be considered. Linkages across groups should also be fostered by the lead agency by the development of forums or annual meetings or other effective approaches to fostering understanding.

Recommendation 16: The lead agency should work to build understanding across communities and cultural groups and build partnerships with both provider and consumer groups.

5.0 The impact of the UNHSP and addressing inequalities

Impact of UNHSP on existing screening in New Zealand

As described previously in this report, hearing screening and surveillance in New Zealand currently employs a mixed method system including high risk identification, the Well Child surveillance and questionnaire and the five year old school entry screen. The UNHSAG was not sufficiently informed to make full recommendations about the value of these approaches to identify hearing loss although it could reasonably conclude that the current approaches were failing to identify infants at a sufficiently young age. It was therefore concluded that a change and/or addition to the current system was required and that the status quo could not be recommended.

The UNHSAG however, makes no recommendation as to whether these other approaches to identification of hearing loss (the Well Child questionnaire and surveillance and five year old VHT screening) should continue but does recommend that they be reviewed in conjunction with the implementation of the UNHSP.

The UNHSAG was also strongly of the view that no new local newborn hearing screening services should be implemented at a DHB level until such time as clear national guidance can be provided regarding the full range of screening programme issues, for example referral guidelines and equipment purchasing.

Addressing inequalities

Various options for newborn hearing screening were considered including hospital and birth centre only newborn screening. However, hospital and birth centre only hearing screening would not provide universal coverage. This is currently how screening is provided in the Waikato and Tairawhiti DHB region. This approach may impact differently on different groups within the community, for example women who discharge from the hospital early, or who elect to have a home birth. Rural women, in particular, could be disadvantaged by hospital only screening. In addition the UNHSAG considered that the inverse care law was likely to apply and babies whose care was not managed in a hospital environment may be at greater risk of hearing loss. Hospital only screening was consequently considered inequitable, although it was recognised that various logistical and resourcing issues arise with extending screening beyond the major hospitals.

To achieve universal coverage, a community outreach system would need to be developed that was appropriate to the local community. This is likely to significantly increase the cost of newborn hearing screening, although it is entirely feasible to screen in community settings, as the equipment is fully portable and a baby could be readily screened at any time up to six weeks of age. Beyond the age of six weeks the baby is likely to be harder to screen as they are more wakeful and alert and the care network supporting the labour and birth episode ends. Between four and six weeks of age the infant's routine Well Child care is transitioned from Lead Maternity Carer (LMC) to Well Child health providers. Consequently, the UNHSAG determined that efforts should be taken to achieve a high level of participation in newborn hearing screening at an age as close to birth as possible, most commonly through the birth hospital network but employing a range of locally appropriate strategies to engage with babies and families who are born at home or have discharged from the birth hospital early. Current estimates suggest that about 80 percent of screening could be undertaken within hospital settings and that high rates of participation in this setting are achievable (Pokorny, 2004). The NSU has commissioned the Waikato DHB to undertake piloting of community outreach initiatives in two distinct regions within the Waikato. The results of these initiatives will be available in 2006.

Inequalities and ethnicity

An issue for all healthcare services is inequality. “Particular groups are consistently disadvantaged in regard to health…the reasons for health inequalities are complex and generally beyond the control of the groups most affected” (MoH, 2002). Not only are some groups within the population more likely to have a condition or disease, they may also have greater difficulty accessing the level of care they need. Screening programmes can exacerbate existing inequalities and increase the level of inequality that already exists. Special efforts need to be taken to ensure that this does not occur.

Inequalities are known to exist for those on the lowest incomes and for particular ethnic groups such as Māori and Pacific. As has already been highlighted, Māori and Pacific infants and children have a higher proportional incidence of hearing loss and have their hearing loss diagnosed later than non-Māori, non-Pacific children. If a UNHSP is implemented, steps will need to be taken to ensure that services offered are acceptable and appropriate to Māori and Pacific communities so that inequalities are lessened not exacerbated. Achieving this will require effective partnership and participation with Māori throughout the design and implementation phases of a programme. In addition specific research will need to be undertaken to determine if newborn hearing screening is proving effective for detecting significant hearing losses in Māori and Pacific infants. This research would need to consider both the degree of hearing loss present at birth and age at onset. A Health Equalities Assessment has been undertaken. This can be seen in Appendix 4.

6.0 Conclusion

The UNHSAG strongly endorses the introduction of a universal newborn hearing screening programme for New Zealand to address the late age of detection, and delayed and poorly coordinated intervention services, for children born with significant hearing loss in New Zealand. This would align New Zealand with other developed countries and allow New Zealand infants and their families to maximise the potential benefits of early intervention choices.

The UNHSAG acknowledges that a variety of complex issues will need to be addressed with a range of stakeholders but is pleased to be able to offer a model that is unanimously endorsed by the group and which is both pragmatic and offers the best chance of success. Implementation of the model will require a great deal of effort on the part of many individuals and organisations but the UNHSAG is hopeful that the collaboration required will in fact strengthen services and communities overall.

If a high quality newborn hearing screening programme is not introduced, and New Zealand continues to detect hearing loss so late and to offer intervention services only after the best window of opportunity for improved outcomes has passed, the costs will continue to be born by children and families throughout their lifetimes. These costs can be expected to increase and inequalities widened as the proportion of Māori and Pacific in the population as a whole increases and due to their greater proportional incidence of deafness and hearing loss. Costs will also be borne by society as a whole in the form of support payments for and the lost productivity of thousands of its citizens. The UNHSAG strongly commends the National Screening Unit of New Zealand to implement its 16 recommendations.

1. New Zealand should implement a universal newborn hearing screening programme to reduce the age of detection and intervention for infants with permanent congenital hearing loss.
2. The UNHSP should identify permanent congenital hearing loss present at birth that is likely to impact on the development of speech and language and maximise communication and language opportunities through early intervention/s.
3. The UNHSP should be implemented in conjunction with efforts to ensure that early intervention services are available to infants who are deaf or have a hearing loss and their families as a nationally consistent, co-ordinated programme.
4. Irrespective of the implementation of a UNHSP, an early intervention working group should be convened between the Ministries of Health and Education to ensure that nationally consistent, co-ordinated early intervention services are provided.
5. Given the inter-agency nature of early intervention services and the need for commitment, inter-agency cooperation and co-ordination, the NSU needs to ensure that the relevant Ministers are informed of the likely impact of a UNHSP on a range of services.
6. Establish a UNHSP, which screens, diagnoses and prepares an initial action plan with the family and then refers to and monitors the outcomes of a clearly defined and appropriately resourced early intervention programme.
7. Early Intervention services should be enhanced through the introduction of an organised early intervention programme for children aged from birth to five years of age. This programme would be available to infants with hearing loss regardless of the method of identification of their hearing loss.
8. Develop nationally coordinated, consistent strategic and operational policy which is child/tamaiti and family/whanau centred, ensures informed choices and endeavours to ensure the best outcome for the child/tamaiti and family/whanau.

9. Develop a nationally recognised qualification for newborn hearing screener training.
10. A single lead agency should take on the role of the screening programme's management, policy development and service monitoring under a single funding stream.
11. Appropriate resourcing of early intervention services will need to be reviewed along with the implementation of an early intervention programme for the screen detected cohort of children.
12. A single national information system for the UNHSP should be developed.
13. Quality standards for the screening programme that reach across the entire screening pathway and include both health and education services need to be developed and monitored against an agreed set of national indicators and targets. Standards and indicators need to be developed with consumers, service providers and stakeholders.
14. UNHS Programme monitoring must measure programme outcomes across the screening pathway until children are five years of age and include both health and education services.
15. An appropriately resourced research and development plan for the UNHSP should be developed at the establishment phase of the UNSHP.
16. The lead agency should work to build understanding across communities and cultural groups and build partnerships with both provider and consumer groups.

Appendices

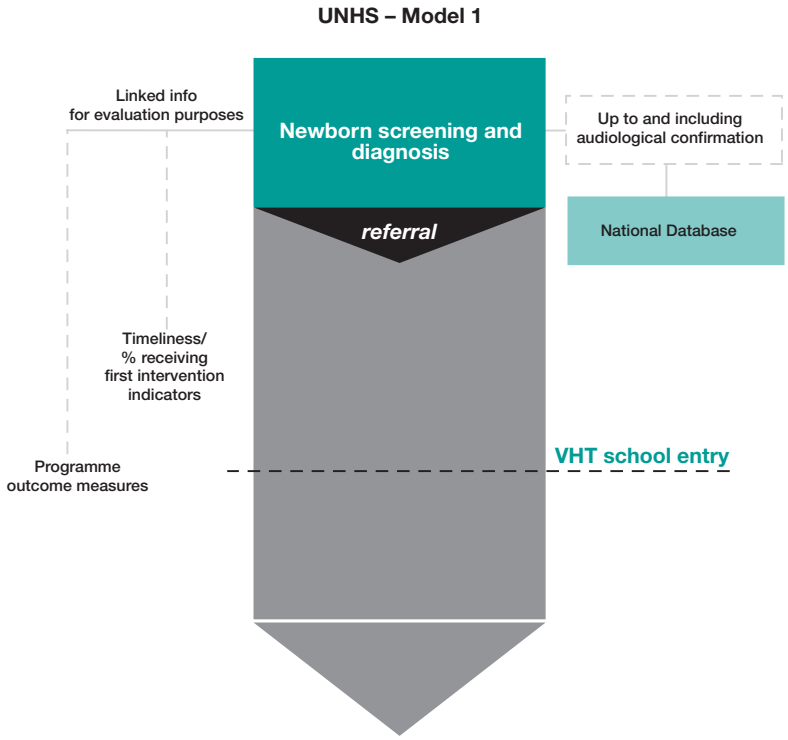
Appendix 1: Principles for a Newborn Hearing Screening Programme

1. Governance	Accountability is clear and arrangements have the capacity to ensure desired outcomes are achieved.
2. People Centred	The programme involves families, whanau and other stakeholders and is responsive to their needs and values.
3. Equity and Access	People receive equivalent services on the basis of need and likely benefits and the programme reduces inequalities.
4. Efficiency	The programme gives the greatest possible benefit for the resources used.
5. Effectiveness	The programme achieves an expected measurable benefit.
6. Coverage/Yield	The programme delivers the highest participation and identifies all positive cases of significant hearing loss.
7. Safety	Harms are minimised.
8. Integration/Interface	The service user can transition throughout the screening and intervention pathway with ease.
9. Ethical Implications	The programme ensures that babies with hearing loss identified through the screening programme can access effective intervention services.
10. Service Impact and Workforce Implications	The programme can be delivered within the current health context and workforce impact can be managed. The skills and competency of the screening and intervention workforces are maintained over time.

Appendix 2: Models considered by the UNHSAG

Model 1

Model 1 would comprise a universal newborn screening hearing programme that concludes at audiologic diagnosis although some outcome measures beyond this point would be collected and reported on by the screening programme. Model 1 would include health promotion, invitation and informed consent, application of the screening test and audiological confirmation of a positive screening result. These services fall solely within the current health portfolio. Following this the infant would be referred appropriately to intervention services providers. This is shown diagrammatically below.



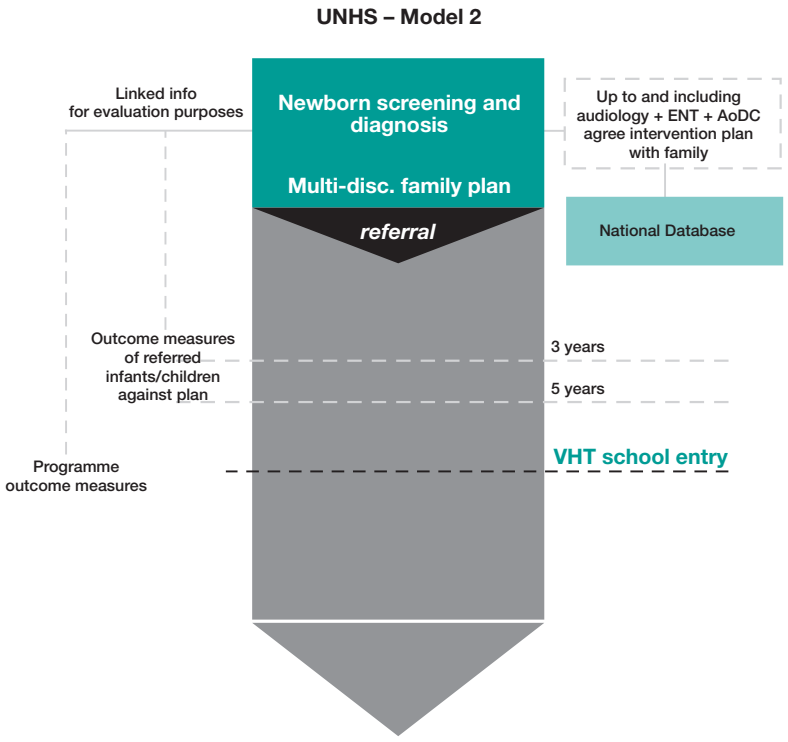
Note: contracts to obtain data may be needed or could be LP's responsibility

Conclusion

The UNHSAG considered that Model 1 could not guarantee the quality, consistency or accessibility of intervention services provided to families and infants and could as a consequence result in harm for some families and infants.

Model 2

Model 2 describes a universal newborn hearing screening programme which concludes with the multi-disciplinary development of an intervention plan for the infant identified through the screening pathway. Some outcome measures beyond this point would be collected and reported on by the screening programme. Model 2 would include health promotion, invitation and informed consent, application of the screening test, audiological confirmation of a positive screening result and the multi-disciplinary development with the family of an intervention plan. The services of the AoDC are currently funded through the Education Portfolio. All of the other services currently reside within the Health Portfolio. Following this the infant would be referred to intervention services providers. This is shown diagrammatically below.



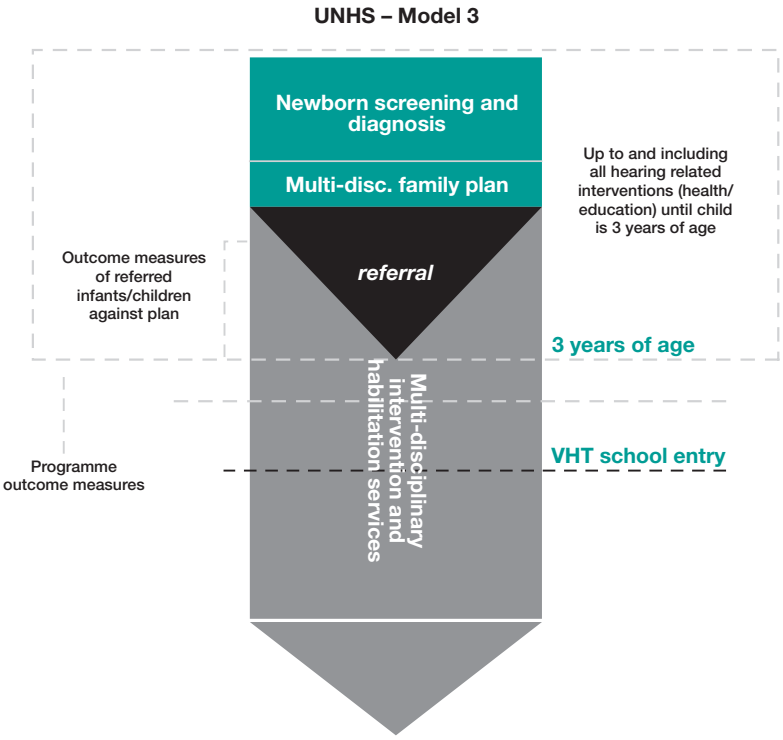
Note: contracts to obtain data may be needed or could be LP's responsibility

Conclusion

The UNHSAG considered Model 2 improved on Model 1 by increasing the potential for consistency through the creation of a family intervention plan, but that it could still not guarantee the appropriateness or quality of intervention services. For this reason further recommendations were made for developing early intervention services.

Model 3

Model 3 describes a universal newborn hearing screening programme which takes responsibility for all health and education interventions relating to the child's hearing loss up till the child reaches three years of age. Intervention effectiveness would be measured up to this time and the VHT programme could potentially provide information on outcomes of UNBHS, but would need significant enhancement (although this service would remain separate from the UNHSP). Model 3 would include health promotion, invitation and informed consent, application of the screening test, audiological confirmation of a positive screening result, multi-disciplinary development with the family of an intervention plan and provision of intervention services and co-ordinated care until the child reaches three years of age. Services would be provided under health, education and welfare portfolios. Following this the infant would be referred appropriately to existing services that maintain the care and support of the child and their family. This is shown diagrammatically below.

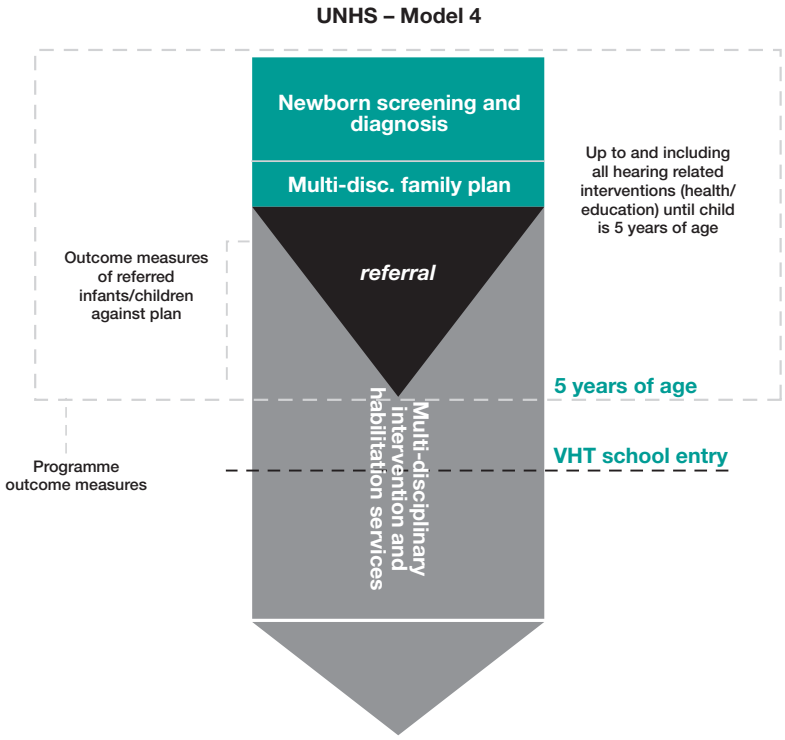


Conclusion

The UNHSAG decided that while there were advantages associated with Model 3 which could result in a clear path into early intervention services, a programme of this magnitude would be difficult to manage, and over-ride a number of existing policies, service structures and arrangements. It was also unclear how well children could be transitioned into existing follow up services at the age of three years.

Model 4

Model 4 is an extension of Model 3 in that the universal newborn hearing screening programme takes responsibility for all health and education interventions relating to the child's hearing impairment until the child reaches five years of age, at which time he/she begins school. Intervention effectiveness would be measured up to this time. The VHT programme could potentially provide information on outcomes of UNBHS, but would need significant enhancement (although this service would remain separate from the UNHSP). Model 4 would include health promotion, invitation and informed consent, application of the screening test, audiological confirmation of a positive screening result, multi-disciplinary development with the family of an intervention plan and provision of intervention services and co-ordinated care until the child reaches five years of age. Services would be provided under health, education and welfare portfolios. Following this the child would begin their schooling and be referred appropriately to services that would maintain the care and support of the child and their family as required. This is shown diagrammatically below.

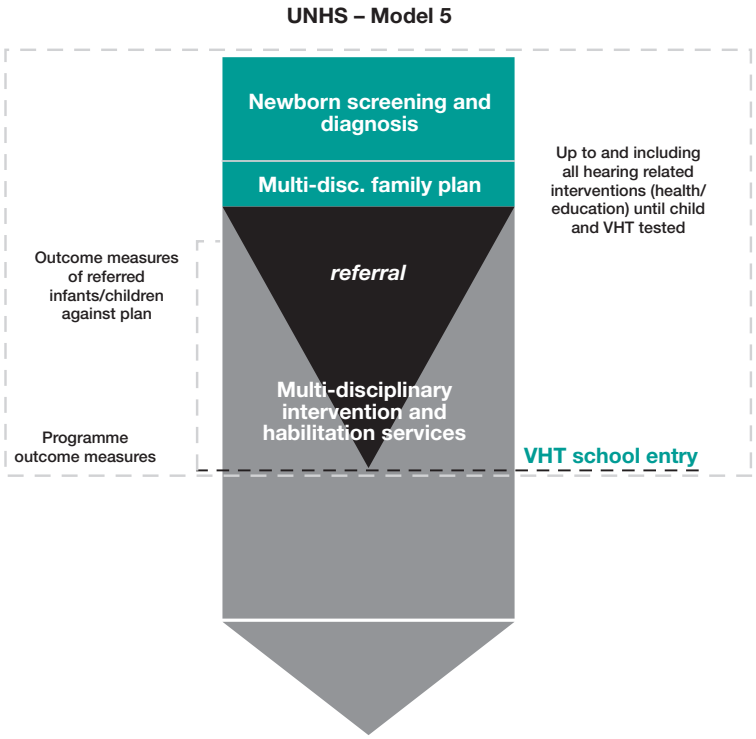


Conclusion

The UNHSAG considered that Models 3 and 4 were very similar, except on their age at hand-over. Model 4 handed over responsibility at an age when children were moving into a clear education-led system at five years of age. As with Model 3, Model 4 would be difficult to manage and would require significant re-alignment of existing arrangements.

Model 5

Model 5 describes a universal newborn hearing screening programme which takes responsibility for all health and education interventions relating to the child's hearing impairment up till the child reaches five years of age and manages the VHT five year screening programme. Intervention effectiveness would be measured up to this time. The VHT programme could potentially provide information on outcomes of UNBHS, but would need significant enhancement. Model 5 would include health promotion, invitation and informed consent, application of the screening test, audiological confirmation of a positive screening result, multi-disciplinary development with the family of an intervention plan, provision of intervention services, co-ordinated care until the child reaches five years of age and the VHT on school entry. Services would be provided under health, education and welfare portfolios. Following this, the child would be referred appropriately to services that maintain the care and support of the child and their family as required. This is shown diagrammatically below.

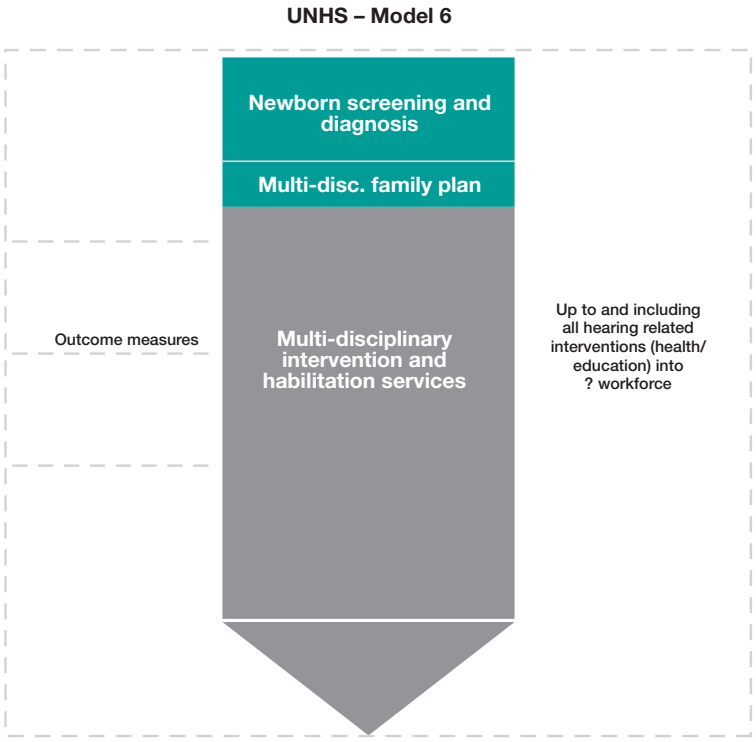


Conclusion

Model 5 incorporates the management of the current VHT programme under the management structure of newborn hearing screening and early intervention services. The UNHSAG considered that this would be a very large management task for a new programme and may result in a loss of focus on the primary task of identifying hearing loss in newborns. The UNHSAG was of the view that this model had the weakness of Models 3 and 4 and it would add unnecessary complexity to also run the VHT programme.

Model 6

Model 6 describes a universal newborn hearing screening programme which takes life-long responsibility for the hearing related needs of all those babies and children identified with hearing loss at birth through to five years of age. It would also provide the interventions the child and family received for the life span of the person with hearing loss. It would not be responsible for identifying later onset hearing losses. Services would be provided under health, education and welfare portfolios. This is shown diagrammatically below.



Conclusion

Option 6 was viewed by the UNHSAG as practically unworkable but valuable theoretically in that it acted as a reminder that the effects of hearing loss remain throughout life and need periodic adjustment and ongoing management for individuals, families and communities throughout the life-course. It was also a valuable reminder that the outcomes being sought went throughout childhood and beyond the formal education sector into the workplace and general community.

Appendix 3: Matrix of the screening pathway against key programme deliverables

PATHWAY/ DELIVERABLE	HEALTH PROMOTION	INVITATION	SCREENING PROCEDURE	DIAGNOSTIC PROCEDURE	INTERVENTION
Service Development (Operational Policy)	No role for sub-optimal services anywhere (high quality) Protocols need to be developed: best practice, nationally consistent (consistent) Consistent, nationally developed information needs to be available at each step which allow choice and empower families (empowering) Programme policy must be family centred and based on understanding of families needs, especially Māori (family/whanau centred)				
	Relationships and Responsibilities Engage with all key stakeholders including LMCs, PHOs, antenatal educators, media Education and Information Provide national education, ante natal classes, hospital education Give women information during pregnancy Ensure consistency between local and national materials Educate about risk of progressive/acquired at later ages **Cultural** Hold hui and obtain advice on protocols for Māori engagement Respect Whare Tapa among Māori women Use te whare tapu wha model Increase awareness about deafness, communication and language development Philosophy Family centred plus support parents Focus on empowerment	**Relationships and Responsibilities** Engage LMCs, paediatricians, WellChild, PHOs, Media Obtain informed consent – who responsible –LMC or screener? Specify responsibility for ensuring access (and end of responsibility) - LMCs via section 88? **Eligibility** Include all babies (hospital, NICU and elsewhere, eg via community centres within 6 weeks of age) **Cultural** Develop protocols for invitation, customised approaches for ethnic groups to ensure, acceptability	**Relationships and Responsibilities** Build on existing bodies of work – international best practice and interest group work like SoA Require linkage with appropriate professional groups eg Audiologists, AoDC Well Child health book – ? tick box to ensure follow-up/chase up/ increased surveillance Track and assist DNAs to attend Establish responsibility for signing off result - screeners or LMC Consider link with VHTs - however local solutions required with small numbers of babies in most DHBs Consider linking with National testing centre for blood screens as programme development **Providers and Services** Support family psychologically Provide mobile screening services esp. for smaller cities/rural ? home visits/high density Māori areas. Develop with individual communities. Consider marae based screening Will three year old screening continue if there is a nbsp and how will conductive losses be detected? Use trained screeners Develop proper delivery protocols.	**Relationships and Responsibilities** Develop referral protocols Include paediatricians as appropriate **Providers and Services** Use only accredited audiology providers Specialist centres need to deliver ABR because specialist service, but ensure services in home towns Consider developing a main centre of excellence nationally with accredited satellite units in main centres. Centres would also have interventionists: one stop shop. **Philosophy** Balance quality with access issues	**Relationships and Responsibilities** Develop referral/ links with WellChild **Providers and Services** Specify skills required to intervene with <3 years, and <6 months Develop individual framework and plan for child using clear process based on evidence Develop protocols for EI based on best practice and evidence Acceptable waiting time for CI needs to be defined Build family networks and 'train' parents to provide support. **Cultural** Develop a Māori EI centre (resources, etc.) **Philosophy** Work as a team. Aim for best outcome for child Be holistic – care for emotional and social well-being of child Provide families with clear pathway, built on balanced information and their choices of intervention and habilitation services **Cultural** Develop a competency in working with deafness

PATHWAY/ DELIVERABLE	HEALTH PROMOTION	INVITATION	SCREENING PROCEDURE	DIAGNOSTIC PROCEDURE	INTERVENTION
Service Development (Operational Policy) ***continued***			Consider using community nurses to ensure follow-up. **Equipment** Use same/similar equipment nationally to ensure consistency Implement 2 stage protocol **Case Definition** Specify what we are screening for eg. mild or moderate, unilateral or bilateral and understand trade-offs – can these be mitigated? Set screening threshold at 35dBHL		
Workforce Development (WFD Strategy and Action Plan)	Develop Māori WF Up-skill all to work with hearing impaired little ones				
	Relationships and Responsibilities Educate wider WF about hearing/ hearing screening Consider linkages with other screening, ante-natal information	**Relationships and Responsibilities** Educate LMCs and screening programme staff **Providers and Services** Train screeners in technique as well as ways to approach parents. Develop national course/s for screeners with consistent standards	**Relationships and Responsibilities** VHTs are an existing work-force that already has own training, monitoring, professional society, conferences, have screening mentality and are cost effective **Providers and Services** Introduce NZQA training **Philosophy** Ensure training on-going	**Providers and Services** Develop paediatric audiology as specialty. Increase number of audiologists	**Providers and Services** Develop skills in paediatric hearing aid fitting. Continue to provide signing via KDEC and Van Asch Develop AoDC's role – training and numbers Develop EI teacher training esp Māori and Pacific

PATHWAY/ DELIVERABLE	HEALTH PROMOTION	INVITATION	SCREENING PROCEDURE	DIAGNOSTIC PROCEDURE	INTERVENTION
Overall Management (funding agreements, legislation, national data systems)	Define programme start and end point and responsibility Require national database				
	Relationships and Responsibilities Develop a single, national lead agency which has oversight of the whole process, responsibility for developing, implementing and monitoring policy and national funding. Institute an Advisory or management group **Equipment** Develop a national equipment bank.	**Relationships and Responsibilities** Link with WellChild Establish who is responsible for ensuring access ? LMCs via section 88 **Equipment** Create a national database Link data but consider privacy issues	**Relationships and Responsibilities** Consider governance - where sit in DHB – eg. maternity, public health? Consider how links to later screening Consider ongoing surveillance **Providers and Services** Contract with DHBs and/or private via nationally determined service specification Variability of screening technology creates concern with liability due to false negatives especially with mild losses. May need systems to pick up 'misses' from nbs plus clarity through informed consent and ongoing education.	**Providers and Services** Contract with appropriate groups (DHB, Private Centres depending on skill) Procedures/funding to bring children to centre for diagnosis/ intervention **Equipment** Need to improve data collection and record actual dBHL reading not just degree of hearing loss. Note: definitive dBHL reading in a child is slowly built up and sometimes not achieved until a child is over two years of age and some losses will progress after birth	**Providers and Services** Increase funding for early childhood CI funding may need to be reviewed **Philosophy** Funding from different streams is causing service fragmentation and can limit families' choices and interrupt service continuity eg. health funds speech language therapy for under two years of age but education funds for the over two years.
Quality Improvement, monitoring and evaluation (Quality Standards and Monitoring and Audit Plan)	Collect data across the screening pathway Link databases (two now linked) Monitor and evaluate across the screening pathway Develop monitoring framework with key stakeholders Establish overall advisory or management group to monitor health information acceptability, availability, coverage				
			Providers and Services Monitor screeners' performance centrally. Re-train if high refer rate. Review effectiveness of current systems eg. Can your Child Hear **Equipment** National database linked to NHI for tracking; refer rates indicate screener/ equipment competency, determine coverage (link to NHI will tell this)	**Providers and Services** Set minimum volumes. Specify appropriate qualification/s Monitor diagnosis, detailed family history and of risk factors, identify and monitor follow-up pathway for each child **Equipment** Use only approved equipment Collect data from surveillance cases	**Providers and Services** Specify quality standards for interventions Specify minimum numbers eg. CI Develop an accreditation system Define qualification/s for EI education Defined and standardise outcome measures Monitor outcomes **Equipment** Link with GSE database. Yearly collection of language, educational outcomes

PATHWAY/ DELIVERABLE	HEALTH PROMOTION	INVITATION	SCREENING PROCEDURE	DIAGNOSTIC PROCEDURE	INTERVENTION
Research and Development (R&D Plan and Evaluation Framework)	Develop parallel research and development programme linked to the international community which monitors and evaluates changes in best practice, technology, monitors progress in the pathway and recommends changes according to lower than expected outcomes Identify key research gaps				
		Providers and Services Evaluate why primary health providers not working Monitor OME in high risk groups, as likely to be major factor in false +ve rate, cf Gisborne hearing screening service experience **Cultural** Work on all cultural areas to increase acceptability	**Equipment** Consider monitoring genetic screening developments and gene based treatments.		**Providers and Services** What interventions do have the best outcomes (much international evidence/best practice available to build on) Evaluate outcomes Link health and education research Programmes **Equipment** Undertake research to establish feasibility and effects of reducing screening threshold to 30dBHL. **Cultural** Because there is no screening programme we do not know the true rates of PCHL at birth vs progressive. Need to better understand for Māori eg. wrt CMV

PATHWAY/ DELIVERABLE	HEALTH PROMOTION	INVITATION	SCREENING PROCEDURE	DIAGNOSTIC PROCEDURE	INTERVENTION
Partnership and Understanding (Communications Plan)	Communicate and partner with all stakeholders, professionals and especially parents Develop professional champions Develop a programme vision eg. language developmental not hearing deficit Build on Treaty of Waitangi, Disability Strategy, Cultural competency with the Deaf community				
	Cultural Engage with Māori through hui and Māori network development. **Philosophy** Make parents/whanau and parent groups central	**Relationships and Responsibilities** Utilise links built through LMCs and Plunket for hard to find and F/U families **Providers and Services** Utilise existing infrastructure, eg. Well Child, Project Hiedi and existing stakeholder groups Consider use of iwi providers currently linked to VHT programme **Cultural** Develop the right language – communication (2 way) (take care that message not confused with speech pathology), hearing impairment (not deficit) **Philosophy** Understand needs of parents			

Appendix 4: Health equalities assessment tool

NEW SCREENING PROGRAMMES HEAT TOOL	APPLICATION OF THE TOOL	COMMENTS
What health issue is the new screening programme trying to address?	The programme will address the late age of detection of and intervention in significant permanent congenital hearing loss. The aim will be to reduce the age of identification from 45.3 months of age (in 2004) to less than three months of age. This will allow Interventions to begin by six months of age.	
What inequalities exist in this new screening programme/ existing disease management? What does the incidence and mortality data show with ethnicity breakdown?	Context: The demographic profile of 0–4 year olds in New Zealand includes an increasing proportion of Māori (28% and Pacific (11%) children in 2004. These children are also much more likely to be over-represented in the highest deprivation scores. Māori children are more likely to have a hearing loss than other children, accounting for nearly half of all deafness notifications but less than a quarter of the relevant population group. In addition the hearing loss in Māori children is identified later than in other children and the time from identification and intervention is longer. Of note, the nature of deafness in Māori children is more likely to be mild loss (26–40 dBHL). Pacific children are also somewhat more likely to have hearing loss (13.5% of all notifications in 2000–2004 compared with 10.9% of the population) and they are likely to be identified even later than Māori children with 50 percent identified by 70 months and 80 percent identified by 80 months of age. Pacific children are more likely to have a moderate loss (41–65 dBHL) European and Asian children are under-represented in hearing notification statistics. No data is collected on the age of enrolment in intervention programmes, but this is likely to occur after identification. The late age of identification of all children, but especially Māori and Pacific children is a cause for alarm.	Māori and Pacific participation rates in the two current cancer screening programmes is lower than non Māori non Pacific rates. This suggests that presently those two programmes have not adequately addressed screening for Māori or Pacific. The NSU is in the process of undertaking research which aims to provide a better understanding and insight into Māori women's access to services along both BSA and NCSP screening pathways. The NSU will need to ensure it engages actively with Māori at all levels to ensure uptake of this screening programme meets its target. Additional efforts need to be made to encourage Māori and Pacific peoples to participate in screening through health promotion activities and that institutional barriers to participation and access to services need to be removed.
Who is the most advantaged and how? What research exists to show trends in incidence amongst different ethnic groups? Does existing service configuration contribute to advantage for one group over others? How extensive has awareness raising been used with different groups?	The current system of identification with only a targeted high-risk approach to identification, but no formal screening programme may suggest that babies who have known risk factors, eg. jaundice may be advantaged. Secondly, under the current approach, general socio-economic advantage facilitates institutional access to diagnostic audiology and intervention services. Other institutional barriers may also exist that inhibit access for some groups relative to others. Consideration of features such as family friendly appointment times need to be considered. Using the indicator of age of detection, European and Asian children are advantaged by comparison with Māori and Pacific children , although they are also not well served by the existing system by comparison with international data.	
How did the inequality occur?	Epidemiological basis – Māori children are more likely to have a lesser hearing loss (ie. Moderate to mild rather than severe to profound). This makes the hearing loss less apparent outside of objective screening testing. Structural basis – access to health services generally, due to economic and cultural factors contribute to the health disadvantage experienced by Māori and Pacific children.	

NEW SCREENING PROGRAMMES HEAT TOOL	APPLICATION OF THE TOOL	COMMENTS
What are determinants of this inequality? (General socio-economic and environmental conditions; gender and culture; living and working conditions; social and community influences; individual lifestyle factors; age, sex and hereditary factors)	Anecdotally, there is thought to be a genetic (hereditary) basis for the higher rate of hearing loss experienced by Māori, but this is not fully understood and needs to be further researched. A screening programme will assist to provide vital information for this research. It is possible that there may be an environmental component but this is not yet known. Socio-economic and cultural factors play a part in accessing services including through appropriateness, acceptability, accessibility and affordability.	
How will you address the TOW in the context of the NZ Public Health and Disability Act 2000?	The Treaty of Waitangi informs the process of the programmes development. Three Māori representatives are included in the advisory group which is working to develop advice for the Minister. Māori participation will be central to the success of the programme. The benefits to Māori from a programme could be considerable at the level of the specific disease but also because of its wider impact – deafness affects the ability to learn and participate through communication leaving deaf people over-represented in low income jobs, unemployment and in mental health. Strategies for engaging with Māori have been presented to the advisory group.	

NEW SCREENING PROGRAMMES HEAT TOOL	APPLICATION OF THE TOOL	COMMENTS
Where/how will you intervene to tackle this issue? Use the MoH Intervention Framework to guide your thinking.	Firstly, all cases of hearing loss need to be identified at an early age. The aim of the programme will be to identify deafness by age three months. Special efforts will need to be made to ensure that Māori participate in screening – an evaluation and pilot are being undertaken to inform the NSU how best to achieve this. In particular the evaluators have been asked to assess whether the current service in Waikato is acceptable to Māori and, if not, how it needs to alter to be acceptable and thereby encourage participation. Developing a Māori screening workforce will be important. Please note that currently a newborn hearing screening workforce is not in existence. Secondly, efforts to ensure that those that are screen positive attend for diagnostic assessment. It is not yet determined how this will occur but may involve providing transport and/or allowances to facilitate access. Such systems would be built into contractual mechanisms with providers. By Māori for Māori services will be considered where possible, but at this stage it is acknowledged that the various workforces have limited Māori participation. Cultural competency will be built into a programme at all levels. Education will be an important component of the programme. Education will assist with participation and with raising awareness of other forms of deafness (eg. acquired and progressive) and the importance of dealing with it. Māori will be involved with the development of appropriate education resources. Resources in Te Reo will be developed. Thirdly, identification without intervention would be pointless. It is not yet determined how access to and participation in interventions will be facilitated, but it is expected that Māori providers or co-ordinators that have a specific role to assist Māori children and their whanau throughout the intervention pathway may be engaged. The overall service design will need to be acceptable to Māori. Māori will be engaged in service design. Fourthly, service and programme evaluation will be undertaken which will explore participation rates. Consideration is already being given to how data can be best collected to reduce errors, including ethnicity. Finally, the impact on the family can be minimised by facilitating access to income support and increasing awareness of the availability of relevant support services. Currently the Advisors on Deaf Children through Group Special Education provide this function. At this stage it seems unlikely that their role would alter, however monitoring would be implemented. To this end the NSU is also trying to engage inter-sectorally with MoE and the Office of Disability. Inter-sectoral collaboration will be an important component to ensure success and minimise existing inequalities.	
How could this new screening programme affect health inequalities?	A properly designed and implemented programme must aim to reduce inequalities and improve health outcomes.	
Who will benefit the most from the new screening programme?	If the programme centres on Māori and Pacific children they should gain the benefits of this new screening programme. However, the two current cancer screening programmes most benefit non Māori, non Pacific women.	

NEW SCREENING PROGRAMMES HEAT TOOL	APPLICATION OF THE TOOL	COMMENTS
What will the unintended consequence be in the implementation of this new screening programme?	Early intervention services are important for this programme. Kohanga reo may be affected by earlier identification. Skills may need to be developed by Kohanga to support Māori infants with hearing loss. However the aim is to avoid or mitigate any unintended consequences. An unintended consequence is that if focus is placed on Māori and Pacific this may discourage non Pacific and non Māori participation although other programmes such as the Meningococcal B programme provides evidence to counter the above statement.	
What will the NSU do to make sure the new screening programme reduces/eliminates inequalities?	The NSU is already focussed on the existing inequalities and will be setting out to reduce/eliminate them both through the successful implementation of a programme with significant input from Māori and Pacific representatives and through further research and evaluation strategies aimed at reducing inequalities. The NSU would develop a position paper on strategies for reducing inequalities within a newborn hearing screening programme and obtain advice from the NSU Reducing Inequalities Steering Group and the Māori Advisory Group. Advice may also be sought from the Māori Health Directorate.	
How will you know if inequalities have been reduced/ eliminated?	We will know if inequalities have been reduced when the data demonstrates that hearing loss in Māori and Pacific infants is identified at under three months of age and that they are accessing appropriate interventions by the age of six months. Additional outcome data relating to age appropriateness of communication perception will take longer to gather. Additional research into the reasons why Māori are over-represented in deafness notifications may also provide valuable information about how to reduce inequalities. Such information would be acted upon once it was verified and assuming that there were practical steps that could be taken to reduce the incidence (eg. if there were environmental factors which could be altered).	

Glossary

ABR	Auditory Brainstem Response
AoDC	Advisor on Deaf Children
BOA	Behavioural Observation Audiometry
CMV	Cytomegalovirus
dBHL	Decibel Hearing Level
DEANZ	Deaf Education Aotearoa / New Zealand
DHB	District Health Board
EIP	Early Intervention Programme
ENT	Ear Nose and Throat
GP	General Practitioner
GSE	Group Special Education
HIEDI	Hearing Impairment Early Detection and Intervention
LMC	Lead Maternity Carer
MoE	Ministry of Education
MoH	Ministry of Health
MSD	Ministry for Social Development
NAC	National Audiology Centre
NHC	National Health Committee (NZ)
NZQA	New Zealand Qualifications Authority
OAE	Otoacoustic Emission
OME	Otitis Media with Effusion
PCHL	Permanent Congenital Hearing Loss
UNHS	Universal Newborn Hearing Screening
UNHSP	Universal Newborn Hearing Screening Programme
VHT	Vision Hearing Technician

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