

NSW DEPARTMENT OF HEALTH
EVALUATION OF THE STATEWIDE INFANT
SCREENING – HEARING (SWISH) PROGRAM

FINAL
REPORT



Health Outcomes International

Suites 1 & 4, 51 Stephen Terrace, Kent Town SA 5069

Phone: 08 8363 3699
Facsimile: 08 8363 9011
Email: info@hoi.com.au
ABN 80 081 950 692



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GLOSSARY OF TERMS

Automated ABR	Automated Auditory Brainstem Response Testing
AHS	Area Health Service
AOAE	Automated Oto-acoustic Emissions
Care Pathways	The range of possible pathways an infant may take from their initial neonatal hearing scan dependent on their health care needs following that scan
CALD	Culturally and linguistically diverse
Corrected Age	The age an infant born prematurely would be if born on the determined due date
EDHI	Early Detection Hearing Intervention Program (United States)
Follow-up rates	Refers to the rate of infants who get a refer result from initial screening and any subsequent rescreening. At least 90% should complete a comprehensive audiological evaluation by 3 months of age, according to the updated benchmarks for universal neonatal hearing screening in developed countries, issued by the Joint Committee on Infant Hearing in 2007.
FTE	Full time equivalent
HNEAHS	Hunter New England Area Health Service
HOI	Health Outcomes International
JCIH	Joint Committee on Infant Hearing
NHSP	Newborn Hearing Screening Programme (England)
NICU	Neonatal Intensive Care Unit
Healthy Hearing Program	Queensland Infant Hearing Screening Program
Referral rates	Less than 4% of all newborn infants should get a refer result from their initial screening and any subsequent rescreening before being referred for comprehensive audiological evaluation, according to the updated benchmarks for universal neonatal hearing screening in developed countries, issued by the Joint Committee on Infant Hearing in 2007.
SESIAHS	South Eastern Sydney Illawarra Area Health Service
SWISH	Statewide Infant Screening - Hearing
TRG	Technical Reference Group
UNHS	Universal Neonatal Hearing Screening programs
UNHSEIP	Universal Newborn Hearing Screening and Early Intervention Programme (New Zealand)
UNIHP	Universal Newborn and Infant Hearing Program (Canada)
UNHSP	Universal Neonatal Hearing Screening Program (South Australia)
VIHSP	Victorian Infant Hearing Screening Program





EXECUTIVE SUMMARY

E.1 THE SWISH PROGRAM

According to the American Academy of Paediatrics significant permanent bilateral hearing loss occurs in 1%-3% of every 1,000 live births¹. Significant bilateral hearing loss is defined as being greater than 40dB in the better ear. Early diagnosis of children with significant permanent hearing impairment combined with appropriate intervention strategies can lead to greatly improved health, educational and social outcomes for these children. The primary objective of hearing screening programs is therefore, to screen at least 95% of newborn infants before 1 month of age with the intention of identifying those with significant hearing loss so they can be referred for early intervention.

The NSW SWISH Program is an early hearing detection and intervention (EHDI) program for infants born or residing in NSW. The core elements of the SWISH Program include: Screening of all newborn infants; diagnostic audiology for those infants who get a refer result from the screening test; paediatric/medical assessment and parent support services for those diagnosed with a hearing impairment; and referral to early intervention services. The screening program is offered in the then eight Area Health Services (AHSs), whilst diagnostic audiology, paediatric/medical assessment and parent support services are undertaken in John Hunter Children's Hospital, Sydney Children's Hospital and the Children's Hospital at Westmead.

E.2 EVALUATION OF THE SWISH PROGRAM

The NSW Department of Health (the Department) appointed Health Outcomes International (HOI) July 2009 to conduct an evaluation of the NSW Health Statewide Infant Screening –Hearing (SWISH) program.

The terms of reference (objectives) for the evaluation were to:

- Evaluate the appropriateness, effectiveness and efficiency of the SWISH program in meeting the performance indicators and international benchmarks for newborn hearing screening programs.
- Evaluate processes including: Program management, Referral processes, Service networks and the Satisfaction of parents/families.
- Develop a monitoring system and make recommendations for ongoing management and reporting of all aspects of the SWISH program.

The eight principles contained in the Joint Committee on Infant Hearing² 2007 position statement³ provide a foundation for implementing and maintaining an effective Early Hearing Detection and Intervention (EHDI) program and have been used as a benchmark for the SWISH evaluation.

The methodology for the conduct of the evaluation included; a review of similar EDHI programs both nationally and internationally; analysis of program data for the last five years and benchmarking

1 American Academy of Paediatrics (1999) "Newborn and Infant Hearing Loss: Detection and Intervention". Paediatrics. Volume 103, Issue 2, p257, 1999.

2 Established to make recommendations concerning the early identification of children with, or at-risk for hearing loss and newborn hearing screening

3 Joint Committee on Infant Hearing (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. <http://pediatrics.aappublications.org/cgi/content/full/120/4/898?ikey=oj9BAleq21OIA&keytype=ref&siteid=aapjournals#SECA>.

against the JCIH principles; consultation with a range of stakeholders including SWISH program staff, early intervention services and parents/families; and the development of a monitoring system.

E.3 KEY EVALUATION FINDINGS

The evaluation included a review of the appropriateness, effectiveness and to a lesser extent the efficiency of the program.

E.3.1 APPROPRIATENESS OF THE SWISH PROGRAM

Whilst structural differences in the design of the SWISH program exist between the eight AHSs, the fundamentals of a universal newborn hearing screening program are evident in each AHS and are delivered in accordance with the SWISH program guidelines. The SWISH program offered to infants is fully integrated and highly coordinated with a clearly connected pathway from initial screen through to the point that infants are referred to early intervention services. The service models implemented by AHSs address the objectives of the program, clearly evidenced by the achievement of screening performance indicators and the high levels of satisfaction reported by the parents of the infant screened.

SCREENING

Screening is provided by either a dedicated screener or a midwife who has been trained to undertake hearing screening. Additionally, AHSs have been willing to adapt the model and trained other personnel to conduct the screens such as a Child Health Nurse or Aboriginal Health Worker, ensuring benchmark screening rates are achieved and exceeded.

AUDIOLOGICAL ASSESSMENT

Audiology services are provided at the three tertiary Childrens' Hospitals and this has been a strategic decision to ensure audiological assessment is carried out by personnel with a high level of expertise in paediatric audiology. A SWISH travel subsidy has been implemented to assist those parents who need to travel more than 100km for the assessment. The screening equipment was selected on the basis of minimising the number of 'false positives' that might arise in the screening process and thus limiting the number of unnecessary referrals for audiological assessment. Analysis of referral data is needed to establish whether the majority of referrals subsequently require medical assessment, or whether opportunities for alternative audiological assessment (e.g. tele-audiology) warrant further exploration.

SOCIAL WORK SERVICES

Part-time Social Work positions are available at each of the three diagnostic sites. The social workers' role has many facets including: coordinating/navigating the parents through their pathway; information provision; coordinating baby hearing clinics; general emotional support/follow up and where required counselling. The feedback gained through consultation with parents, service managers, SWISH coordinators and the social workers themselves is that the service is critical and highly valued. It is noted that the role of social workers in the program has expanded beyond the initial scope when the program was implemented. It is proposed that the current Social Work positions be further examined with respect to the scope and expectations of the role and subsequently the level and type of resources that might be required to provide an appropriate support service.

PAEDIATRIC/MEDICAL ASSESSMENT

Each of the assessment centres has established Hearing Clinics in order that paediatric and medical assessment and management of infants can occur through a multi-disciplinary approach. This facilitates a comprehensive multi-disciplinary review of the infant that is efficient both for the clinicians and the parents.

Given the better practice approach these clinics offer, it is considered that they could be reviewed to ensure that the maximum value that might arise from their operation is realised. This could include an analysis of; whether they are sufficiently resourced; what additional quality of care or learning might arise from further investment; and are better outcomes arising from the multi-disciplinary approach.

EARLY INTERVENTION

Early intervention and support services are not part of the SWISH program and are provided by a range of 'external' agencies. No significant issues were raised with respect to the referral of SWISH clients to these services.

PARENT/FAMILY SATISFACTION

A key measure for assessing the appropriateness of the SWISH program was the analysis of feedback provided by parents who are the major program stakeholder. High levels of satisfaction were reported with respect to: having relevant information related to screening; performance of the screening process including convenience and timing; and the audiological assessment. Parents were generally satisfied with the level of support from the social work service but a number noted it was insufficient to meet their needs.

PROGRAM INFORMATION SYSTEM

The key to efficiently monitoring the performance of the SWISH program against international and the programs own benchmarks is a comprehensive and integrated information system. Whilst a spreadsheet system for reporting program data from the AHS to the Department currently exists, it is inefficient and subject to data quality and integrity issues. This was evidenced by some difficulty experienced in the process of data analysis for the evaluation. All stakeholders interviewed agreed that it was essential to implement a comprehensive statewide monitoring and evaluation system to support the operations of the SWISH program. The priority areas for consideration in the development of this system include the provision of:

- A capability to trace babies through pathways from birth, initial screen to follow up to audiological assessment to re-referrals is required.
- Data analysis to support ongoing quality improvement process.
- An integrated system to support benchmarking, trends and longitudinal analysis, quality improvement and research activities.
- A systematic process to follow-up and periodically monitor those infants who have had a 'Pass' screen but who are classified as 'At Risk'. Currently, data in relation to risk factor babies and pathways are not fed back to SWISH coordinators.

Whilst it is understood that the Department has commenced a process to procure an appropriate SWISH information system, it is the view of the evaluation team that addressing the requirements for an integrated state-wide management information system for the SWISH program is of a high priority.

E.3.2 EFFECTIVENESS OF THE SWISH PROGRAM

KEY PERFORMANCE INDICATORS

As noted earlier, the primary objective of a Hearing Screening program is to screen at least 95% of newborn infants before 1 month of age with the intention of identifying those with significant hearing loss.

In achieving this objective, the following key performance indicators for the program are:

- Population coverage for screening is 95% of all newborn babies.
- Hearing screening is provided for each newborn by one month of age.
- Hearing diagnosis is provided for newborns identified with hearing loss through screening by three months of age.
- Intervention programs are commenced for babies identified with hearing loss through diagnosis by six months of age.

The existing program information system is not date driven and hence it is not possible to assess whether the programs key performance indicators meet the timing requirements stipulated. However, some internal auditing processes have concluded that these timing parameters are being met.

The following illustrates the performance of the NSW SWISH program against the key performance indicators:

- Overall screening rate has consistently met the benchmark of 95% each financial year since 2003/04.
- Since 2006/07, all AHSs exceeded the benchmark of 95% and the overall rate has consistently been greater than 99%.
- The percentage of declined screens was 0.2% in 2008/09.
- The number of infants diagnosed with a permanent Bilateral hearing loss (> 40dB in the better ear) per 1000 births ranged between 0.89 and 1.06 (2006/07 - 2009/10) which is favourably comparable with similar developed countries.

WORKFORCE

Screening staff levels have remained static from the inception of the program. Given the growth in the number of live births, many of the SWISH coordinators reported that additional resources for extended hours during the week, weekends and public holidays are needed.

The Audiology workforce is on the whole sufficient to meet current demand. Succession planning is necessary to ensure that appropriately qualified audiologists with expertise in assessing infants are available to the program in the future.

As has been discussed, the issue of social work resources has been raised by the social workers, other SWISH personnel, and the parent group. Given this, the current social worker role should be analysed to ensure the range of tasks are allocated to the appropriate position/role. This analysis should also identify any potential 'role creep' that may have evolved over the course of the program.

E.3.3 EFFICIENCY OF THE SWISH PROGRAM

From 2003/04 to 2008/09 the number of births in NSW has increased by approximately 10%. The SWISH program has been able to maintain a screening rate of over 95% during this period of a considerable increase in the birth rate. This indicates that there have been efficiency gains within the program. The efficiency gain is likely to be associated with increased competence of screeners over time.

The SWISH program has been well resourced with respect to screening equipment from the commencement of the program. The Department has completed a tender process to upgrade the screening equipment. All sites are using Algo equipment. This has improved efficiency by reducing screen time as Algo equipment screens the left and right ears simultaneously.

E.4 OPPORTUNITIES FOR IMPROVEMENT

The evaluators and reference group identified a number of opportunities for improving the operational effectiveness of the SWISH program, including:

- Procurement and implementation of a management information system, to enable monitoring and reporting of the program against local, national and international benchmarks.
- Enhancement of SWISH funding to take into account increases in birth rate and consumable costs.
- Further review of existing SWISH social work services to determine the appropriate program and human resource requirements.
- Further development of linkages between stages of the SWISH pathways, and partnerships with other related organisations.

- Consideration of the establishment of a SWISH Quality Management Reference Group to oversee the establishment, implementation and ongoing development of program monitoring.
- Further review of the current diagnostic audiology workload with the objective of recommending opportunities for service improvement for example consideration of using teleaudiology technology to improve accessibility for rural and remote consumers.

E.5 SUMMARY

NSW Health was an Australian leader in establishing and implementing a universal newborn hearing screening program in December 2002, with the objective of identifying all babies born in NSW with significant permanent bilateral hearing loss through universal newborn hearing screening.

It has utilised the Joint Committee on Infant Hearing (JCIH) 2000 and subsequently 2007 position statements to provide a benchmark for the program. In respect to meeting the programs key performance indicators, analysis of the program data and consultation with stakeholders including parents/families illustrates it has been able to achieve high screening, diagnosis and referral rates. Demonstrating this on a consistent basis would be enhanced by the introduction of a program information system.

There is evidence of significant commitment by all personnel working within the program. The SWISH coordinators in particular are to be commended for playing a pivotal role in managing the program.

The excellent screening rates and early intervention are the result of significant staff commitment to establishing and ongoing management of the program.

INTRODUCTION

The NSW Department of Health (the Department) appointed Health Outcomes International (HOI) on 3 July 2009 to assist the Primary Health and Community Partnerships Branch to conduct an evaluation of the NSW Health Statewide Infant Screening –Hearing (SWISH) program.

1.1 PROGRAM CONTEXT

According to the American Academy of Paediatrics significant permanent bilateral hearing loss occurs in 1%-3% of every 1,000 live births⁴. Significant hearing loss is defined as being greater than 40dB in the better ear.

The SWISH Program is an early hearing loss detection and intervention program for infants born or residing in NSW. Early diagnosis of children with significant permanent hearing impairment coupled with appropriate intervention strategies can lead to greatly improved health, educational and social outcomes for these children.

1.2 EVALUATION TERMS OF REFERENCE

The terms of reference (objectives) for the evaluation as agreed with the NSW Department of Health were to:

- Develop a monitoring system, tools and recommendations to conduct ongoing management and reporting of all aspects of the SWISH program. This monitoring system should incorporate existing data sets.
- Evaluate the appropriateness, effectiveness and efficiency of the SWISH program in meeting the performance indicators and international benchmarks for newborn hearing screening programs. These include:
 - Population coverage is 95% of newborn babies
 - Hearing screening is provided for each newborn by one month
 - Hearing diagnosis is provided for newborns identified through screening by three months
 - Intervention is commenced for babies identified through diagnosis by 6 months
- Evaluate processes including
 - Management:
 - review and evaluate the management and coordination of the SWISH program, activities and resources within each Area Health Service
 - review and evaluate training and development of staff employed in the SWISH program

4 American Academy of Paediatrics (1999) "Newborn and Infant Hearing Loss: Detection and Intervention". Paediatrics. Volume 103, Issue 2, p257. 1999.

- review and evaluate quality improvement processes currently used in the program
- Satisfaction of parents/families
- Referral:
 - The referral processes for babies who have been identified as requiring diagnostic assessment, both bilaterally and unilaterally.
 - Data items required to monitor referral timeframes, diagnosis and subsequent referral into early intervention programs and to Australian Hearing.
- Service networks

1.3 EVALUATION METHODOLOGY

The methodology that was agreed with the NSW Department of Health comprised of seven (7) stages as set out below.

Stage 1: Project Planning	HOI met with representatives of the Department to receive an initial project briefing and finalise the parameters for the evaluation. The discussion established the project management and communication processes, arranged the transfer of the relevant documentation to HOI, finalised the process for consulting with the relevant stakeholders involved in the program and developed a list of key stakeholders.
Stage 2: Situation Analysis	HOI prepared a situation analysis paper for the Department. As part of developing the situation analysis HOI analysed the implementation and achievement of the SWISH program and conducted preliminary stakeholder consultations. The information collected was a key input into the development of a comprehensive evaluation framework.
Stage 3: Evaluation Framework	HOI developed a detailed evaluation framework that was used to guide the consultation and data collection activities. The framework was presented to the Department and the evaluation Technical Reference Group (TRG) for review and comment. During this stage an ethics application was prepared and submitted to the Human Research Ethics Committee for consideration. The conclusion of the HREC was that an Ethics Application was not required for this research project.
Stage 4: Data collection and analysis	HOI conducted a desk top analysis of SWISH program data over the last 5 years with a focus on assessing the extent to which the program performance indicators were being achieved by AHSs implementing the program. During this stage HOI conducted a review of similar international program monitoring systems and prepared a discussion paper that described options for the implementation of a future state-wide monitoring system. At the conclusion of this stage a progress report was also prepared and submitted to the Department for acceptance.
Stage 5: Case Studies	HOI conducted a comprehensive examination of the programs that had been implemented in eight AHSs through consultations with a broad range of stakeholders (service providers and consumers) involved in the NSW SWISH program to gain an understanding of the program's appropriateness, effectiveness, efficiency and opportunities for improvement. At the conclusion of this stage a case study report was prepared and presented to the Department and the TRG for review and comment.
Stage 6: Data synthesis and analysis	HOI synthesised and analysed the data collected during the course of the evaluation to assess the appropriateness, effectiveness and efficiency of the program, and the development of a monitoring system for ongoing management and reporting of all aspects of the SWISH program. A workshop discussion paper was prepared that contained the key findings. This was discussed and feedback obtained at a stakeholder workshop held on the 1 st November.



**Stage 7:
Final Report**

HOI prepared a final report (this document) that consolidated all of the findings from the consultations and data analysis and feedback from the stakeholder workshop.

1.4 STRUCTURE OF THIS REPORT

This report on HOI's findings of the evaluation of the SWISH has been structured as follows:

Chapter 2	Provides a situation analysis, including an overview of the SWISH program and contextual information on universal infant hearing screening.
Chapter 3	Presents the key themes emerging from the case studies
Chapter 4	Presents the evaluation findings with respect to the assessment of the appropriateness of the program.
Chapter 5	Presents the evaluation findings with respect to the assessment of the effectiveness of the program.
Chapter 6	Presents the evaluation findings with respect to the assessment of the efficiency of the program.
Chapter 7	Presents the opportunities for improving the future operations of the program
Chapter 8	Presents a discussion of the proposed SWISH Monitoring System



SITUATION ANALYSIS

This Chapter provides an overview of the SWISH program and contextual information on universal infant hearing screening in Australia and overseas.

2.1 SWISH PROGRAM CONTEXT

The SWISH program was implemented in December 2002 with the objective of identifying all babies born in NSW with significant permanent bilateral hearing loss through universal newborn hearing screening. Upon implementation of the SWISH program in 2002 there were 17 AHSs. Each of the 17 AHSs implemented a SWISH program. On 1 January 2005, following an organisational re-structure of NSW Health, the former seventeen NSW AHSs merged to form eight new AHS. Figures 2.1 and 2.2 illustrate the NSW AHS' as at 2002 and 2005 respectively.

The screening program is provided in both Public and Private birthing facilities throughout NSW to ensure the objective of ALL babies being screened can be achieved.

SWISH Coordinators in NCAHS, GSAHS and GWAHS undertook considerable work at the commencement of the program in particular to ensure the smooth transfer of patients who accessed services across borders in these AHS.

Figure 2.1: Pre 2005 NSW Area Health Services

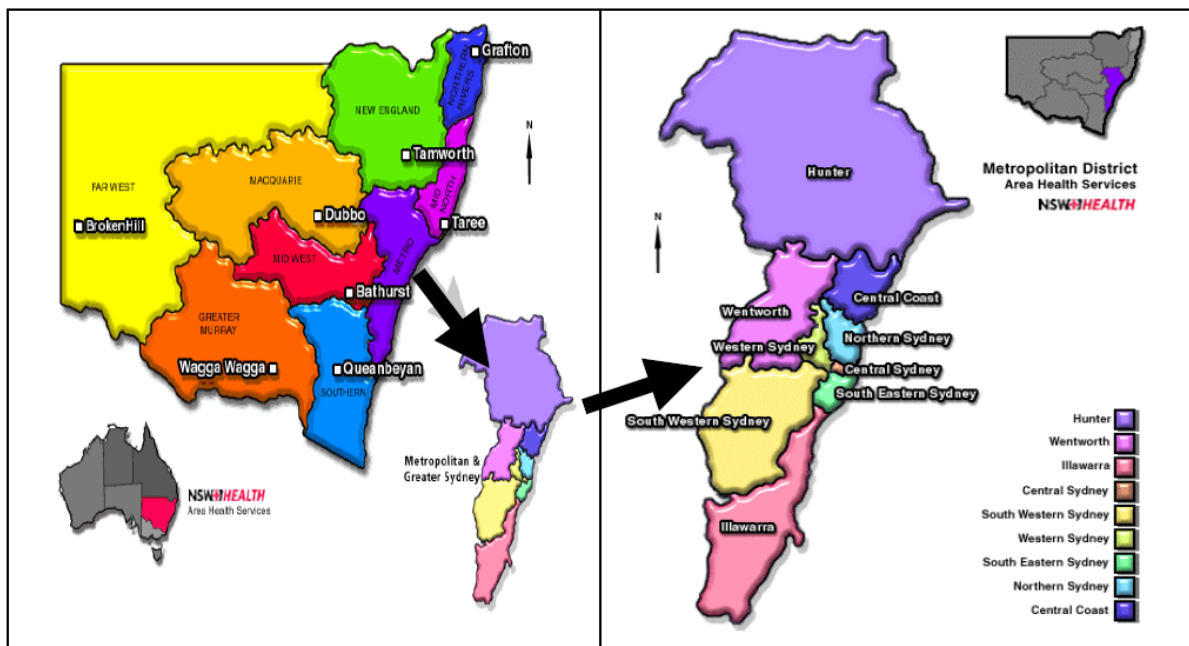
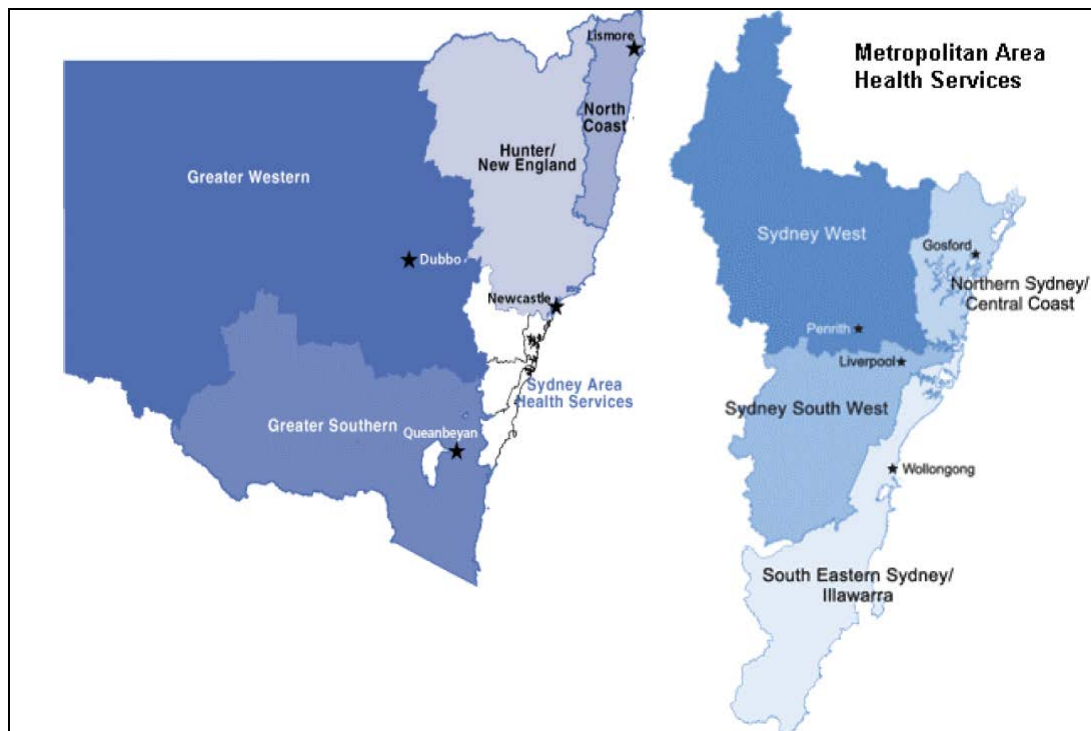


Figure 2.2: Current NSW Area Health Services



The SWISH program was designed to encompass several of the core elements and principles outlined in the Joint Committee on Infant Hearing (JCIH) 2000 position statement⁵ and the United Kingdom (UK) National Health Service Newborn Hearing Screening Program (NHSP)⁶. The core elements of the SWISH Program include:

- The Screening program
- Diagnostic audiology services utilised by SWISH
- Tertiary diagnostic services provided under SWISH including paediatric/medical assessment and parent support services
- Referral to early intervention services

Three Child Health Networks were established in NSW in 2001 to facilitate clinical networking of paediatric services: Northern Child Health Network, Greater Eastern and Southern Child Health Network and Western Child Health Network. Each of the Networks is funded by NSW Health and represents a partnership between AHSs and a Children's Hospital: John Hunter Children's Hospital, Sydney Children's Hospital and the Children's Hospital at Westmead.

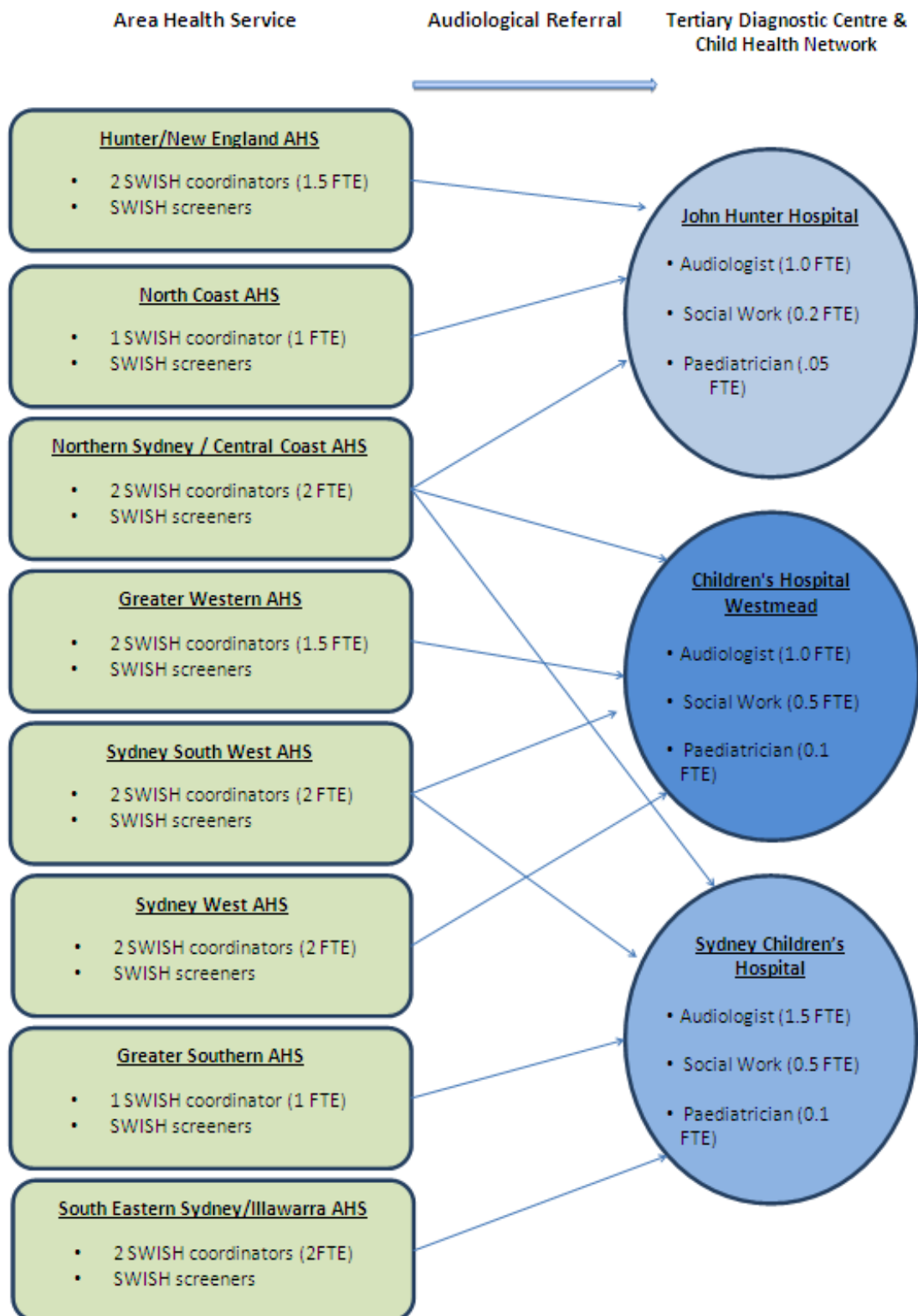
SWISH diagnostic audiology and tertiary diagnostic services are situated in each of the three NSW Child Health Networks. Overflow services can be accessed at Jim Patrick Audiology Centre at the Royal Institute for Deaf and Blind Children (RIDBC) for unilateral referrals as needed. Early in the program, Liverpool audiology services could also be accessed for children with unilateral referrals as needed, however, the service no longer receives child referrals.

Figure 2.3 overleaf illustrates at a high level the referral pathways and stakeholders involved in the SWISH program at present.

5 Joint Committee on Infant Hearing 2000 position statement <http://www.jcih.org/posstatemts.htm>

6 National Health Service Newborn Hearing Screening Program website <http://hearing.screening.nhs.uk/>

Figure 2.3: NSW Health SWISH Program



2.1.1 SWISH PROGRAM GUIDELINES

SWISH program guidelines⁷ were recently developed that outline the common requirements for each AHS to effectively deliver the SWISH Program. The guidelines provide AHSs with the flexibility to deliver the program in order to meet specific consumer needs. For example, SWISH Coordinators have adopted innovative approaches to maximise screening rates for Indigenous and culturally and linguistically diverse (CALD) populations.

The guidelines provide program staff with a standardised “operations manual” that can be referred to in order to gain a level of consistency across all AHSs with respect to:

- The Screening pathway
- Referral for audiological assessments
- Referral for paediatric medical assistance
- Staff roles and responsibilities
- Equipment use in screening
- Access to parent support services
- The SWISH travel assistance program

The guidelines were a key input into the formulation of the evaluation framework and were used as the evidence base for undertaking the preliminary assessment of the appropriateness of SWISH services which is discussed further in chapter 4.

2.2 THE SCREENING PROGRAM

The SWISH screening program uses a two stage Automated ABR screening model. This means that if a refer result is obtained for the initial screen, a second screen is undertaken to confirm the results of the initial screen. If newborns receive a refer result in the second stage of screening they are referred for a diagnostic audiological assessment.

As outlined in the guidelines, the two stage Automated ABR screening model has two screening pathways; one for a well baby and one for a Neonatal Intensive Care Unit (NICU) baby. The rationale for having two screening pathways is that NICU babies have a higher risk of auditory neuropathy or other neurological problems that are more likely to be identified by Automated ABR. In both pathways all screens are conducted by competently trained screeners on well babies (medically stable baby) between birth and one month of age (corrected age). Screening can however be done on a baby up to six months (corrected age) using physiological assessment technology in accordance with the equipment manufacturer’s instructions.

2.3 INFANT SCREENING PATHWAYS

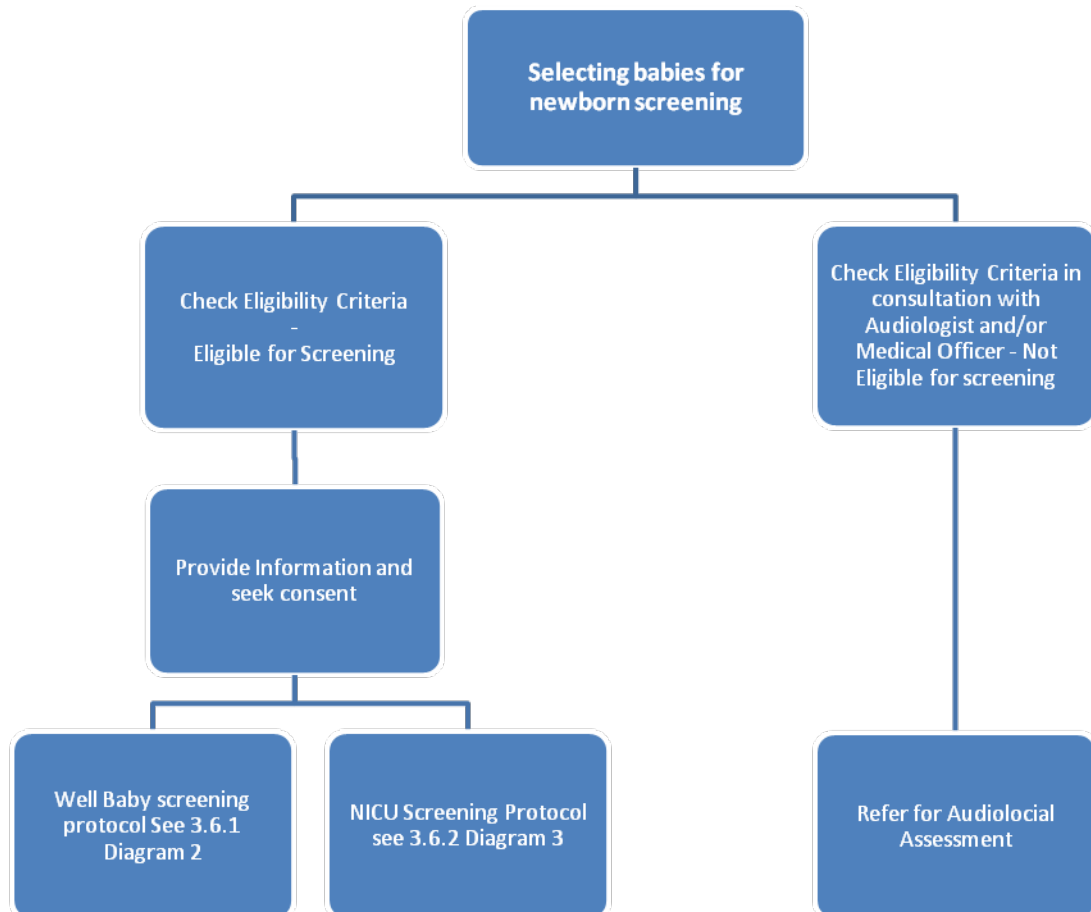
The SWISH guidelines illustrate how the infant’s eligibility for screening either as a well baby or NICU baby is determined. These guidelines have been utilised by SWISH Coordinators for the purposes of program implementation.

7 NSW Department of Health (February 2010) “Guidelines of the Statewide Infant Screening - Hearing (SWISH) Program”
http://www.health.nsw.gov.au/policies/gl/2010/pdf/GL2010_002.pdf

2.3.1 SELECTION OF BABIES FOR SWISH SCREENING

Figure 2.4 below depicts the pathway for infants' eligibility for SWISH screening and the consideration of risk factors in determining which screening pathway.

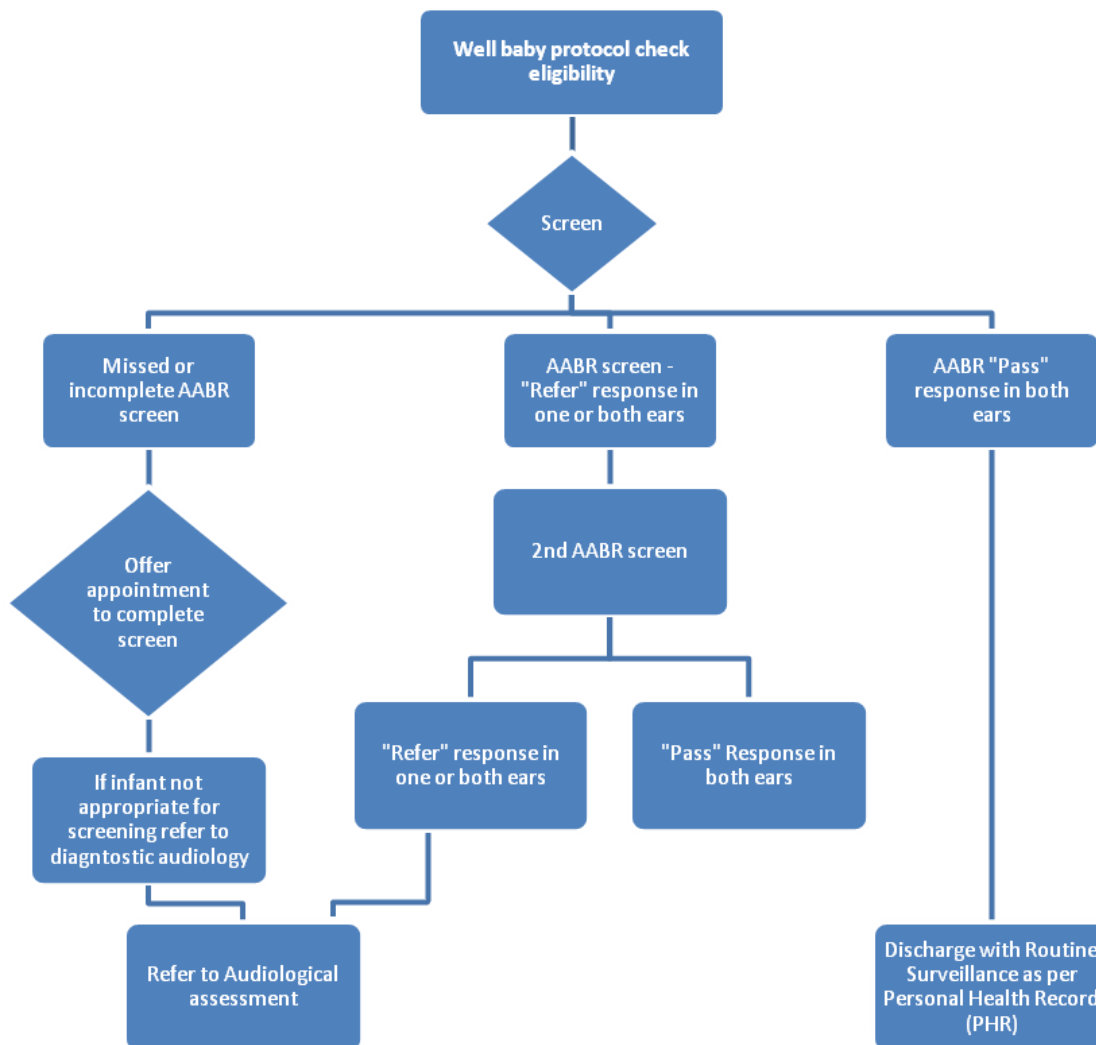
Figure 2.4: Selection of Babies for SWISH Screening



2.3.2 WELL BABY SCREENING PATHWAY

Figure 2.5 below illustrates the protocol for screening for well babies or infants who have not been resident in the NICU for more than 48 hours continuously. In addition, the protocol applies to well baby screening in hospital and community based services.

Figure 2.5: Well Baby Screening Pathway



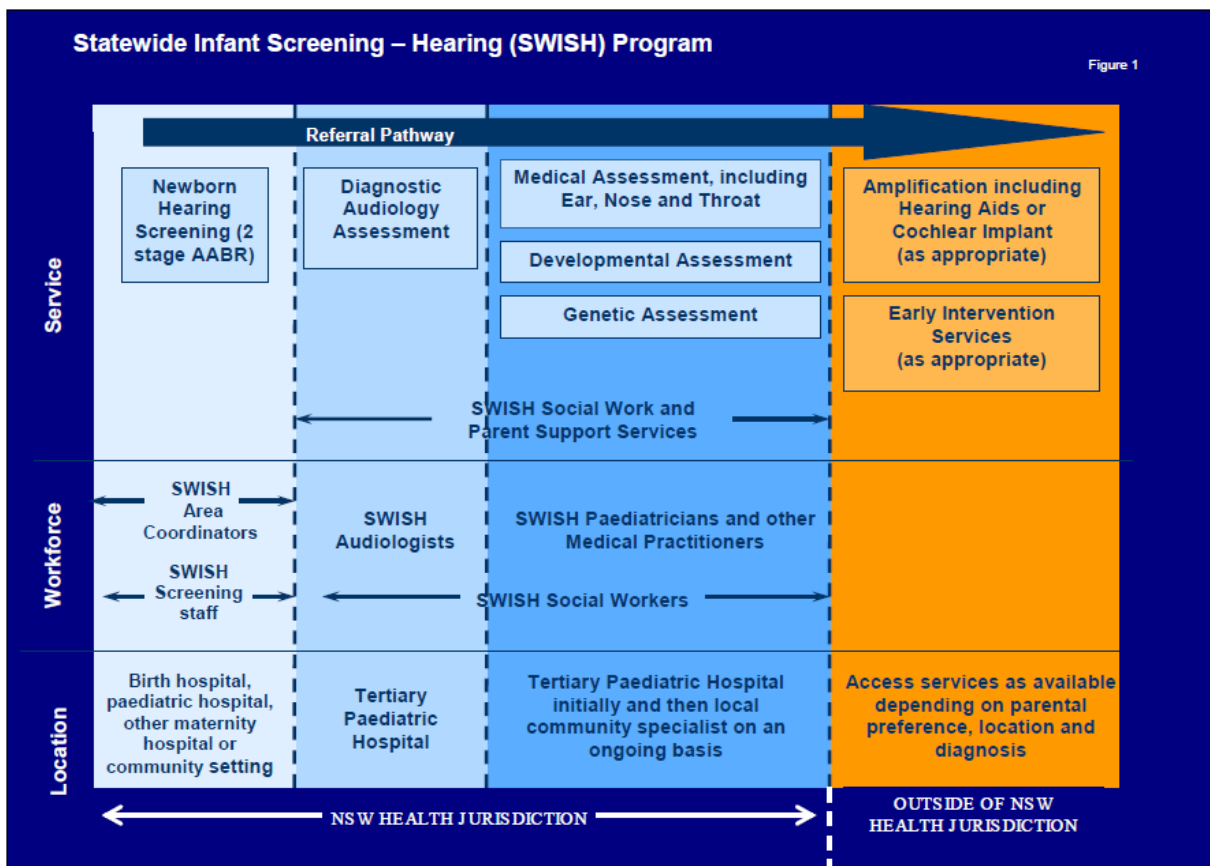
2.4 INFANT REFERRAL PATHWAY

Where a referral is indicated by the Automated ABR screening process, referrals for diagnostic audiological assessments are made to one of three tertiary paediatric hospital audiology units at:

- The Children’s Hospital at Westmead
- Sydney Children’s Hospital, Randwick
- John Hunter Children’s Hospital in Newcastle

Figure 2.6 below provides a diagrammatic summary of the SWISH referral pathway.

Figure 2.6: SWISH Referral Pathway



2.5 ROLES AND RESPONSIBILITIES OF PROGRAM STAFF

As previously discussed, the SWISH program has been implemented by all AHSs and comprises core staff that is integral to the delivery of screening services. Table 2.1 provides a summary of the roles and responsibilities of staff involved in delivering SWISH program services.

Table 2.1: SWISH Program Staff - Roles and Responsibilities

Core Personnel	Responsibilities
SWISH Coordinator	<ul style="list-style-type: none"> • Human resource management (screeners) • Quality assurance • Budget management • Performance reviews • Staff recruitment • Liaison with and referral to audiology services
SWISH Screeners	<ul style="list-style-type: none"> • Screening of infants
SWISH Paediatricians	<ul style="list-style-type: none"> • Medical assessment of babies who are referred on from the SWISH program
SWISH Audiologists	<ul style="list-style-type: none"> • Audiological assessment • Referral for medical management • Determine if screening is appropriate for a NICU baby (in conjunction with paediatrician)
SWISH Social Workers	<ul style="list-style-type: none"> • Provide counselling and resources to families • Support parents of infants diagnosed with hearing impairments and help them access services

2.6 JOINT COMMITTEE ON INFANT HEARING (JCIH)

The JCIH⁸ was established in the United States of America in late 1969 and is composed of representatives from audiology, otolaryngology, paediatrics, and nursing. It was established with the purpose of making recommendations concerning the early identification of children with, or at-risk for hearing loss and newborn hearing screening. Subsequently, the Committee's primary activity has been publication of position statements summarising the state of the science and art in infant hearing, and recommending the preferred practice in early identification and appropriate intervention of newborns and infants at risk for or with hearing loss. The committee is regarded as an international leader in driving global initiatives in relation to infant hearing. In this respect it is regarded as providing an international standard or benchmark for infant hearing screening programs.

The JCIH 2007 position statement⁹ outlines eight principles that provide the foundation for implementing and maintaining an effective Early Hearing Detection and Intervention (EHDI) program.

Understandably, health departments/services internationally and within Australia use the JCIH principles as the basis for the establishment of their UNHS programs. This includes NSW Health.

2.6.1 THE EIGHT JCIH PRINCIPLES

The following outlines the eight principles contained within the JCIH 2007 position statement with respect to an appropriate EHDI program.

⁸ JCIH website <http://www.jcih.org>

⁹ Joint Committee on Infant Hearing (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. <http://pediatrics.aappublications.org/cgi/content/full/120/4/898?ikey=oj9BAleq21OIA&keytype=ref&siteid=aapjournals#SECA>.



Principle 1:	All infants should have access to hearing screening using a physiologic measure at no later than 1 month of age.
Principle 2:	All infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than 3 months of age.
Principle 3:	All infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than 6 months of age. A simplified, single point of entry into an intervention system that is appropriate for children with hearing loss is optimal.
Principle 4:	The EHDI system should be family centred with infant and family rights and privacy guaranteed through informed choice, shared decision-making, and parental consent in accordance with state and federal guidelines. Families should have access to information about all intervention and treatment options and counselling regarding hearing loss.
Principle 5:	The child and family should have immediate access to high-quality technology including hearing aids, cochlear implants, and other assistive devices when appropriate.
Principle 6:	All infants and children should be monitored for hearing loss in the medical home. Continued assessment of communication development should be provided by appropriate professionals to all children with or without risk indicators for hearing loss.
Principle 7:	Appropriate interdisciplinary intervention programs for infants with hearing loss and their families should be provided by professionals who are knowledgeable about childhood hearing loss. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.
Principle 8:	Information systems should be designed and implemented to interface with electronic health charts and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels.

2.6.2 COMPARISON OF SWISH STANDARDS WITH JCIH QUALITY INDICATORS

NSW Health has developed SWISH program guidelines¹⁰ that encompass the protocols and procedures for the program. The guidelines in many respects mirror the JCIH 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. The SWISH program guidelines include:

- protocols for screening, coordination, audiological assessment and paediatric medical assessment
- referral pathways
- a description of the roles and responsibilities of staff
- equipment used

Table 2.2 presents the comparative analysis of the SWISH program standards relative to the JCIH quality indicators.

Table 2.1: Comparative Analysis of SWISH Program Standards with JCIH Quality Indicators

Performance Benchmark	JCIH Quality Indicators	SWISH Program Standards
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10 NSW Department of Health (2010) "Guidelines Statewide Infant Screening - Hearing (SWISH) Program" http://mhcs.health.nsw.gov.au/policies/gl/2010/pdf/GL2010_002.pdf



Performance Benchmark	JCIH Quality Indicators	SWISH Program Standards
Screening	>95% of all newborn infants complete screening by 1 month of age	95% of newborn screening should be completed by 1 month of age Infants can be screened up until three months of age if they are not well enough until this time.
	<4% of all newborn infants who fail initial screening and fail any subsequent rescreening before referral for comprehensive audiological evaluation	All newborns who fail initial screening and subsequent rescreening are referred for audiological evaluation immediately upon receiving the results The appointment for audiological evaluation is made within three weeks of completing the screen
Confirmation of hearing loss	>90% of infants who fail initial screening and any subsequent rescreening, complete a comprehensive audiological evaluation by 3 months of age	Infants referred for audiological assessment within 3 weeks of failed screening Performance indicator is for diagnosis of hearing impairment to be confirmed by three months of age
	>95% of infants with confirmed bilateral hearing loss receive amplification devices within 1 month of confirmation of hearing loss	Early Intervention and Amplification services (such as device fitting and management and habilitation) are outside of the SWISH program
Early intervention	>90% of infants with confirmed hearing loss who qualify for Part C services, the percentage for whom parents have signed an IFSP be no later than 6 months of age	Not applicable
	>95% of children with acquired or late-identified hearing loss, the percentage for whom parents have signed an IFSP within 45 days of the diagnosis	Infants who pass SWISH AABR screening, but at the time of screening are identified as having hearing risk factors, should receive ongoing monitoring of their hearing status All infants with a risk indicator for hearing loss, regardless of surveillance findings, are referred for an audiological assessment at least once by 24 to 30 months of age.
	>90% of infants with confirmed hearing loss who receive the first developmental assessment with the standardised assessment protocols for language, speech, and nonverbal cognitive development by no later than 12 months of age	If an infant does not pass the speech-language portion of the global screening in the medical home or if there is physician or caregiver concern about hearing or spoken-language development, the child should be referred immediately for further evaluation by an audiologist and a speech-language pathologist for a speech and language evaluation with validated tools All infants with a risk indicator for hearing loss, regardless of surveillance findings, should be referred for an audiological assessment at least once by 24 to 30 months of age



KEY THEMES EMERGING FROM CASE STUDIES

This Chapter presents an assessment of the key themes that were identified by stakeholders during the conduct of the case studies.

3.1 CONSISTENCY WITH BEST PRACTICE

The time period between announcement and commencement of the SWISH program was extremely short and described as a demanding process by those who were involved in the implementation. AHSs had significant flexibility to design the program in accordance with local requirements. This has resulted in structural differences in the design of the SWISH program from each AHS.

Despite these differences the fundamentals of a universal newborn hearing screening program is evident in each AHS. The SWISH program offered to infants is fully integrated and highly coordinated with a clearly connected pathway from initial screen through to early intervention. The service model is based on evidence based best practice principles in accordance with Joint Committee of Infant Hearing international guidelines¹¹ namely that all programs offer:

- Access to hearing screening using a physiologic measure before 1 month of age;
- Those babies who do not pass the initial hearing screen and the subsequent rescreening referral for appropriate audiological and medical assessment to confirm the presence of hearing loss before 3 months of age;
- Infants with confirmed permanent hearing loss referral to intervention services before 6 months of age; and
- Results of hearing diagnosis and consultations are provided to the families' GPs.

The service models implemented by AHSs address the objectives of the program, clearly evidenced by the achievement of screening performance indicators. In addition, the parents of infants screened reported high levels of satisfaction with the service provided.

3.2 SWISH MODEL DESIGN

Screening is provided by either a dedicated screener or a midwife who has been trained to undertake hearing screening. The balance between dedicated screeners and midwives varies from AHS to AHS and is dictated by the particular service delivery structure and geography of each AHS. AHSs have also been willing to adapt the service model in response to changes within the respective AHS. For instance, the closure of birthing facilities in certain communities is a good example of situations where the delivery of the SWISH program has been modified.

11 Joint Committee on Infant Hearing (2007). Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs.
<http://pediatrics.aappublications.org/cgi/content/full/120/4/898?ijkey=oj9BAIeq210IA&keytype=ref&siteid=aapjournals#SEC4>.

Factors such as the reducing length of stay post birth, a shift to birthing outside of government facilities and meeting the needs of Aboriginal populations have all been responded to by the SWISH Coordinators. The SWISH program coordinators appear to be highly focussed on achieving benchmark screening rates and are constantly open to adapting the model to ensure these are maintained and improved.

Audiology services are provided through three sites; Sydney Children's Hospital, Randwick, The Children's Hospital at Westmead, Westmead and John Hunter Children's Hospital in Newcastle. These centralised services are on the whole appropriate to meeting the needs of parents, however it does provide challenges for those who need to travel great distances to undertake audiological testing. Given only one in four infants referred to audiology are diagnosed, opportunities for alternate models of audiological services such as mobile or remote services are worthy of exploration (see Section 7 'Opportunities for Improvement'). It is noted however that referrals for diagnostic assessment have facilitated identification of conditions other than those which SWISH was designed to detect, including unilateral and mild hearing loss as well as severe medical conditions.

The initial aim of newborn hearing screening programs was to identify children with significant permanent bilateral hearing loss however the scope of the SWISH program has since changed somewhat. This is due to increasing evidence that unilateral, conductive and mild hearing losses may develop into bilateral hearing loss, or facilitate the identification of more significant medical conditions such as retrocochlear hearing loss caused by a tumour. Advances in hearing technology, appropriate counselling and monitoring of children with mild, unilateral or conductive loss also contribute to better long term outcomes for these children.

Paediatric medical and social work services are likewise based in these three major sites and this is considered to be appropriate given the specialised nature of the services and the associated diagnostics required.

3.3 KEY PERFORMANCE INDICATORS

The effectiveness of the SWISH program is best assessed in terms of the extent to which the program has achieved desired impacts in accordance with the specified KPIs. The SWISH program has been based on the benchmarks established by the Joint Committee on Infant Hearing.

In this respect the SWISH program has been highly effective in achieving and exceeding the benchmark of screening 95% of the total number of live births. Where data was provided, this was illustrated to be the case across every birthing centre within an AHS and was not below the benchmark in centres where a dedicated screener was not used for screening.

3.4 PARENT SATISFACTION

A further measure of the effectiveness of the SWISH program can be measured by the extent to which the program met the needs of parents. In summary, parent's perceptions of the service included:

- Overall a high level of parent satisfaction with the efforts taken by screeners to explain the screening process and the timing of the screening process;
- Parents were satisfied with the provision of information relating to the screening process and were made aware of who they can contact should they have any further questions after the SWISH screen was carried out;
- Parents with high risk family histories for hearing loss felt that additional information should be provided;
- Parents indicated that they had a positive experience with the audiology diagnostic process; and
- Additional social support services were needed both during second screening and at the time of diagnosis.

3.5 LINKAGES BETWEEN THE VARIOUS SERVICE PROVIDERS

On the whole service providers reported effective linkages between the various service providers along the screening pathway. They reported that the system of referral and communication works effectively.

Minor concern was expressed in relation to communication between audiology and SWISH coordinators when no hearing loss was detected in babies who attended audiological assessment. This is assumed to be a workload issue.

Additionally, some concern was expressed in relation to the responsiveness of Australian Hearing following diagnosis.

3.6 WORKFORCE

As discussed above in relation to the service model, the AHSs have recruited a balance of dedicated screeners and midwives (employed by hospitals) to provide the core screening service. This has been amended as required to ensure the effectiveness of the program. Other personnel engaged to conduct screening to ensure the effectiveness of the program include child and family health nurses and Aboriginal Health workers.

A range of training has been provided to ensure both initial and refresher training is provided to screeners. This includes a combination of both written material and practical training.

3.7 DATA REPORTING AND MONITORING PROCESSES

The following emergent themes related to date were highlighted by stakeholders during the case study consultations:

1. **Current data collection approaches.** AHSs collected the required data elements in accordance with the guidelines, and these were reported to NSW Health for analysis. This process involves coordinators inputting data into excel spreadsheets.
2. **Statewide information management and reporting** The processes for collecting, analysing and reporting screening data at a statewide level have been highlighted through the evaluation as an area for improvement. This shortcoming has been recognised by NSW Health who are currently preparing to procure a database system. Various AHSs demonstrate a strong commitment to the existing data collection and reporting procedures and indeed have expressed a strong desire for a statewide system.
3. **Research activities.** It was interesting that a small number of SWISH coordinators are utilising data for specific research processes. This is exemplified by analysis of the screening rate of Aboriginal infants in one specific service where screening was prioritised for this group. This data analysis process informed strategies which achieved improvements in screening rates.
4. **Need for ongoing service monitoring and evaluation.** One of the key issues that engendered a lot of interest was the lack of a comprehensive information management database capable of enabling ongoing patient monitoring and service evaluation. The key area of concern related to the inability to monitor infants 'At Risk' of hearing loss who have the potential to slip through the cracks of the system undetected.
5. **Consider interstate management systems.** Stakeholders also identified that Victoria and Queensland had implemented effective data management systems for infant hearing screening programs that have the functionality to support operational, trend and benchmark analysis. It was suggested that these systems should be reviewed to ascertain their utility to SWISH.

3.8 ISSUES RELATING TO RESOURCE ALLOCATION

It is our understanding that services have not received any growth in funding for screening since the inception of the SWISH program. Despite this, screening rates have increased over the same time period. This efficiency gain is likely to be associated with increased competence of screeners over time and an ongoing review of the program structure to ensure the service continues to be both effective and efficient.

The rebalancing of the workforce to maximise the screening process as required, exemplifies the efficiency of the program. The program has also proved to be efficient through the sharing of resources with existing or new programs operating within the AHS. The STEPS program provides one example.

The main cost pressures of the program have been attributed to:

- Increased birth rates leading to increased screening activity without adjustment in funding levels;
- Inability to fill vacant positions for screeners
- Increasing cost of consumables

3.9 MONITORING OF RISK FACTORS

Parents of newborns are interviewed by screeners at the time of the newborn hearing screen to identify risk factors for post-natal hearing loss. 'At risk' children are offered audiological testing at 9 months of age. This system depends on parent's awareness and disclosure of these risk factors, as well as their attendance at the follow-up procedure. All parents are provided with a list of behavioural milestones to assess whether their child is progressing normally, and are advised to seek professional help if they are ever concerned about their child's hearing.

Referral pathways for infants who pass SWISH to access diagnostic and early intervention services later as needed are essential. In particular, the awareness of General Practitioners and Paediatricians of such services is key in ensuring that progressive hearing losses appearing after SWISH screening can be identified and managed at the earliest opportunity.

It is essential that in the future the SWISH programs monitoring and evaluation system will take account of the risk factors and opportunities to link neonatal screening databases with those of other childhood hearing support networks. This information base would support the evaluation of the effectiveness of current practices and determine the need for improved or additional screening and diagnostic procedures.

There is a need for more research to identify the risk factors that have a significant yield of progressive hearing loss to determine how much and what kind of follow up is required for at risk children. This has been the subject of a literature review published by SWISH staff at the Sydney Children's Hospital.

3.10 ORIENTATION AND TRAINING PROGRAM

SWISH Coordinators provide orientation and training for SWISH screening staff which includes education in the following areas:

- An overview of the anatomy and physiology of the ear.
- The history of the SWISH program from commencement in December 2002 to the present time, including an overview of the implementation of universal newborn hearing screening programs in other states.

SWISH Coordinators have developed comprehensive manuals outlining the selection of babies for screening, screening preparation, screening process, infection control procedures and use of the screening equipment for reference by screeners as needed. Such manuals are an excellent resource at time when more experienced screeners or the Coordinator are not immediately available to respond to questions.

Screeners are also provided with training around the completion of documentation, which includes:

- An overview of the role and importance of medical records and of recording medical record numbers accurately
- Printing the bed lists and using this document to ascertain which babies need to be screened on that date
- Completing and understanding the SWISH Report form which is filed in the baby's medical record
- An overview of the NSW Personal Health Record and the importance of recording the SWISH screen results in this Record

SWISH Coordinators may also organise additional training for screeners, which have proven to be a highlight for participants and typically include:

- Program updates including: audit results of documentation, satisfaction surveys, screening procedures, sharing of knowledge and networking with other screeners;
- Special speakers such as experts in hearing loss and parents of children diagnosed with hearing loss as a result of the SWISH program.
- Field trips to Australian Hearing and the Shepherd Centre for example.



ASSESSMENT OF APPROPRIATENESS OF THE SWISH PROGRAM

This chapter presents HOI's evaluation findings with respect to the assessment of the appropriateness of the SWISH program in terms of the following parameters:

- Consistency with international best practice
- SWISH program model design
- Management of data
- Program Leadership
- Client satisfaction

4.1 CONSISTENCY WITH INTERNATIONAL BEST PRACTICE

The Joint Committee on Infant Hearing (JCIH) 2007 position statement is considered the most appropriate benchmark for assessing the NSW SWISH program for consistency with international best practice in universal newborn hearing screening. As discussed in Chapter 2, the JCIH 2007 position statement outlines eight principles that provide the foundation for implementing and maintaining an effective Early Hearing Detection and Intervention (EHDI) program.

The NSW SWISH program largely meets the JCIH principles particularly with respect to screening, assessment, referral to early intervention and being family centred. The exception lies in the existence of appropriate information systems for reporting which is discussed both in this and Chapter 5. Additionally, it is our understanding this issue is currently being addressed by the NSW Department of Health.

4.2 SWISH PROGRAM MODEL DESIGN

As highlighted previously, the time period between announcement and commencement of the SWISH program was extremely short and described as a demanding process.

This provided AHSs with significant flexibility to design the program in accordance with local requirements. This resulted in structural differences in the design of the SWISH program across AHSs.

Despite these differences the fundamentals of a universal newborn hearing screening program is evident in each AHS and is consistent with the SWISH program guidelines. The SWISH program offered to infants is fully integrated and highly coordinated with a clearly connected pathway from initial screen through to the point that infants are referred to Australian Hearing and early intervention services. The service models implemented by AHSs address the objectives of the program, clearly evidenced by the achievement of screening performance indicators and the high levels of satisfaction reported by the parents of the infant screened.

4.2.1 SCREENING

Screening is provided by either a dedicated screener or a midwife who has been trained to undertake hearing screening. The balance between dedicated screeners and midwives varies from AHS to AHS and is dictated by the particular service delivery structure and geography of each AHS. AHSs have also been willing to adapt the service model in response to changes within the respective AHS.

Likewise, factors such as increasingly reducing length of stay post birth, a shift to birthing outside of public hospitals and meeting the needs of Aboriginal populations have all been responded to with changes to the service model design to ensure a greater level of appropriateness. This has included introducing other personnel to conduct the screens (other than dedicated screeners and midwives) such as a Child Health Nurse or Aboriginal Health Worker. It was our observation through the analysis of screening data and discussions with SWISH coordinators and screeners that they are highly focussed and motivated to achieve benchmark screening rates. On this basis they are constantly open to adapting the model to ensure these outcomes are maintained and improved.

4.2.2 AUDIOLOGICAL ASSESSMENT

Audiology services are provided through three sites; Sydney Children's Hospital, Randwick, The Children's Hospital at Westmead, and John Hunter Children's Hospital in Newcastle. This was a strategic decision in the design of the SWISH program to ensure that the audiological assessment is carried out by personnel with a high level of expertise in paediatric audiology. Since the commencement of the program, the Children's Hospital at Westmead has directed overflow unilateral referrals to the Jim Patrick Audiology Centre.

As a consequence of this arrangement, a number of infants and their parent(s) are required to travel to undergo the audiological assessment and for some this can mean long distances and a couple of days away from home. To assist with this burden, a SWISH travel allowance is payable to those parents who meet the criteria of living more than 100km away from one of the three SWISH assessment facilities. Additionally, the choice of screening equipment at program inception was made on the basis of minimising the number of 'false positives' that might arise in the screening process and thus limiting the number of unnecessary referrals for audiological assessment.

The arrangement for having three 'centralised' audiology assessment services are on the whole appropriate to meeting the needs of parents, however it does provide challenges for those who need to travel great distances. Analysis of referral data is needed to establish whether the majority of referrals subsequently require medical assessment, or whether opportunities for alternative audiological assessment (e.g. tele-audiology) warrant further exploration. Such alternative arrangements are not likely to be straightforward to implement. This is discussed further in the chapter on opportunities for improvement.

4.2.3 SOCIAL WORK SERVICES

SWISH funded Social Work services are based at each of the three above-mentioned Hospitals in conjunction with the audiological assessment and paediatric medical services. The two children's hospitals are each resourced with a 0.5 FTE position whilst John Hunter is funded for 1 day per week (0.2 FTE). This does result in Social Workers not being available on each day of the week, despite screening and assessment occurring each day.

On the basis that an infant is referred through the screening process for audiological assessment and possibly medical assessment and early intervention if required, social work services are generally available to support parents in what is for most a very challenging, emotional and uncertain time.

The social workers' role has many facets including: coordinating/navigating the parents through their particular pathway; information provision; coordinating baby hearing clinics; general emotional support/follow up and where required counselling. The role has proven to be particularly important for parents from a culturally and linguistically diverse backgrounds, where it is critical to ensure that they fully appreciate the infants impairment and the need for assessment and where indicated early

intervention services. In addition, there are the necessary documentation and administrative aspects of the role to be completed.

The feedback gained through consultation with parents, service managers, SWISH coordinators and the social workers themselves is that the service is critical and highly valued.

It is our view that the resourcing of Social Work positions should be further reviewed to ensure that parents feel sufficiently supported and informed at this point in their infants care.

It is proposed that the current Social Work positions be further examined with respect to the scope and expectations of the role and subsequently the level and type of resources that might be required to provide an appropriate support service.

This issue is further discussed in Chapter 5.

4.2.4 PAEDIATRIC / MEDICAL ASSESSMENT

SWISH funded paediatric services have been established at Sydney Children's Hospital - Randwick, The Children's Hospital - Westmead, and John Hunter Children's Hospital in Newcastle.

The SWISH Social Worker arranges referral to the relevant service as required following the audiological assessment. The case studies of the AHS program models did not reveal any significant concerns with respect to accessing medical assessment for newborns.

Each of the assessment centres has established Baby Hearing Clinics in order to assess and manage infants through a multi-disciplinary approach. This facilitates a comprehensive multi-disciplinary review of the infant that is efficient both for the clinicians and the parents. The social worker provides a key intermediary role in the clinic ensuring that the parent is fully conversant with the opinions and views of the clinicians. The social worker 'case manages' any clients referred to the Hearing clinic and arranges any ongoing referral for diagnostics, follow up of results, onwards referral to Australian Hearing.

4.2.5 EARLY INTERVENTION AND SUPPORT SERVICES

As previously discussed early intervention and support services are not part of the SWISH program. These services are provided by a range of agencies 'external' to the SWISH program (refer section 5.1.2 below). In most cases the interaction of the SWISH program involves the Social Worker assisting with referral of the infant/parent through to the relevant service. In having access to this range of early intervention and support services, the principles of the 2007 JCIH position statement are being met and an appropriate model for early detection and intervention is in place. The effectiveness of these arrangements is discussed in the following chapter.

4.3 DATA COLLECTION, ANALYSIS AND REPORTING

The Department collects deidentified aggregate data on screening, referral and diagnostic services provided on a monthly basis from each coordinator and audiologist. It was our observation that there was a strong commitment across all AHSs for the collection and timely reporting of this data. It was apparent that SWISH coordinators have implemented comprehensive processes to ensure the capture of all screening data both within the AHS and for 'events' occurring outside of the area.

The screening data collected is forwarded by the SWISH coordinator to the Department on a monthly basis and subsequently uploaded into a database for the purpose of state-wide monitoring and reporting of screening rates. Ideally, this process will be superseded through the implementation of a statewide information system for the SWISH program.

In consulting with SWISH coordinators it was clear that whilst they utilise different approaches, they do go to extraordinary lengths to identify a new birth and ensure that infant has been screened. This can include looking through 2-3 different infant birth record lists for matching purposes. This would clearly be made simpler should a SWISH information system be implemented and have an interface or be integrated with a recently introduced statewide obstetric information system.

Principle 8 of the 2007 JCIH position statement notes that;

Information systems should be designed and implemented to interface with electronic health charts and should be used to measure outcomes and report the effectiveness of EHDI services at the patient, practice, community, state, and federal levels.

Currently no SWISH program information system exists in NSW that facilitates an integrated and systematic process for:

- identification of a newborn infant
- recording of the screening result
- recording of referral date/type
- analysis of the relevant outcome
- monitoring of 'at risk' and/or 'vulnerable' infants
- reporting at local, area and state level.

Additionally, it is our understanding that the current data collection process does not allow for state-wide reporting on JCHI benchmarks of:

- screening occurring by 1 month of age
- diagnosis being undertaken by 3 months of age
- intervention services being provided by 6 months of age

All stakeholders interviewed agreed that it was essential to implement a comprehensive statewide monitoring and evaluation system to support the operations of the SWISH program. The priority areas for consideration in the development of this system include the provision of:

- Data analysis to support ongoing quality improvement process;
- A capability to trace babies throughout the SWISH pathway from birth, initial screen to follow up to audiological assessment to re-referrals if required. Currently there is no formalised data linkage to monitor or inform the follow up of those infants who are referred to diagnostic audiology and then to intervention.
- An integrated system to support benchmarking, trends and longitudinal analysis and research activities;
- An effective system for the collection, analysis and reporting of client data and outcomes. There is no linkage to client's case management to enable follow-up of those infants who have received a refer result from their screen to ensure that referrals to diagnostic audiology and then to intervention have occurred and that ongoing treatment is both systematic and effective;
 - A systematic process to follow-up and periodically monitor those infants who have had a 'Pass' screen but who are classified as 'At Risk'. Currently, data in relation to risk factor babies and pathways are not fed back to SWISH coordinators;
- Data in relation to risk factor babies and pathways are not fed back to SWISH coordinators;
- The data management requirements to support the system are currently inadequate . Coordinators have utilised any administrative hours as screening hours to manage the increase in birth rates considerable amounts of time are spent entering data into local systems and in data transmission to NSW Health.

The capacity of other jurisdictions to report a comprehensive range of information, as recently presented at a National conference, was cited as evidence of what is possible and could be pursued by NSW.

It is our understanding that the Department has commenced a process to procure an appropriate SWISH information system.

It is also important to note that a small number of program coordinators are utilising data for specific research processes. This is exemplified in one service that analysed changes in screening rates following the introduction of a new protocol that would prioritise screening for Aboriginal people before 9 am. This data collection and analysis process illustrated improvements in screening rates as a result of this change in screening protocol.

4.4 PROGRAM LEADERSHIP

Coordinating leadership for the program is provided by the Community and Government Relations Unit within the Primary Health and Community Partnerships Branch of NSW Health. Operationally the program is managed at the AHS level.

Feedback from SWISH personnel highlighted that direction from and a sense of partnership with the Department of Health was evident and continuously improving. Examples included; production of the SWISH program guidelines and SWISH coordinators being invited into the tender processes for replacement equipment and procurement of a new information system.

Understandably, the reporting relationships for SWISH program staff vary across AHSs. The reporting line can be to Administrative, Hospital clinical, Allied Health or Community Health management. This variance in reporting lines does not appear to have had an impact on program outcomes, with all AHSs satisfactorily meeting the key performance indicators.

One area of concern that was raised related to the fact that the dedicated screeners did not always report to the SWISH coordinator. This arose with the AHSs moving to clusters and thus funding and screeners were reallocated to the devolved structures. Whilst not necessarily detrimental to the program outcomes, it does provide challenges for management of the program across the AHS.

Whilst recommendations could be made for the way the program is 'structured' this is likely to be overridden with the proposed implementation of Local Hospital Networks which is the cornerstone of the national health reform agenda. Principally however, it would seem logical that the person responsible for service delivery and outcomes should wherever possible have the necessary resources under their management and 'control'.

4.5 PARENT SATISFACTION

The key measure used to assess the appropriateness of the SWISH program was the analysis of feedback provided by parents who are the major program stakeholder. It seems axiomatic that in order to develop the most sensitive and responsive newborn hearing screening services, it is essential to gain an understanding of the perspectives of parents who have first-hand experience of the screening program and of those parents whose children have been diagnosed with a hearing impairment.

This section presents a thematic analysis of the perceptions and experiences of parents (involving 20 informants) with respect to the SWISH program.

4.5.1 SATISFACTION WITH THE EXPLANATION OF THE SWISH PROCESS

For the most part there was a high level of parent satisfaction with the approach taken to explain the screening process indicating that:

- SWISH screeners took the time to explain the process in plain English to the mother at the time of the screen
- Consumers reported that they were encouraged to ask questions and the screeners were both accommodating and able to answer the questions satisfactorily

4.5.2 PROVISION OF RELEVANT INFORMATION

The parents were invited to comment on their level of satisfaction with the provision of information relating to the screening process as demonstrated by the following responses:

- At the time of screen, all parents interviewed indicated they had received “the brochure” which is consistent with the SWISH guidelines
- Parents were made aware of who they could contact should they have any further questions after the SWISH screen was carried out
- Parents of infants going through the newborn hearing screening process as well as parents of children with hearing loss prefer learning about the screening process before their child's birth and want user-friendly patient education materials available
- The majority of parents interviewed reported that more information should be provided to parents as part of the ante-natal program. It was evident the dissemination of infant hearing information as part of the ante-natal education program was implemented a number of years following the commencement of the SWISH program
- Parents with high risk family histories considered additional information should be provided to support the specific information needs of these people

4.5.3 SATISFACTION WITH THE PERFORMANCE OF THE SCREENING PROCESS

Parents were invited to comment on their level of satisfaction with the performance of the screening process. The analysis of responses demonstrated there was a high level of satisfaction with the screening process. SWISH screeners were reportedly patient with the infants whilst undertaking the screen

4.5.4 EFFICIENCY OF EQUIPMENT USE

Parents were invited to comment on their perspective in relation to the confidence of the screener in using the equipment. The analysis of responses has demonstrated there was:

- A high proportion of parents considered that the SWISH screeners were confident and efficient in using the screening equipment

4.5.5 CONVENIENCE OF SCREENING TIME

Feedback was sought from parents as to whether the appointment time for screening was convenient. Our analysis of responses indicated that:

- There was a high level of satisfaction with respect to the timing of the screen

4.5.6 TIMELINESS OF SCREENING PROCESS

Comments provided by parents with respect to the timeliness of the SWISH screen indicated that:

- There was a high level of parent satisfaction with the efficiency of the screening process which required approximately 10 minutes to complete

4.5.7 AUDIOLOGY ASSESSMENT

Parents were invited to comment on their perceptions and experiences of the audiology assessment process. The findings of our analysis of responses were:

- All parents interviewed indicated that they had a positive experience with the audiology diagnostic process
- It was reported that all audiologists engaged with families and explained the process of diagnostic testing in a way that made the parents feel at ease
- A number of informants indicated that the audiologists also provided advice regarding social support to the family to ease anxiety of the overall experience
- Consumers considered that the wait time for an audiological appointment was reasonable and ranged between 1 to 4 weeks

- The audiological assessment took anywhere between ½ a day and 1 whole day depending on the nature of the infant at the time; and parents were accepting of the time required and appreciated the degree of clinical rigour that was required

4.5.8 SATISFACTION WITH SOCIAL SUPPORT SERVICES

The responses from parents with respect to their level of satisfaction with the social support services indicate that:

- A number of parents were not offered access to social support services whilst one respondent indicated that a social worker was not available at the time of referral
- There were views expressed that the social workers were not very proactive, that parents were required to initiate ongoing dialogue with social workers. (A number of parents made reference to the family support facilitators that provided support to families in the Queensland program)
- There was a high level of consensus amongst the parents interviewed regarding the need for increased support both during repeat screens and at the time of diagnosis
- Social workers need to be sensitive to the needs of parents and additional training may be required on how to communicate the findings of diagnostic results to parents, particularly at times when parents are experiencing strong emotions
- Parents need more information regarding the wearing of aids in very young children
- Some children with additional medical, developmental, and behavioural problems need specialised approaches to testing

4.5.9 OPPORTUNITIES FOR IMPROVING THE SCREENING PROGRAM

Based on the assessment of the feedback provided by parents the evaluators have identified a number of opportunities for improvement including:

- Increased access to social support services
- More proactive support with filling in the forms required for referrals
- A greater awareness of the sensitivities of families in terms of their emotional disposition which may need additional training
- The conduct of regular staff satisfaction surveys as part of the program's quality assurance processes to ensure that the SWISH program is responsive to the needs of families

Many of these issues were identified by service providers who confirmed that the program does require additional Social Work and/or more general support services such as that for completing forms, making appointments and 'navigating' the pathway.

ASSESSMENT OF THE EFFECTIVENESS OF THE SWISH PROGRAM

This Chapter presents HOI's evaluation findings with respect to the assessment of the effectiveness of the SWISH program in terms of:

- SWISH program performance against international benchmarks
- Evidence of access to all components of the model
- Evidence of effective and timely referral
- Availability of data to measure performance
- Staff Training
- Quality and parent/carer satisfaction

5.1 KEY PERFORMANCE INDICATORS

The effectiveness of the SWISH program was assessed in terms of the extent to which the program achieved desired impacts in accordance with the specified KPIs. The SWISH program has been based on the benchmarks established by the Joint Committee on Infant Hearing.

The JCIH KPI's which are specific to the effectiveness of the SWISH program are:

1. More than 95% of newborn infants complete a hearing screen by 1 month of age.
2. Less than 4% of children are referred for audiological evaluation.
3. 90% of children who need a diagnostic audiological evaluation have one before 3 months.

The following section provides a comprehensive analysis of the operation of the SWISH program and its performance against the JCIH benchmarks as well as some other performance indicators.

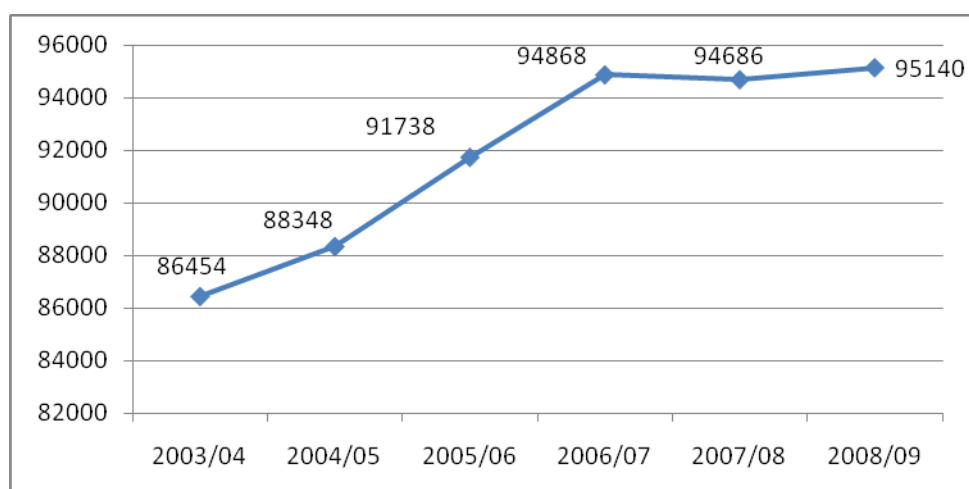
5.1.1 SCREENING

The findings of the assessment of newborn hearing screening process are presented below.

LIVE BIRTHS

Figure 5.1 overleaf presents the total number of live births in NSW each financial year from 2003/04 to 2008/09. It shows that over this period, the number of live births has grown by 10.04% from 86,454 to 95,140. This equates to over 2% annual growth in births since the beginning of the program.

Figure 5.1: Total live births, July 2003 – June 2009



SCREENING RATES

Table 5.1 presents the screening rate for each AHS by financial year from July 2003 to June 2009 and Figure 5.2 presents the overall screening rate during this period. The data shows that:

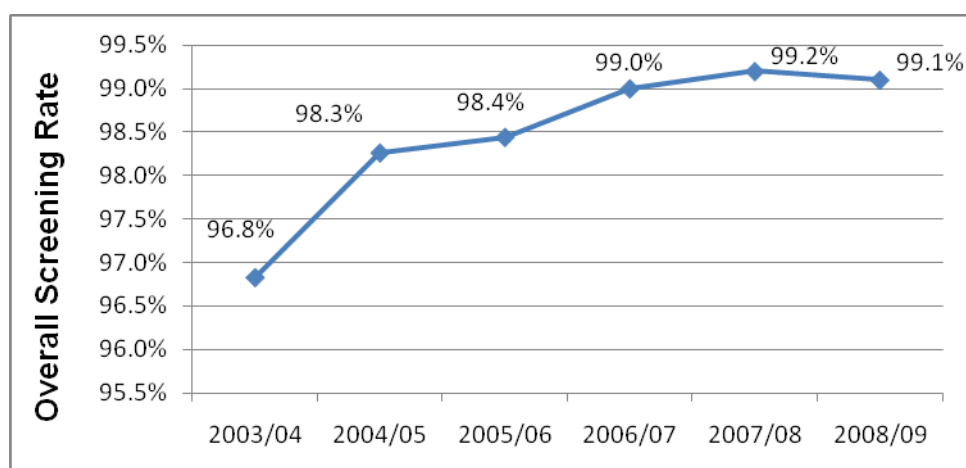
- Since 2006/07, all AHSs have exceeded the JCIH benchmark of >95% and the overall rate across NSW has consistently remained above 98%.
- Overall the screening rate improved significantly between 2003/04 and 2006/07, from 96.3% to 99.0% percent in 2008/2009.

Table 5.1: Screening rates by AHS, July 2003 – June 2009

AHS	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
GSAHS	93.1%	93.8%	94.8%	98.7%	99.1%	99.2%
GWAHS	94.6%	98.2%	98.7%	99.5%	99.5%	99.6%
HNEAHS	95.4%	96.8%	97.9%	97.5%	98.2%	97.8%
NCAHS	97.6%	97.3%	97.6%	97.9%	98.4%	98.4%
NSCCAHS	98.3%	99.1%	98.9%	99.5%	99.5%	99.5%
SESAHS	97.3%	99.2%	99.0%	99.5%	99.5%	99.5%
SSWAHS	96.0%	98.7%	99.2%	99.1%	99.1%	98.9%
SWAHS	97.9%	98.6%	98.4%	99.3%	99.3%	99.2%



Figure 5.2: Overall screening rate, July 2003 – June 2009



Screening rate: Total number of screens / (Total live births – Total deaths).

HEARING SCREENING BY ONE MONTH OF AGE

Principle one of the JCIH 2007 position statement notes that all infants should undergo a hearing screen by one month of age. The deidentified aggregated data maintained by the Department indicates that more than 99 % of babies are screened. SWISH Coordinators maintain databases of personal client records which allow the timeliness of screening to be monitored.

NUMBER DECLINING SCREENING

Table 5.2 and Figure 5.3 present the number of declined screens in the SWISH program as a percentage of all live births for individual area health services.

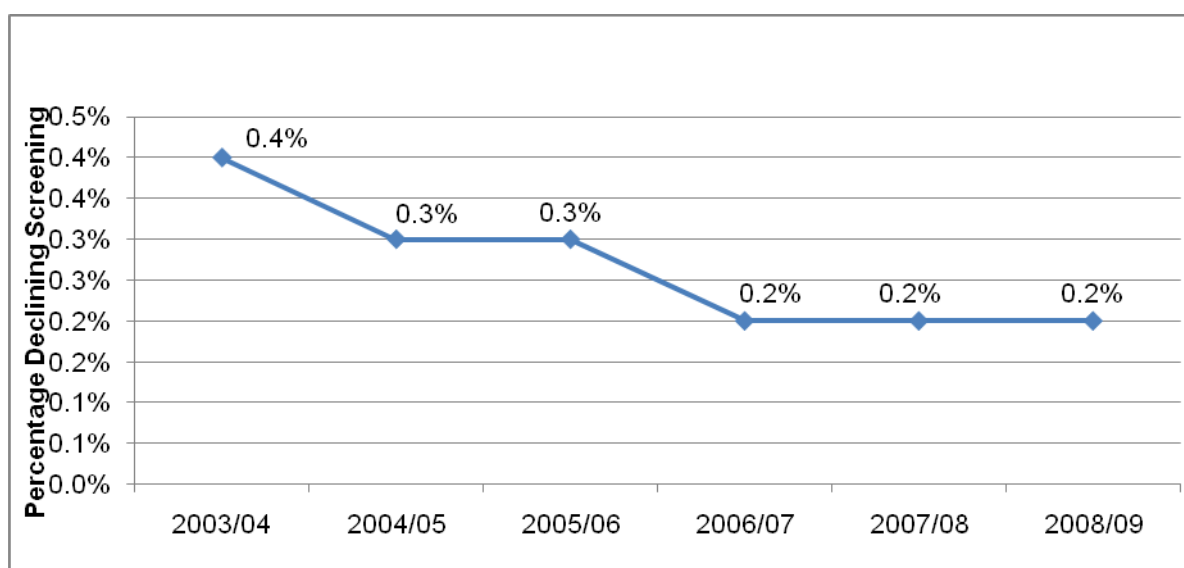
Table 5.2: Percentage declining screening by AHS, July 2003 – June 2009

AHS	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
GSAHS	0.6%	0.6%	0.3%	0.3%	0.4%	0.2%
GWAHS	1.4%	1.3%	1.2%	1.1%	0.6%	0.4%
HNEAHS	0.1%	0.3%	0.2%	0.4%	0.2%	0.2%
NCAHS	0.6%	0.4%	0.5%	0.3%	0.5%	0.7%
NSCCAHS	0.2%	0.2%	0.1%	0.2%	0.2%	0.1%
SESAHS	0.3%	0.2%	0.2%	0.1%	0.1%	0.1%
SSWAHS	0.7%	0.1%	0.2%	0.2%	0.2%	0.1%
SWAHS	0.0%	0.2%	0.1%	0.1%	0.2%	0.1%

The data shows that in most Area Health Services the percentage of screens declined has improved over time.



Figure 5.3: Overall percentage declining screening, July 2003 – June 2009



It is noted that a factor in the **overall low rate of decline** is that the service is provided at no cost to the parent in both public and private hospitals.

PROPORTION REQUIRING SECOND SCREENING

Table 5.3 presents the number of babies requiring a second screening as a percentage of those receiving a first screening.

Table 5.3: Proportion requiring second screening by AHS, July 2003 – June 2009

AHS	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
GSAHS	6.9%	6.2%	6.9%	6.5%	2.2%	4.7%
GWAHS	4.3%	4.2%	3.6%	3.8%	3.1%	4.4%
HNEAHS	9.7%	8.5%	7.2%	8.9%	9.5%	9.5%
NCAHS	6.0%	6.1%	7.3%	7.8%	8.3%	8.8%
NSCCAHS	4.9%	4.4%	4.3%	5.3%	5.7%	5.5%
SESAHS	5.6%	4.3%	5.0%	6.1%	7.5%	7.0%
SSWAHS	6.7%	7.2%	6.0%	6.0%	6.4%	6.8%
SWAHS	7.7%	4.6%	3.7%	3.3%	4.0%	4.2%

Table 5.3 shows considerable variation between AHSs in the percentage of babies requiring a second screening. The percentages range from 4.4% (Greater Western AHS) to 9.5% (Hunter New England AHS) in 2008/2009.

A number of variables in a program could also potentially affect the proportion of babies needing a second screen such as;

- competence of casual screeners
- a policy of quick discharge from hospital (testing very young babies before fluid or temporary conductive loss can be resolved).
- Ease of use of the screening equipment and screening environment in this case the fixed model of equipment versus the portable brand of equipment and the screening environment.

Figure 5.4: Proportion requiring second screening, July 2003 –June 2009

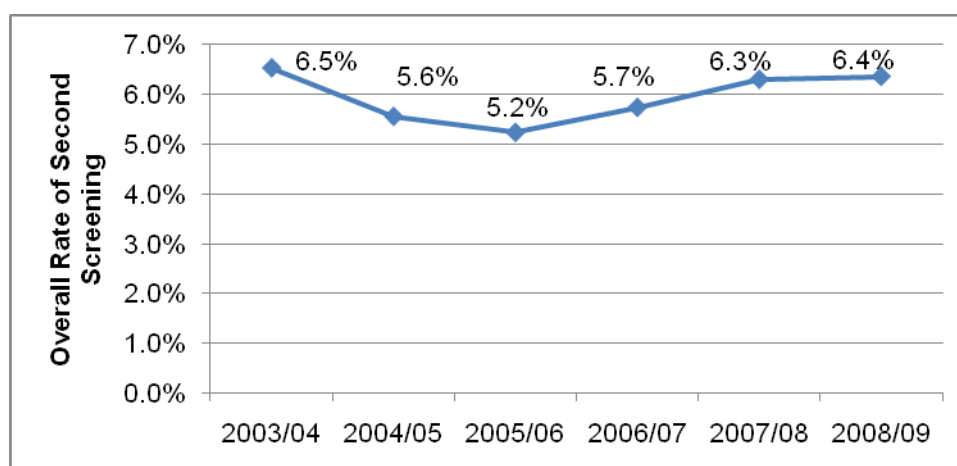


Figure 5.4 shows that between July 2003 and June 2009, the portion of all babies screened who require a second screen fluctuated between 5.2% and 6.5%.

The “rule of thumb” of the program is to keep this second screening rate below 10%. The fact that this rate has been achieved is further testament to the effectiveness of the screening staff and the use of AABR equipment.

RATE OF SECOND SCREENING

Table 5.4 presents the percentage of babies who were referred for a second screen who attended and had the second screen in each Area Health Service.

It is very important that babies who do not pass the first screen are followed up with a second screen. This second stage of the program is to reduce the number of babies sent to diagnostic audiology unnecessarily.

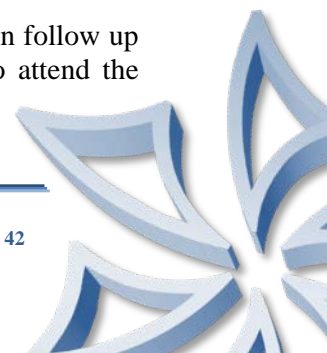
Importantly the follow-up to second screen rate must be high to ensure that the program is effective in identifying all children who have a hearing loss.

Table 5.4: Rate of second screening by AHS, July 2003 – June 2009

AHS	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
GSAHS	90.1%	91.0%	94.0%	95.5%	93.7%	98.9%
GWAHS	86.6%	94.7%	96.4%	97.9%	100.0%	99.4%
HNEAHS	95.0%	96.4%	96.6%	95.9%	97.1%	95.9%
NCAHS	96.1%	95.5%	99.5%	98.2%	98.3%	98.9%
NSCCAHS	98.7%	99.7%	98.2%	99.3%	100.0%	96.9%
SESIAHS	97.8%	98.8%	98.2%	99.0%	99.4%	99.6%
SSWAHS	99.3%	97.0%	95.5%	97.6%	97.5%	98.1%
SWAHS	99.7%	99.5%	99.4%	99.8%	99.6%	99.1%

The data indicates that there are some areas which might where it might be harder to encourage parents to attend a second screen for example in Hunter New England area health service.

While the overall rate is high, there is an opportunity to continue to work on second screen follow up in some Area Health Service to explore and overcome barriers in recruiting parents to attend the second stage screen.



Many AHS's have received a consistently high follow up rate of > 99% which is another indicator of the effectiveness of the SWISH screeners and coordinators in the program.

Figure 5.5: Rate of second screening, July 2003 – June 2009

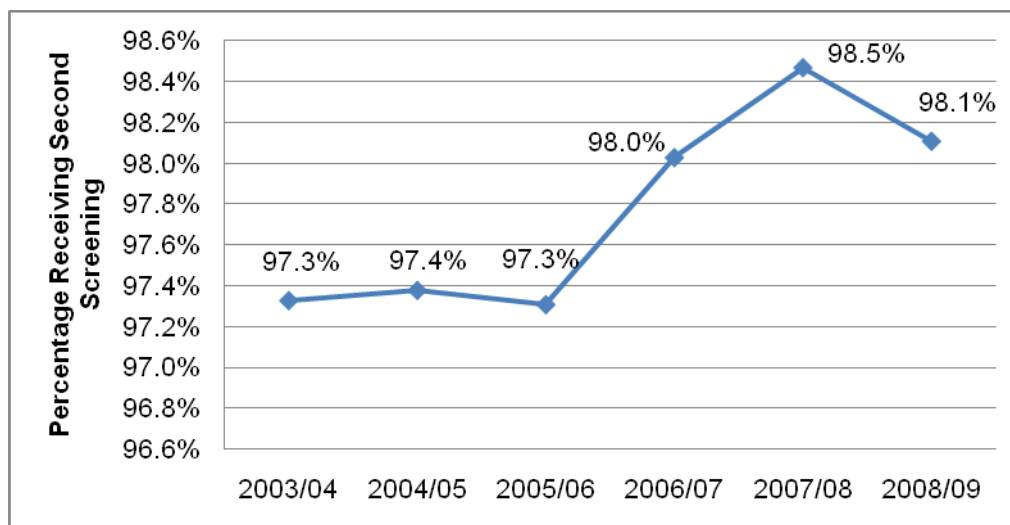


Figure 5.5 looks at the overall follow up rate across the program which is consistently high.

This data reveals an overall improvement in the rate of second screening between 2005/06 and 2007/08 from 97.3% to 98.5%. Note there has been a slight decline from 98.5% in 2007/8 to 98.1% in 2008/2009.

PERCENTAGE OF REFERRALS TO DIAGNOSTIC AUDIOLOGY

Babies who do not pass the hearing screen on one or both ears will be referred for diagnostic audiology.

The JCIH and National Newborn Hearing Framework benchmark is that less than 4% of children should be referred to audiology through the screening program.

5.1.2 AUDIOLOGICAL ASSESSMENT

DIAGNOSES

The NSW Statewide Infant Screening - Hearing (SWISH) Program is aimed at identifying all babies born in NSW with significant permanent hearing loss. Significant hearing loss is defined as being greater than 40dB in the better ear.

While the program aims to identify these children as they are the children who will require the most significant intervention in terms of hearing aids, cochlear implants and habilitation. Children with other degrees and types of hearing loss for example mild permanent losses or unilateral hearing loss who may benefit from early intervention and management of their hearing loss will also be identified in the program.



Table 5.5 Hearing Diagnosis of Target condition by financial year.

Financial Year	Number diagnosed with >40dB Permanent Bilateral Hearing Loss	Significant Bilateral Hearing loss diagnosed per 1000 live births	Number diagnosed with >40 dB unilateral Hearing Loss	Unilateral hearing loss diagnosed per 1000 live births
2006/07	101	1.06	70	0.74
2007/08	85	0.90	57	0.60
2008/09	97	1.02	37	0.39
2009/10	86	0.89	43	0.44

Table 5.5 shows the number of children diagnosed with the target condition over the last 4 years of the program. The data shows that about 1 in a thousand children are being identified with a significant permanent bilateral hearing loss which is consistent with International programs.

HEARING DIAGNOSIS BY THREE MONTHS OF AGE

Principle Two of the JCIH 2007 position statement notes that all infants who do not pass initial screening and subsequent rescreening, should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than 3 months of age.

Anecdotally it appears that this benchmark is largely being met, however information on the date of birth and date of assessment/diagnosis to allow for measurement of this key performance indicator is not yet collected at a program level.

REFERRAL TO EARLY INTERVENTION

Principle Three of the JCIH 2007 position statement notes that all infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than 6 months of age. Additionally, a simplified, single point of entry into an intervention system that is appropriate for children with hearing loss is optimal.

The SWISH program deals mainly with the front end of the pathway which is the detection and diagnosis process. The intervention management after this falls into the responsibility of other agencies.

Early intervention and support service partners involved in early hearing detection, intervention and support within NSW include:

- Australian Hearing (manage all children under 21 who have been identified with a permanent hearing loss)
- The Shepherd Centre
- Royal Institute of Deaf and Blind Children (RIDBC) includes Jim Patrick Audiology Centre
- Sydney Cochlear Implant Centre
- Catholic Centre for Hearing Impaired Children (CCHIC)
- Department of Education and Training (DET)
- Parents of the Deaf (PoD) groups



Discussions with the early intervention and support service provider and the SWISH program staff indicate that the system of referral and communication between the various partners along the screening to early intervention pathway is on the whole effective.

The Sydney Cochlear Implant Centre, for example, noted that they enjoyed being part of 'the network' discussing issues with other audiologists and being included in discussion on matters such as equipment. They provided further feedback that patient knowledge has improved significantly since the inception of SWISH, highlighting the effectiveness of information provision by SWISH personnel.

Consultation with both Department of Education and Training (DET) and the Sydney Cochlear Implant Centre (SCIC) revealed significant pressure had arisen for these service providers since the SWISH program had been established. The pressure on these services essentially comes from much earlier detection of infant hearing impairment. Both were however at pains to point out that they consider the SWISH program to be invaluable.

SCIC noted that they had undertaken 75 cochlear implants on children under the age of 12 months since 2002, approximately 8-9 per year. This represents a significant increase over previous years.

DET is required to become involved with a child/parent at the point of diagnosis of hearing impairment. Whilst this was occurring at a much older age (i.e. 18mths-2yo); this can now be as early as few weeks old. One of the observed outcomes of this very early intervention is that parents have not had time to 'build up' to the diagnosis. That is, what appears to be a perfectly healthy baby is suddenly given a hearing impairment diagnosis. This leaves the parents much more 'shell-shocked' than was the case previously when they observed problems and went seeking answers. A parent in this emotional state is a much more challenging case to deal with and the DET teachers have had to adjust and develop the skills to manage these new dynamics.

A further issue raised by DET is the relative inconsistency between AHSs in regard to their linkages with DET. Whilst recognising that AHSs are highly autonomous, DET considers it would be advantageous if there were state-wide protocols established for interaction between the two Departments in respect to the referral and management of the infant. They also consider this to be a particular problem in disadvantaged communities where staff turnover is higher.

Concern was also expressed by some service providers in relation to the responsiveness of Australian Hearing. This was particularly with respect to providing feedback to SWISH staff on referrals made to the Australian Hearing service.

5.1.3 SUMMARY

With respect to the performance of the SWISH program against international benchmarks the following can be concluded:

- The program has been highly effective in achieving and exceeding the benchmark of screening greater than 95% of the total number of live births. All AHSs are consistently screening 98% or more of live births in their area.
- There is evidence of good follow up with over 98% of children who require a second screen receiving one.
- Less than 4% of babies being screened are being sent to audiology. The model is therefore effectively funnelling a small number of babies who require diagnostic assessment.
- The program has identified significant permanent bilateral hearing loss (>40dB) at a rate of about 1 per thousand since the beginning of the program which is in line with international programs of similar nature.
- The deidentified aggregated data maintained by the Department indicates that more than 99 % of babies are screened. SWISH Coordinators maintain databases of personal client records which they monitor to ensure timeliness of screening (within one month of age) and referral.

- On the whole there is an effective relationship between the SWISH program and the early intervention and support services however there is no method of currently tracking children through the SWISH program to Australian Hearing and intervention services such as the Department of Education and Training and other Non Government early intervention centres.
- Development of a new database which collects and analyses identified data will enable better monitoring of the program as well as reporting against the National framework.
- Some gaps were identified in the existing data which need to be systematically reviewed to enable a more comprehensive evaluation of other aspects of the program.

5.2 WORKFORCE

This section provides a discussion of the issues relating to the SWISH program workforce in terms of staffing levels, orientation and training.

5.2.1 SCREENING

Most AHSs reported that the screening staffing levels were sufficient to meet current demand, albeit many of the programs would like to see additional resources for extended hours during the week, weekends and public holidays.

Given the growth in the number of live births, the screening staff resource will need to be continuously monitored to ensure that screening rates are not unduly affected by not being able to meet demand. There is evidence in some regions that SWISH coordinators are undertaking an increasing number of screens and this may not be sustainable in the long term.

There was significant variation in the amount and type of training available for screeners from AHS to AHS. SWISH coordinators provide a form of orientation that can be relatively informal through to highly structured approach. The programs include technical input, written materials and practical training. Training of midwives is provided by either the SWISH coordinator or an experienced dedicated screener.

Ongoing training and development also varies widely and includes:

- Group training for screeners providing regular networking opportunities
- 3 monthly forums for screeners
- 'Buddy' screeners for new employees
- One-to-one support on site visits in country areas
- Video-conferencing has been used to access programs offered by equipment providers.
- Analysing the outcome of screening against each individual screener
- Use of competency checklists
- Equipment technicians providing in-service training
- Statewide forum which is attended by at least the area co-ordinator
- Attendance at Australasian hearing conference
- Special speakers
- Self-education such as the online Nurse Audiometry course

Some stakeholders reported that there was minimal access to training and development. This related to a lack of funding and difficulty in organising education and training events because of the existing screening demands and minimal staff back-up available.

Suggestions proposed by SWISH program staff include:

- Consideration be given to the conduct of an annual forum for staff involved in the infant hearing program similar to the forum conducted in Queensland.
- A centralised pool of funds to assist program staff to participate in significant training and education opportunities.

5.2.2 AUDIOLOGY

Similar to screening, the Audiology workforce is on the whole sufficient to meet current demand, however, is said to be increasingly feeling the pressure. Audiologists also have limited administrative and other supports that exacerbate the increasing workload pressures.

It has been suggested that NSW has a significant shortage of appropriately trained and qualified audiologists especially those with infant and child training and expertise. This will need to be systematically addressed to ensure the SWISH program has sufficient resources available to meet the inevitable increased demand from a growing number of live births.

5.2.3 SOCIAL WORK

As has been discussed, the issue of social work resources has been raised by the social workers themselves and other SWISH personnel as well as the parent group.

It is our view that the various roles undertaken by the Social Worker above need to be sufficiently resourced by the SWISH program to ensure that parents feel sufficiently supported and informed at this point in their infants care.

The social work role has many facets including: coordinating/navigating the parents through their particular pathway; information provision; coordinating baby hearing clinics; general emotional support/follow up and where required counselling. Some of these tasks require the input of a skilled and experience counselling professional to ensure that the parents are provided appropriate and relevant support and where required referral.

Other aspects of the role such as coordination, navigation and basic information provision could be provided by a 'non-professional' person. The 'Navigator' positions being utilised in Cancer services in NZ provide one example; they guide and assist individuals along their treatment and management pathway as required.

Given this, the current social worker role should be analysed to ensure the range of tasks are allocated to the appropriate position/role. This analysis should also identify any potential 'role creep' that may have evolved over the course of the program.

ASSESSMENT OF THE EFFICIENCY OF THE SWISH PROGRAM

This Chapter presents HOI's evaluation findings with respect to the assessment of the efficiency of the SWISH program in terms of:

- Whether the inputs were efficiently used
- The level of staffing and other resources available to support the Program

It should be noted that HOI was unable to undertake a comprehensive evaluation of the efficiency of the program as no data was provided with respect to either the funding or AHS expenditure.

6.1 PROGRAM RESOURCING

6.1.1 STAFFING

From 2003/04 to 2007/08, the number of live births has grown by 10% from 86,454 to 95,140; an average growth of 2.3% per year. During this period of an increasing birthrate, the SWISH program staff has maintained a screening rate of over 95%. This increase in activity while there has been no increase in staffing levels indicates an increase in the efficiency of the program. This efficiency gain is likely to be associated with increased competence of screeners over time and an ongoing review of the program structure to ensure the service continues to be both effective and efficient.

It is further noted that the number of audiological assessments completed has risen in proportion to the increases in screening.

6.1.2 EQUIPMENT AND CONSUMABLES

The SWISH program has been well resourced with respect to screening equipment from the commencement of the program. Universal Newborn Hearing Screening Programs predominantly use Automated Auditory Brainstem Response and/or Oto-Acoustic Emissions technologies for screening. The NSW Department of Health elected to utilise AABR equipment only for the SWISH program because it offers greater sensitivity, specificity and fewer false positive results than OAE despite a longer screening time (8-21 minutes on average versus approximately 5 minutes), greater skill required to performed screening and more expensive equipment and consumables.

The Department is currently going through a tender process to further upgrade the screening equipment that will further ensure the program will be delivered using the most appropriate screening equipment.

OPPORTUNITIES FOR IMPROVEMENT

This chapter presents the key findings with respect to the opportunities for improving the operational effectiveness of the SWISH program.

7.1 INFORMATION MANAGEMENT SYSTEM

The evaluator's efforts to analyse the performance of the SWISH program against international and the program's own benchmarks has illustrated the problems associated with not having a sufficient SWISH program management information system.

Additionally, the multiple processes to ensure all newborns have been identified and screened and the recording and reporting of program data is an area for improvement.

It is our understanding that the Department is currently in the process of procuring an Information Management System for SWISH. This will both improve operational efficiencies and facilitate improved monitoring against all specified program benchmarks.

The evaluators consider that NSW Health should commence work on the design and implementation of a comprehensive information management system for the SWISH program as a matter of priority. This data is essential to facilitate State-wide reporting against national benchmarks. The information system should have the capacity to:

- trace babies from birth and initial screen through to follow up to audiological assessment and referrals if required. There is currently no linkage to an infant's management to enable follow-up of those infants who have received a refer result from the screen to ensure that referrals to diagnostic audiology and then to intervention have occurred and that ongoing treatment is both systematic and effective.
- support benchmarking, trends and longitudinal analysis, quality improvement and research activities.
- follow-up and periodically monitor those infants who have had a 'Pass' screen but who are classified as 'At Risk'. Currently, data in relation to risk factor babies and pathways are not fed back to SWISH coordinators.

7.2 ADDITIONAL SCREENING FUNDING

Despite the significant increase in births between 2004/2005 and 2006/2007, funding for the then eight Area Health Services to deliver SWISH services hasn't been enhanced since the beginning of the program, aside from annual Consumer Price Index increases. The change in consumable type used by the program since the implementation of new equipment in late 2010 has also increased the costs of delivering the program. It is recommended that additional funding is considered given the growth in the number of live births, the increased clinical hours required and consumable costs to ensure that screening is not unduly affected. There is also evidence in some regions that SWISH coordinators are undertaking an increasing number of screens and this may not be sustainable in the long term.

7.3 SOCIAL WORK SERVICES

In respect to staffing of the SWISH program, the consensus of all stakeholders including the parent group is that the Social Work service is under-resourced. It is agreed that this is a critical service given that parent's are very suddenly presented with a diagnosis that they did not expect. This is followed up by a range of assessments that in many cases can mean extensive travel away from the family home, sometimes for multiple days.

It is recommended that:

- The function of supporting families from the point of referral to audiology through to attending early diagnosis services is fully reviewed to determine the appropriate financial and human resource requirements.
- Issues of support and counselling for families once 'outside' of the SWISH program parameters be documented for further consideration of the Department.
- The above processes include a review of the level and extent of support provided in other jurisdictions.

This review is considered to be a high priority for the program given the reported levels of under-resourcing from SWISH program personnel and parents.

7.4 PATHWAYS & LINKAGES

Further development of linkages will benefit monitoring and operations of SWISH by improving the accessibility of information to the Department and program staff. For instance, improved feedback mechanisms between stages of the SWISH pathway (for example, between coordinators and audiologists), and also beyond SWISH with other programs and organisations, such as Australian Hearing and the NSW Department of Education and Training regarding the referral and management of infants diagnosed with hearing loss. These mechanisms will inform local and state assessments of the effectiveness of current procedures.

The statewide database may contribute significantly to this need, which is also discussed in detail in the next chapter.

7.5 DEVELOPING A SWISH PROGRAM MONITORING SYSTEM

It is proposed that the Department establish a SWISH Quality Management Reference Group (or similarly named group) that will have the primary role for overseeing the establishment, implementation and ongoing development of program monitoring. Similar to the UK Quality Assurance Board, a multi-disciplinary group should be established and membership could include representatives of consumers, screening, audiology, social work, paediatric/medical data management/epidemiology and policy.

It is essential that these standards are aligned to the National Neonatal Hearing Screening Framework once these are finalised and the current New South Wales SWISH Program Guidelines. The proposed National Quality Standards are included in Section 8.9, and include targets for 6 key areas: Screening performance; SWISH parent support staff (social worker) performance; Data collection and management; Management of babies with risk factors; Diagnosis; Parent/Guardian Consent.

7.5.1 DESIGN OF THE SWISH PROGRAM MONITORING SYSTEM

The initial project for the Quality Reference Group is the design of the program monitoring system. Aspects that would need to be considered include:

- Objectives
- Key outcomes measures to be reported

- Other issues that should be considered in the development of the monitoring system
- Future SWISH program monitoring and evaluation strategies and processes

7.5.2 SWISH QUALITY MANAGEMENT IMPLEMENTATION ACTION PLAN

Given this group would be starting from a zero base in relation to a systematic approach to Statewide program monitoring, a staged implementation action plan is proposed. It would be envisaged that the action plan would include activities such as:

- Build resource capacity within NSW Health and the AHS's to undertake value added collaborative projects aimed at supporting the achievement of the State's strategic and operational health service improvement objectives.
- Support service providers with the development and implementation of quality standards for comparative performance analysis of provided services.
- Develop standards for consistent recording and reporting of the SWISH program.
- Enable improved standardisation of information for monitoring, reporting and analysing performance of the health sector.
- Enable more effective planning of service provision and resourcing.
- Facilitating review of practices and processes relative to service improvement and policy decision making.
- Support the development of standard measures within service and governance frameworks.
- Support efficient service delivery through standards for cost comparison.

7.5.3 TERMS OF REFERENCE

The proposed terms of reference for this group will be to provide:

- Support the development of the Quality Assurance Implementation Action Plan that will describe the components of the Quality Management System including:
 - Identification of Program service gaps (based on the findings of the SWISH Program evaluation)
 - Quality Assurance Action Plan implementation processes
- Support the ongoing evaluation of the effectiveness and efficiency of the program
- Publish quality benchmark data

7.5.4 SUGGESTED MEMBERSHIP

The Quality Reference Group membership should include SWISH Audiologists and SWISH Coordinators, representatives from Health System Quality, Performance and Innovation branch as well as consumer representatives and other SWISH Program stakeholders.

7.6 AUDIOLOGY ASSESSMENTS

Having three (3) centralised audiology assessment centres was a purposeful decision at commencement of the program to ensure that this assessment process was undertaken by experienced personnel. However, it does require considerable travel for many people living in regional and rural locations and was raised as a concern.

Notwithstanding the difficulty in obtaining experienced paediatric audiologists and the potential expense of attempting to replicate the service outside of the three main centres, some consideration of additional audiology assessment services particularly for non-metropolitan locations should be

considered. This may include reviewing the potential for utilising tele-audiology or purchasing the service from other providers should they have capacity.

In the interests of ensuring equitable access to specialist diagnostic audiology services the evaluators are of the view that NSW Health should:

- Undertake a review of the current diagnostic audiology workload with the objective of recommending opportunities for service improvement.
- Evaluate the current evidence for outcomes of targeted surveillance of children identified with risk factors for hearing loss who pass universal newborn hearing screening.



PROPOSED SWISH MONITORING SYSTEM

This Chapter presents HOI's evaluation findings with respect to the implementation of a SWISH program monitoring system in terms of:

- The monitoring system objectives and principles
- A conceptual monitoring system model

8.1 SCENE SETTING

There is a well established body of evidence that demonstrates hearing-impaired children that are identified late are at risk of substantial delay in their acquisition of language and communication skills. Some of these children are consequently are at longer term risk to education achievement, mental health and quality of life.

8.1.1 CONTINUOUS QUALITY MANAGEMENT

Internationally it has been widely acknowledged there is a need to design and implement evidenced based monitoring and evaluation activities to support the assessment of population health screening progress such as infant hearing. The evidence base demonstrates that the ongoing evaluation of the achievement of infant hearing screening objectives needs to be based on a framework for quality assurance and associated service guidelines.

Ideally, the development of quality monitoring and evaluation systems should be aligned to the goals and objectives of the infant hearing program in quantifiable terms. Structures, processes and outcomes need to be defined in such a way as to make program evaluation and quality management possible. To the greatest extent practicable, these considerations should be addressed prior to the implementation of the Program.

8.2 MONITORING SYSTEM OBJECTIVES

Our review of the evidence base indicates that the Quality Management Systems^{12;13;14;15} that have been implemented internationally for population screening programs share seven (7) key objectives to ensure that the outcomes of these programs are maximised. These systems provide a mechanism to facilitate the establishment of:

12 Australian Health Ministers Advisory Council (2008) "Population Based Screening Framework" [http://www.health.gov.au/internet/screening/publishing.nsf/Content/pop-based-screening-fwor/\\$File/screening-framework.pdf](http://www.health.gov.au/internet/screening/publishing.nsf/Content/pop-based-screening-fwor/$File/screening-framework.pdf)

13 New Zealand Ministry of Health (2005) "Improving Quality: A Framework for Screening Programmes in New Zealand" [http://www.moh.govt.nz/moh.nsf/0/EB2DDDC99768E392CC2570BC00775D6F/\\$File/improvingquality-nzqualityframework.pdf](http://www.moh.govt.nz/moh.nsf/0/EB2DDDC99768E392CC2570BC00775D6F/$File/improvingquality-nzqualityframework.pdf)

14 National Cancer Screening Service Ireland (2009) "Guidelines for Quality Assurance in Cervical Screening" <http://www.lenus.ie/hse/bitstream/10147/92075/1/Guidelines%20for%20quality%20assurance%20in%20cervical%20screening.pdf>

15 NHS Quality Improvement Scotland (2005) "Clinical Standards: Pregnancy and Newborn Screening" [http://www.nhshealthquality.org/nhsqis/files/Pregnancy%20%20Newborn%20Screening%20\(Oct%202005\).pdf](http://www.nhshealthquality.org/nhsqis/files/Pregnancy%20%20Newborn%20Screening%20(Oct%202005).pdf)

1. An overarching system and process that ensures quality assurance; quality improvement and utilisation management activities are incorporated and become integrated into the ongoing Program operations at the policy and service provider levels including reporting and management functions.
2. Integrated risk management processes (that link knowledge, structures, processes and outcomes) for measuring the performance, efficiency and effectiveness of local screening, audiology, education and social care services to ensure continuous improvement of services.
3. Quality, utilisation and risk management activities and work practices to achieve the optimal program outcomes.
4. Screening programs that are trusted by and serve the needs of individuals and communities by ensuring fair access for all eligible people, safety, effectiveness and efficiency.
5. Processes that enable high quality parent - child interaction in the first months of life for all children.
6. Processes that empower parents of hearing impaired children to make informed choices about early communication and support options so that interactions can be of high quality.
7. An evaluative culture of service provision and partnership through training, ongoing workforce development and quality assurance.

8.3 MONITORING SYSTEM PRINCIPLES OF SCREENING PROGRAMS

The design of evidenced based quality management frameworks are predicated on a set of quality management principles including evidence based systems and processes for quality management and monitoring, including development of:

- Standards
- Performance measures
- Data dictionary
- Quality assurance processes which are applicable to all elements of the program
- Accreditation processes (as required)
- Risk management plans
- Processes to ensure screening programs are safe for participants both physically and psychosocially
- Processes that support ongoing professional development and training to support and sustain the workforce
- Policies that ensure adequate and realistic funding allocations to achieve objectives – short, medium and long term
- Policies and strategies to ensure equity and consistency of service regardless of regional, rural or remote status
- A cycle of ongoing improvement through:
 - Systems for individual and program evaluation and feedback
 - The development and updating of standards, policies and processes
 - Ongoing measurement and analysis to monitor safety and effectiveness
 - Publication of the results of such monitoring, and their incorporation into further program developments

The United States' Joint Committee on Infant Hearing (JCIH) has produced a set of guidelines that provide some guidance in terms of newborn hearing quality program monitoring and evaluation. As

demonstrated in our analysis of SWISH activity data, the basic JCIH benchmarks for timeliness of screening are being met and in fact exceeded. Further, we have evidence that the SWISH Program in NSW is considered to be a best practice model with respect to the rates of follow-up to diagnostic audiology and early intervention.

Notwithstanding the performance of this program, the Department of Health together with SWISH service providers have identified the need for the development and implement of a framework to ensure that the program outcomes are monitored and evaluated on an ongoing basis that are consistent with continuous quality improvement principles.

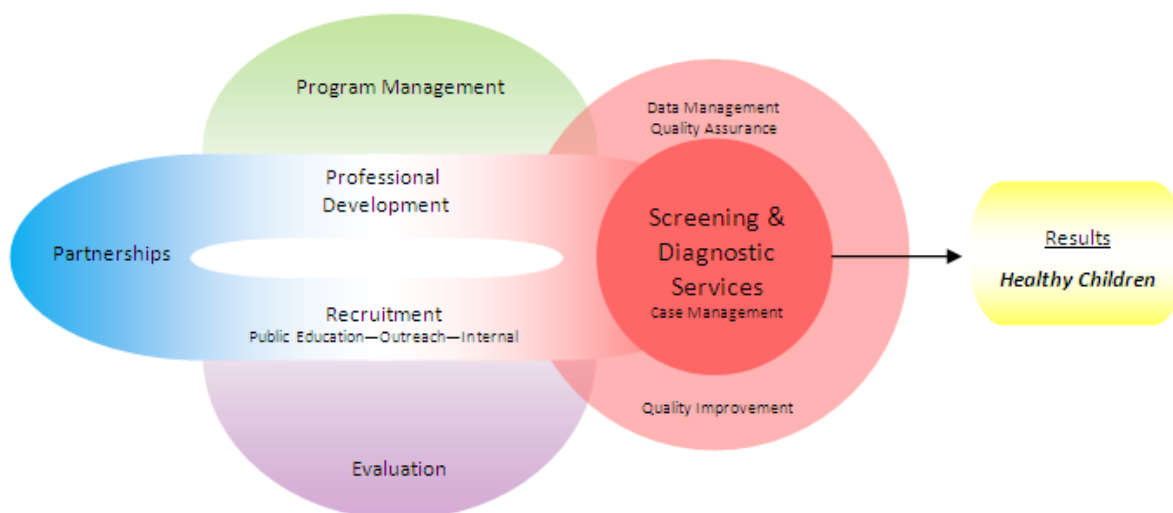
8.4 CONCEPTUAL MONITORING SYSTEM MANAGEMENT MODEL

As previously discussed, there is now a growing world-wide emphasis on implementing quality management systems in order to facilitate continuous improvement in services from infant hearing screening to the identification of deafness and enrolment into appropriate and comprehensive intervention for these children.

8.4.1 MONITORING SYSTEM FRAMEWORK

One of the essential elements of designing the SWISH Monitoring System is the formulation of conceptual Quality Management Framework. The framework needs to address the key areas to be incorporated into the research and the information needed to support the analysis and development activities. It will also describe the method of collection of data, the type of analysis to which the data will be subject and the indicators derived from the data. Figure 8.1 below depicts the proposed conceptual Monitoring System Framework that will underpin the SWISH monitoring system.

Figure 8.1: Conceptual Monitoring System Framework



This framework will provide a blueprint for developing the SWISH monitoring system and will ongoing program quality improvement, monitoring and evaluation together with tools for data collection to be applied on a statewide basis by SWISH service providers. The key components of the framework are as follows:

1. **Purpose.** The framework should be developed based on a clear articulation of the key SWISH program objectives and should be developed in consultation with program stakeholders.

2. **Strategic direction.** The framework should also be designed to reflect the strategic direction of national and State government policies and the legislative requirements for providing quality universal newborn hearing screening services.
3. **Standardised data collection and reporting.** The framework design should include a selection of a common set of quality performance indicators to facilitate consistency of reporting and benchmarking, improve data accuracy and data utility. The measures will:
 - Be linked to national and State policies
 - Have a clear and compelling use for policy making, service planning and service provision
 - Not impose an undue burden on reporting agencies
 - Support decision making aimed at improving delivery of services
 - Support families and carers

In developing the reporting processes there will be a need for NSW Health to provide regular performance reports that are targeted to stakeholder needs and their uses.
4. **Evidence base.** It is important that the framework is based on a demonstrated evidence base.
5. **Quality improvement.** A key component of the framework should provide program stakeholders with relevant information to support the implementation of quality improvement initiatives and the tools to achieve these objectives. It will also assist in service planning and program management.
6. **Implementation.** The framework should also include the development of an implementation plan that will identify the change management process and timeframe required to implement the framework.

8.5 PROGRAM EVALUATION AND QUALITY IMPROVEMENT INITIATIVES

Program evaluation is the mechanism by which funders and providers of the SWISH Program can determine whether the overall goals objectives of the Program are being achieved and to identify opportunities for quality improvement from a policy and service delivery perspective.

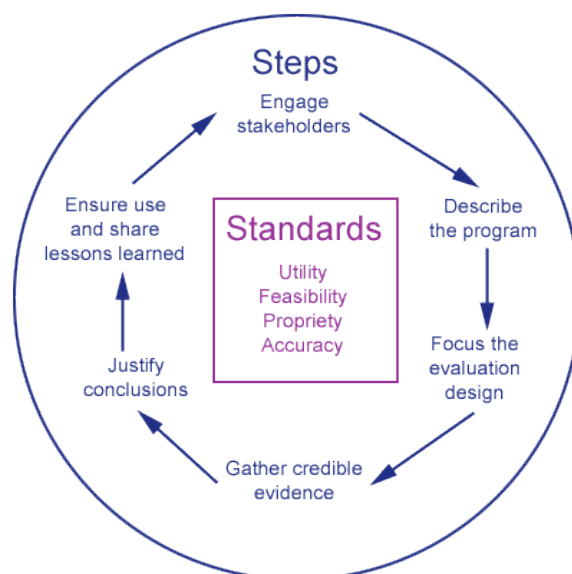
Quality assurance is a related approach that incorporates ongoing and continuous quality assessment of the key Program elements. The objective is to systematically assess whether the Program is functioning as effectively and efficiently as possible, and to determine when and where issues arise and the strategies to be implemented to address these issues.

Program evaluations are generally undertaken within the construct of a broad conceptual framework comprising of a series of tasks that will culminate in the application of an accepted evaluation framework. The conceptual framework (depicted in Figure 8.2 below) has been designed by the CDC and has been used by a number of evaluations of similar infant hearing screening programs overseas.^{16;17}

16 Examples of Statewide Evaluations of Early Hearing Detection & Intervention Programs <http://www.infanthearing.org/programevaluation/stateexamples.html>

17 Centres for Disease Control and Prevention. "Program evaluation tool kit: A blueprint for public health management" <http://www.cdc.gov/eval/framework.htm>

Figure 8.2: Conceptual SWISH Program Evaluation Framework



At the central core of the framework is a set of Evaluation Criteria that will underpin the conduct of the SWISH evaluation which will include:

1. **Utility.** Utility criteria ensures that the information needs of the evaluation are satisfied which will include the identification of data elements that will need to be collected for the purposes of data analysis and reporting.
2. **Feasibility.** Feasibility criteria, ensures that the evaluation process is viable and pragmatic. In this regard, our objective will not to create an additional administrative burden on regional management with respect to undertaking the funding trial.
3. **Propriety.** Propriety criteria, ensures that the evaluation processes are conducted legally, ethically, and with due regard for the welfare of those involved and those.
4. **Accuracy.** Accuracy criteria, ensures that the findings of evaluation can be considered as correct.

The conceptual framework outlined above will be used as to ensure that evaluation of all the components of the SWISH Program is addressed.

8.5.1 OUTCOME MEASURES

Based on our review of the literature, the outcome measures that a high quality infant hearing screening program should routinely quantify and document are listed below. Measurements may include both true outcomes and process events that may serve as proxies for true outcomes. The latter type of measurement is common in situations wherein true outcomes are difficult, expensive or impossible to obtain.

- The number and proportion of the overall target population successfully screened by 1 month of age, or within one month of discharge from the birth hospital admission
- The numbers and proportions of infants with a refer result from screening overall and broken down by screening site, screening personnel and risk status
- The numbers and proportions of screening referrals for whom audiological assessment is initiated by 3 months of age and within two months of the initial screening result
- The numbers and proportions of screening referrals with completed audiological assessments by 4 months of age and within one month of assessment initiation

- The numbers and proportions of the target birth, screened and referred cohorts of infants who have confirmed permanent childhood hearing impairment (PCHI) at 6 months of age, also broken down by ear and severity categories, risk status and assessment site/personnel
- The numbers and proportions of infants with PCHI who have been recommended for hearing aids by 6,9 and 12 months of age
- The numbers and proportions of infants with PCHI who have received medical intervention for otitis media (OM) by 6 months of age
- Documentation of reasons for non-fitting of hearing aids by 6, 9 and 12 months of age, broken down by risk status
- The number of infants with confirmed PCHI at 12 and 24 months of age who passed newborn screening and was detected by surveillance and referral-in routes
- Family satisfaction with the program
- Communication development outcomes¹⁸

8.5.2 PERFORMANCE BENCHMARKS

The outcome measures outlined above could be used to determine if performance benchmarks have been achieved.

INTERNATIONAL BENCHMARKS AND PERFORMANCE INDICATORS

The Joint Committee on Infant Hearing (JCIH) through a series of regularly updated position statements provides international guidelines and an evidence base on benchmarking and quality indicators. The following performance benchmarks represent a consensus of expert opinion in the field of newborn hearing screening and intervention and according to the JCIH, are the minimal requirements that should be attained in the delivery of high-quality EHDI programs.

QUALITY INDICATORS FOR SCREENING

- Percentage of all newborn infants who complete screening by 1 month of age; the recommended benchmark is more than 95% (age correction for pre-term infants is acceptable); and
- Percentages of all newborn infants who fail initial screening and fail any subsequent rescreening before comprehensive audiological evaluation; the recommended benchmark is less than 4%.

QUALITY INDICATORS FOR CONFIRMATION OF HEARING LOSS

- Of infants who fail initial screening and any subsequent rescreening, the percentage who complete a comprehensive audiological evaluation by 3 months of age; the recommended benchmark is 90%; and
- For families who elect amplification, the percentage of infants with confirmed bilateral hearing loss who receive amplification devices within 1 month of confirmation of hearing loss; the recommended benchmark is 95%.

QUALITY INDICATORS FOR EARLY INTERVENTION

- For infants with confirmed hearing loss who qualify for Part C services, the percentage for whom parents have signed an IFSP be no later than 6 months of age; the recommended benchmark is 90%.

¹⁸ Canadian Working Group on Childhood Hearing. Early Hearing and Communication Development: Canadian Working Group on Childhood Hearing (CWGCH) Resource Document. Ottawa: Minister of Public Works and Government Services Canada, 2005.

- For children with acquired or late-identified hearing loss, the percentage for whom parents have signed an IFSP within 45 days of the diagnosis; the recommended benchmark is 95%.
- The percentage of infants with confirmed hearing loss who receive the first developmental assessment with the standardised assessment protocols for language, speech, and nonverbal cognitive development by no later than 12 months of age; the recommended benchmark is 90%.¹⁹

8.5.3 AUSTRALIAN NATIONAL NEONATAL NEWBORN HEARING SCREENING DRAFT FRAMEWORK

In March 2002, the National Health and Medical Research Council (NHMRC) released a report titled *Child Health Screening and Surveillance: A Critical Review of the Evidence*. The Report found that there was evidence to recommend national neonatal hearing screening, but urged serious consideration of the logistics and quality of the testing system, and the follow up systems for babies who test positive, before the implementation of a national neonatal hearing screening program.

In July 2002, the Australian Health Ministers Conference (AHMC) requested the Medical Service Advisory Committee (MSAC) undertake an assessment on the safety, effectiveness and cost-effectiveness of universal neonatal hearing screening. In 2008, MSAC released the *Universal Neonatal Hearing Screening Assessment*.

In March 2008, the Screening Subcommittee of the Australian Population Health Development Principle Committee (APHDPC) agreed to examine the feasibility of a national approach to neonatal hearing screening. It established the Neonatal Hearing Screening Working Group with the following terms of reference:

1. Assess neonatal hearing screening against the Population Based Screening Framework.
2. Develop minimum national standards for screening services and post screening follow-up with regards to audiology, medical intervention, family counselling, early intervention and education.
3. Consider and develop screening pathway to improve population coverage for neonatal hearing screening in Australia.
4. Develop a national quality and reporting framework for consideration by the Screening Subcommittee of the Australian Population Health Development Principle Committee and Australian Health Ministers Advisory Council.
5. Establish an agreed national approach to data collection and management and data sharing.

The Working Group has developed a standards framework in accordance with the Terms of Reference above, for screening, diagnosis, ongoing management, intervention and education. *Towards a National Approach to Newborn Hearing Screening: Draft National Standards* provides background and context as well as minimum standards for developing a universal newborn hearing screening program that includes post-screening diagnosis, medical assessment, early intervention and education, see the components below:

- Recruitment
- Screening
- Parent Support
- Diagnosis (confirmation of hearing loss)
- Early intervention and management

¹⁹ Ibid pp. 914-915.

- Co-ordination, monitoring and evaluation
- Professional education

In June 2009, the Prime Minister proposed to the Council of Australian Governments (COAG) that universal neonatal hearing screening would be available in all states and territories by the end of 2010. COAG agreed to this proposition at its meeting in Darwin on 2 July 2009.

NEONATAL HEARING SCREENING GUIDELINES

The National Framework includes national guidelines designed for all states and territories screening programs to have a consistent approach to neonatal hearing screening. These guidelines are supported by evidence-based standards of practice to ensure quality outcomes. The development of the guidelines and standards of practice has been a collaborative approach between all stakeholders. The Guidelines contain major components of the screening pathway.²⁰

The rationale for the implementation of the National Guidelines on Neonatal Hearing Screening is based on the fact that currently only 84% of children in Australia is screened for hearing impairment at birth. Each year approximately 46,000 babies do not undergo screening for hearing impairment in Australia. A national approach will aim to screen all babies in Australia for potential permanent childhood hearing impairment, and provide access to interventions to minimise the impact of hearing impairment. The Population Based Screening Framework takes into account the World Health Organisation (WHO) principles and elaborates on them in the Australian context.

The aim of the draft neonatal hearing screening guidelines is to:

- Maximise early detection of PCHI (permanent childhood hearing impairment) in Australian babies through approved screening test and appropriate follow up medical, and support services
- Ensure all Australian families are offered the opportunity to participate in neonatal hearing screening
- Ensure equitable access to neonatal hearing screening for all Australian babies irrespective of their geographic, socioeconomic or cultural background

8.5.4 ECONOMIC EVALUATIONS

There is a growing need to conduct economic evaluations for health programs²¹ in order to conduct a systematic appraisal of costs and benefits of these programs. There are a number of economic evaluation approaches depending on the purpose of the evaluation. Four common types of formal economic evaluation are:

1. **Cost minimisation.** This is the simplest evaluation technique and involves demonstrating that a new project or amended process provides at least the same quality of outcome as existing procedures at either the same or lesser cost.
2. **Cost effectiveness analysis.** This is used where new or amended procedures are demonstrated to offer an improved outcome although possibly at an increased cost. The measure of cost-effectiveness is the incremental cost per additional unit of outcome obtained.
3. **Cost-utility analysis.** This involves an analysis of benefit to patients through a utility measure such as quality adjusted life years (QALYs). QALYs measure both increased *quantity* of years of life and *quality* of life through measures such as changes in activities of daily living (i.e., ADL scores).

20 Towards a National Approach to Neonatal Hearing Screening May 2010 draft

21 National Information Center on Health Services Research and Health Care Technology (NICHSR). United States Of America National Library. Glossary of Frequently Encountered Terms in Health Economics- Economic Evaluation. <http://www.nlm.nih.gov/nichsr/edu/healthecon/glossary.html>

4. **Cost-benefit analysis.** This involves placing monetary values on all benefits and costs. Lives saved are often given monetary value estimates utilising comparisons with other economic sector expenditures such as averted road deaths or prevention of accidental drowning.

In addition to the outcome measures listed above, that provide information on service processes and associated outcomes; funding agencies routinely require both budgetary and more comprehensive economic evaluations of infant hearing screening programs. These are relevant for accountability and sustainability issues, especially in relation to cost containment and to opportunity costs of alternative health care programs.

Therefore, economic data need to include, but are not limited to, the capital and operating direct costs of all program structures and processes, including infrastructural elements such as information systems. A common problem in such analyses is to differentiate the true costs of the infant hearing screening program from other costs that are associated with the health care environment within which the infant hearing screening program operates. These analyses must also take into account the actual costs that would ultimately be sustained in the absence of the infant hearing screening program, and this is a difficult area for which quantitative data are frequently lacking. Basic measures that are commonly used for infant hearing screening programs are direct cost evaluation are the overall cost per infant screened and the cost per infant identified with a PCHI.

Such analyses are fundamental and are a useful facet of continuous quality improvement, especially for comparative cost-effectiveness analysis of various process options. For example, cost per infant identified may be very sensitive to the referral rates to audiologic assessment that are achieved by specific screening strategies, and this may be more meaningful than simple use of process proxies such as the raw referral rates. However, a much more comprehensive analysis is required to approach true cost-benefit issues, because cost-benefit analysis requires attribution of quantitative, monetary costs to long-term outcomes such as educational achievement, earning capacity and quality of life.²²

8.6 ASSESSMENT OF NEWBORN SCREENING PROGRAM MONITORING SYSTEM

An assessment of the monitoring system options for the SWISH Program was undertaken and this informed the selection of the preferred option. The assessment of options focused on identifying the strengths and weaknesses for each of the four systems that were reviewed. To support the assessment of system options an evaluation framework was formulated which is discussed below.

The preceding sections in this chapter identified and discussed four monitoring systems that had been implemented in the USA, UK, Canada and NZ.

In order to assess these systems we developed a framework that provided a rigorous mechanism for the assessment of these monitoring system options.

8.6.1 CRITERIA FOR ASSESSMENT OF MONITORING SYSTEM OPTIONS

Based on our review of the literature were identified six (6) core components of international monitoring systems. These were used to assess each system option:

- Integrated continuous quality improvement processes
- Integrated risk management processes
- Utilisation of quality data to measure program performance

22 Canadian Working Group on Childhood Hearing. Early Hearing and Communication Development: Canadian Working Group on Childhood Hearing (CWGCH) Resource Document. Ottawa: Minister of Public Works and Government Services Canada, 2005.

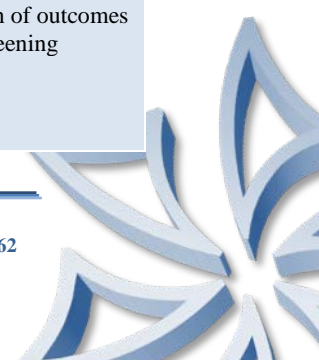
- Incorporates a comprehensive data management strategy
- Incorporates an ongoing program measurement
- Supported evaluative culture of service provision

8.6.2 ASSESSMENT OF MONITORING SYSTEM OPTIONS

Table 8.1 provides the findings of the assessment of the four monitoring system options against the criteria outlined above in terms of the strengths and weakness of each system.

Table 8.1: Evaluation of Quality Management System Options

Quality Management System	Strengths	Weaknesses
USA: EDHI Quality Assurance and Improvement	<ul style="list-style-type: none"> • Integrated of continuous quality improvement processes • Utilisation of quality data to measure program performance • Established data management system • Ongoing program measurement • Evaluative culture of service provision 	<ul style="list-style-type: none"> • System does not provide for the conduct economic evaluation studies to determine appropriate early intervention strategies for infants • System does not assess the effects of parents' participation in all aspects of early intervention • Limited utility of national data set • There is a need to develop nationally accepted indicators of EHDI system performance • System needs to facilitate the identification and development of centres of expertise in which specialised care is provided in collaboration with local service providers • System needs to provide increased involvement o individuals who are deaf or hard of hearing in developing program policies • System needs to support longitudinal evaluation of outcomes and benefits of the screening program
UK NHS: Quality Assurance and Risk Management Framework	<ul style="list-style-type: none"> • Integrated continuous quality improvement processes • Integrated risk management processes • Utilisation of quality data to measure program performance • Established data management system • Ongoing program measurement • Evaluative culture of service provision 	<ul style="list-style-type: none"> • System requires an increased focus on the development of training opportunities for program staff • System requires an increased focus on improving and developing linkages across services • System needs to support longitudinal evaluation of outcomes and benefits of the screening program
Canada: Program Evaluation and Quality Improvement	<ul style="list-style-type: none"> • Integrated continuous quality improvement processes • Utilisation of quality data to measure program performance • Established data management system • Ongoing program measurement • Evaluative culture of service provision 	<ul style="list-style-type: none"> • System does not incorporate a risk management strategy • System needs to support longitudinal evaluation of outcomes and benefits of the screening program



Quality Management System	Strengths	Weaknesses
New Zealand: Universal Newborn Hearing Screening and Early Intervention Programme	<ul style="list-style-type: none"> • Integrated continuous quality improvement processes • Integrated risk management processes • Utilisation of quality data to measure program performance • Established data management system • Ongoing program measurement • Evaluative culture of service provision 	<ul style="list-style-type: none"> • This system is currently being implemented in 21 DHBs • System needs to support longitudinal evaluation of outcomes and benefits of the screening program

8.7 PREFERRED SWISH MONITORING SYSTEM

Our review of the evidence base, the draft Australian National Neonatal Newborn Hearing Screening Framework and discussions with the Department; SWISH stakeholders and the Head of Quality Assurance & Evaluation NHS Newborn Hearing Screening Programme in the UK has confirmed the challenges associated with establishing rigorous SWISH screening standards and performance measures, while balancing the interests of different stakeholders in the development and application of the screening process. For example, effective processes must link to strategic priorities, such as community safety and accountability, and processes while respecting the operational realities of Area Health Service program service providers. In addition, it is important that the processes need to fit with the reality and resources of the Area Health Service organisations, ensuring that the reporting requirements are cost-effective and aligned with national and state program priorities and objectives.

Effective risk management is becoming critically important for the delivery of health services and the ability to make effective decisions about policies, programs and services where future uncertainties are significant is paramount. With increasing frequency, the SWISH Program is faced with difficult decisions about the operational and environmental risks and technology risks, among other things.

Although there is a large body of literature on quality assurance and risk management that is available in the health sector, to date, there has been little published research focusing on these concepts for infant hearing screening apart from the developments in the UK and New Zealand that have been discussed in this chapter.

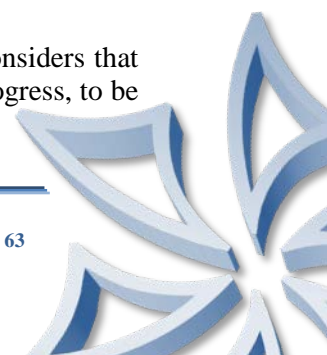
Based on our evaluation of the options above, we are proposing that the Department consider the implementation of a monitoring system that that is a hybrid model of the NHS and Canadian models.

8.7.1 GAP ANALYSIS

The conceptual structure of the proposed SWISH monitoring system has been designed based to focus on continuous quality improvement. This proposed system will enable the Department in collaboration with SWISH coordinators to develop and implement a range of tools that support ongoing quality assurance, such as the development of quality assurance plans, program standards and policies that are consistent with the proposed national guidelines. It will also provide for the development and implementation of information and tools (such as a risk management strategy, service provider and parent satisfaction surveys, peer review protocols, evaluation framework and associated evaluation tools etc.) that will assist in monitoring program delivery, identify risk management issues, improve service delivery and evaluate the follow-up actions taken for program improvement.

The quality assurance and service improvement processes should take account of best practice; service risks and service provider experience in order to meet population health needs.

Due to the complexity and scale of the implementation of the monitoring system, HOI considers that the system design elements contained in this chapter should be considered as a work in progress, to be



implemented over time. Careful staging is required for implementation, based on input from key SWISH Program stakeholders.

In formulating the conceptual monitoring system, a gap analysis was undertaken that compared current data collection processes for the SWISH Program and the proposed key performance indicators and associated data collection requirements specified in the draft National Guidelines for Neonatal Hearing Screening.

8.7.2 CURRENT SWISH DATABASE

NSW Health currently maintains two separate program data sets:

1. **Screening database.** Data is collected on screening activity data for each Area Health Service. This data set comprises information relating to the number of screens, the number of births and the number, type and location of referrals. Currently data is not collected to enable an assessment of performance in relation to age related targets.
2. **Audiological data.** Audiological assessment data is also collected consisting of monthly volume data by each Tertiary Diagnostic Centre where the volumes relate to the number of babies seen, quantity of each referral types and totals of various assessment outcomes. Currently data is not collected to enable an assessment of performance for age related KPIs for the diagnostic components of the program.

8.7.3 COMPARATIVE ANALYSIS OF DATASETS

A comparative analysis of the data currently collected for the SWISH Program relative to the draft National Guidelines for Neonatal Hearing Screening was undertaken. This analysis indicated that as expected, there was a degree of overlap between the two data collection requirements, however the draft National Guidelines have significantly more detailed definition of indicators, particularly those related to age and to the time between the stages of screening, audiological assessment, confirmed diagnosis and commencement of early interventions.

The analysis undertaken has also demonstrated that the current SWISH dataset was significantly deficient for the calculation of all but the simplest of KPIs related to the screening coverage of newborn babies and the overall rate of referrals for audiological assessment.

The outcome of the gap analysis has resulted in the identification of a minimum dataset that would be required to facilitate the measurement of all KPIs based on the National Guidelines.

8.7.4 PROPOSED SWISH MONITORING SYSTEM MINIMUM DATASET

This section presents the minimum dataset for the proposed SWISH monitoring system that addresses draft National Guidelines for Neonatal Hearing Screening.

It should be noted that for the identified required data elements there is no specification of the source, field size, business rules, data management responsibility or required systems integration as this is beyond the scope of the evaluation. However, the complexity of collecting, storing and managing this dataset is considered to be significant given the broad scope of service providers involved and the longitudinal nature of the data compilation and monitoring of performance indicators.

The dataset has been grouped into four (4) performance categories namely:

1. Target performance indicators for recruitment.
 2. Target performance indicators for screening.
 3. Target performance indicators for diagnosis (confirmation of hearing loss).
 4. Target performance indicators for early intervention and management.
- A description of the data elements is presented below.

8.7.5 TARGET PERFORMANCE INDICATORS FOR RECRUITMENT

NSW SWISH Target Performance	National Target Performance	Required Data Elements
<ul style="list-style-type: none"> Population coverage for screening is 95% of all newborn babies. 	<ul style="list-style-type: none"> 100% of eligible babies are offered hearing screening >97% of eligible babies complete a hearing screen All babies not screened prior to hospital discharge are followed up within one month. The number of babies screened between one and six months of age is recorded. 	<ul style="list-style-type: none"> Birth Hospital Code Baby MRN Date of Birth Time of Birth Date of 1st Screen Time of 1st Screen 1st Screen Hospital Code Birth Episode Discharge Date
<ul style="list-style-type: none"> Screening Processes 	<ul style="list-style-type: none"> Description of the screening process and the reason for screening is provided to parents. 	<ul style="list-style-type: none"> Screening process components

8.7.6 TARGET PERFORMANCE INDICATORS FOR SCREENING

NSW SWISH Target Performance	National Target Performance	Required Data Elements
<ul style="list-style-type: none"> Hearing screening is provided for each newborn by one month of age. 	<ul style="list-style-type: none"> Written parental consent is obtained to perform a screen. <1% of parents decline screening. A decline form is signed by all parents who choose to decline a screen. A decline to participate in screening is recorded appropriately in the infant's medical file. Written consent is obtained to collect data for those babies with a refer (positive) result on the screen. 	<ul style="list-style-type: none"> Consent/Decline Flag Left Ear Result 1st Screen Right Ear Result 1st Screen Date of 2nd Screen Time of 2nd Screen 2nd Screen Hospital Code Left Ear Result 2nd Screen Right Ear Result 2nd Screen
	<ul style="list-style-type: none"> >97% eligible babies complete a hearing screen before one month corrected age. All babies with a 'refer' (positive) result are referred for audiological assessment. 	<ul style="list-style-type: none"> Diagnostic Referral Flag



NSW SWISH Target Performance	National Target Performance	Required Data Elements
	<ul style="list-style-type: none"> All babies admitted to NICU are screened according to NICU protocols. 	<ul style="list-style-type: none"> Date of Birth (Corrected)
	<ul style="list-style-type: none"> All results are provided verbally and in written form. Outcomes are recorded. 	<ul style="list-style-type: none">
	<ul style="list-style-type: none"> >99% parents of babies with a refer result consent to diagnostic assessment. A referral is made to diagnostic assessment within three days of completion of the screening process. 	<ul style="list-style-type: none"> Diagnostic Assessment Consent/ Decline Flag Date of Referral for Diagnostic Assessment Location Referred to
	<ul style="list-style-type: none"> >97% babies with a refer (positive) result are referred, monitored and followed up through to diagnostic services. >97% of referrals are made in less than five days. 	<ul style="list-style-type: none"> Confirmation of Receipt of Referral
	<ul style="list-style-type: none"> At least 0.1% of babies screened will be diagnosed with the target condition. <4% of babies are referred for audiological evaluation. 	<ul style="list-style-type: none"> Type of Referral
	<ul style="list-style-type: none"> All parents of babies screened are provided with a check list of developmental milestones for hearing and signs of hearing loss. Parents with children at higher risk are provided with clear written information of their risk factors. 	<ul style="list-style-type: none"> Confirmation of provision of check list to parents Confirmation of provision of written information to parents



8.7.7 TARGET PERFORMANCE INDICATORS FOR DIAGNOSIS (CONFIRMATION OF HEARING LOSS)

NSW SWISH Target Performance	National Target Performance	Required Data Elements
<ul style="list-style-type: none"> Hearing diagnosis is provided for newborns identified with hearing loss through screening by three months of age. 	<ul style="list-style-type: none"> >97% diagnostic audiology assessment is completed by two months of corrected age, to allow referral for medical evaluation by three months of age and timely access to intervention services including Australian Hearing. >97% of families are referred to Australian Hearing within three days of confirmed hearing loss. All children referred are tested with a full range of diagnostic electrophysiological tests in accordance with agreed national standards. Diagnostic electrophysiological tests and behavioural test outcomes are clearly and accurately documented. Results are included with referrals to Australian Hearing. Families are provided with an explanation of the results on completion of the diagnostic assessment. Families are provided with a written copy of the results within five working days 	<ul style="list-style-type: none"> Date of Diagnostic Assessment Location of Diagnostic Assessment Diagnosis – Left Ear Diagnosis – Right Ear Type of Hearing Loss Date of Referral to Australian Hearing Confirmation flag that diagnostic results were sent to Australian Hearing Appointment Date – Australian Hearing Australian Hearing Centre Code Date of assessment by Australian Hearing



NSW SWISH Target Performance	National Target Performance	Required Data Elements
	<ul style="list-style-type: none"> • An appointment with an otolaryngologist /paediatrician with expertise in paediatric hearing loss should be made within two weeks of confirmation of hearing loss. • Following confirmation of hearing loss, all babies are referred for otological and other appropriate medical evaluation so that a medical management plan including other interventions, can be developed by three months of age in collaboration with the family. • All families are provided with a written explanation of the implications of the outcomes of aetiological investigation. • There is evidence of processes for reviewing and correlating clinical, neurological, audiology (etc) findings for hearing loss that has been detected as a result of screening. • >97% of babies are seen within targeted timeframes. 	<ul style="list-style-type: none"> • Date of Referral to otolaryngologist • Otolaryngologist name • Confirmation Flag that diagnostic results were sent to otolaryngologist • Appointment Date – Otolaryngologist • Date assessed by Otolaryngologist • Confirmed level of Hearing Loss • Date Hearing Loss confirmed



8.7.8 TARGET PERFORMANCE INDICATORS FOR EARLY INTERVENTION & MANAGEMENT

NSW SWISH Target Performance	National Target Performance	Required Data Elements
<ul style="list-style-type: none"> Intervention programs are commenced for babies identified with hearing loss through diagnosis by six months of age. 	<ul style="list-style-type: none"> >97% of families are provided with a range of options regarding amplification technology, communication and intervention within six weeks of diagnosis. Families (particularly in rural and remote areas) are provided with information on eligibility and access to travel assistance particularly for rural and remote areas. Services provide evidence of a mechanism to engage parents in the development of service delivery standards and protocols. 	<ul style="list-style-type: none"> Date of formal engagement with intervention program Number of parents receiving travel assistance Method for engagement of parents in the development of service delivery standards and protocols
	<ul style="list-style-type: none"> Services demonstrate that protocols have been put in place to provide a smooth transition process between other hearing impairment services. Early intervention providers report on continuing enrolment or disengagement quarterly. Families that disengage with an early intervention service provider are offered support through central family advocacy/support services to engage with alternative providers within two months. Service providers assist in the development of a transition plan six months prior to enrolment in an educational system. 	<ul style="list-style-type: none"> Protocols implemented for transition process Date of quarterly early intervention providers reports Date of disengagement with intervention program Date that transition plan was developed prior to enrolment in an education system
	<ul style="list-style-type: none"> Age of initiation of formal early intervention is recorded centrally in the program for all children diagnosed with permanent hearing 	<ul style="list-style-type: none"> Age of initiation of formal intervention Families not attending audiology by 4 months of age



NSW SWISH Target Performance	National Target Performance	Required Data Elements
	<p>impairment.</p> <ul style="list-style-type: none"> • >97% of babies with permanent hearing impairment are engaged in formal early intervention by four months of age. • Families who do not attend audiology or early intervention services are notified to the family's GP and/or Maternity and Child Health Nurse for follow-up within four weeks. 	<ul style="list-style-type: none"> • Families not attending early intervention by 4 months of age • Date of notification to GP or Maternity Child Health Nurse for follow-up
	<ul style="list-style-type: none"> • Services demonstrate that all professional staff members have the skills/qualifications that are necessary for providing families with the highest quality of service specific to children with hearing impairment. • Services have a comprehensive orientation and training program for staff involved in the delivery of services to children and their families. • >97% of babies with confirmed hearing impairment receive a full developmental assessment with standardised assessment protocols (not criterion reference checklists) for language, speech, and nonverbal cognitive development by 12 months of age. • >97% of babies with confirmed hearing impairment in early intervention programs receive a language, cognitive skills, auditory skills, speech, vocabulary, and social-emotional assessment at six-month intervals during the first three years of life. • >97% babies diagnosed with a permanent hearing loss are referred to Australian Hearing 	<ul style="list-style-type: none"> • Qualifications of workforce • Description of workforce orientation and training programs • Date of Full Developmental Assessment • Date of Last Developmental Assessment review • Participation of babies with confirmed hearing impairment in early intervention programs at 6 monthly intervals for the first 3 years of life • Date of referral to Australian Hearing • Date fitted with amplification • Date of referral for cochlear implant candidacy



NSW SWISH Target Performance	National Target Performance	Required Data Elements
	<ul style="list-style-type: none"> • 100% of referrals received by Australian Hearing are confirmed to the referral agency within 5 days • >97% of families attend appointment within three weeks of the referral. • Australian Hearing confirms attendance at initial appointment of all referred newborns. • >85% of children diagnosed with bilateral hearing loss >40 dBHL are fitted with amplification by six months of age. • >95% of children diagnosed with a bilateral hearing loss >40 dBHL are fitted with amplification by 12 months of age. • >97% of children with 3FAHL of ≥ 90 dBHL at the initial diagnostic audiology appointment are offered referral for cochlear implant candidacy • Other children are offered a cochlear implant referral when appropriate to the family's program.²³ 	

²³ Other reasons for referral include: parents' wish to obtain information about cochlear implantation, child's functional auditory performance is measured to fall > 2 standard deviations below average for the child's age; aetiology of the hearing loss is one where research suggests that the child may benefit from a cochlear implant.



8.8 DEVELOPMENT OF A RISK MANAGEMENT STRATEGY

We are proposing that the SWISH monitory system include a Risk Management Strategy that will seek to define how the identified risks will be managed across the screening pathway to improve population coverage for infant hearing screening in New South Wales. It is expected that key risks will be identified as a key output of the current evaluation of the SWISH Program.

The strategy will acknowledge actual and potential threats to the successful achievement of SWISH objectives and will determine the activities required to minimise or eliminate them. Therefore the Risk Management Strategy will be integrated into the monitoring system.

Based on the identified Program risks it is proposed that quality management standards be formulated in order to address these risks.

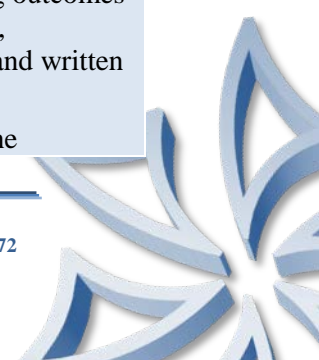
8.9 QUALITY MANAGEMENT STANDARDS

As previously discussed we are proposing that quality management standards be formulated to address the key risks of achieving SWISH Program objectives across the screening pathway. It is essential that these standards are aligned to the future National Neonatal Hearing Screening Framework and the current New South Wales SWISH Program Guidelines.

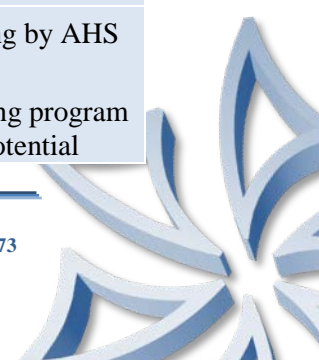
At this stage the National quality standards (presented in Table 8.2 below) should be regarded as illustrative and will be the subject of consultation and refinement.

Table 8.2: Proposed National Quality Standards

Quality Standards	Target
<p>1. Screening performance</p>	<ul style="list-style-type: none"> • All parents provided with sufficient information in a culturally and linguistically appropriate format to allow informed decision making • Easily accessible written information is provided to parents across the screening pathway • Consent is provided by parents/guardians to perform the screen • Refusals to perform screening are recorded appropriately in the infants medical file • 97% eligible newborns to complete a hearing screen before one month corrected age • All newborns with a ‘refer’ result are referred for diagnostic hearing assessment • All babies admitted to NICU and Special Care units for more than 5 days are screened using AABR screening protocol • Parents provided results of screening outcomes is in a culturally appropriate manner, sensitively and effectively verbally and written form • All screening programs to achieve the



Quality Standards	Target
	<p>following performance indicators:</p> <ul style="list-style-type: none"> – 97% eligible newborns receive hearing screen by one month corrected age. – <4% newborns referred for diagnostic assessment – 97% parents/families consent to diagnostic assessment – 100% referrals to diagnostic assessment are made within 5 days
<p>2. SWISH parent support staff (social worker) performance</p>	<ul style="list-style-type: none"> • SWISH parent support services are available to any infant who has accessed the program • SWISH parent support service has developed a referral system to ensure capture of all families who require the assistance of SWISH parent support services • SWISH parent support service conduct ongoing evaluation of what type of parent support is appropriate for and required by each individual family, e.g. parents of infants who have been diagnosed with a hearing impairment • SWISH parent support services develop service delivery models that are appropriate to the needs of the families commensurate with the resources available. The service delivery models incorporate consideration of: <ul style="list-style-type: none"> – Cultural and linguistic needs of families – Socioeconomic status of families accessing their service – Special needs of individual families – Geographical location for families to access the service – Support requirements of individual families • Documentation is maintained on all contacts made with families by the SWISH parent support services, including referral to other agencies in a medical type file, as appropriate to the service • All screening programs to achieve the following parent support performance indicators: <ul style="list-style-type: none"> – 97% parents/families offered support
<p>3. Data collection and management</p>	<ul style="list-style-type: none"> • Monthly data collection and reporting by AHS programs • Evidence that data is used for ongoing program management, planning, follow-up potential



Quality Standards	Target
	<p>screening errors, evaluation and monitoring</p> <ul style="list-style-type: none"> • Appropriate data collection and management systems implement to enable efficient data extraction and maintenance of relevant electronic information privacy policies • SWISH Audiology Services collect data regarding the SWISH program infants offered audiological assessment • Evidence that SWISH Audiology Services use these data are used to monitor the performance of the program and statewide level • Evidence that SWISH Audiology Services used these data for ongoing operation of service to ensure that all babies referred from screening are offered diagnostic audiology services, and that they subsequently attend for diagnostic audiology services within the required timeframes • Audiological services have developed appropriate data collection and management systems which allow for easy extraction of information whilst maintaining the relevant electronic information privacy policies • Audiological services report data from infants referred as a result of the SWISH newborn hearing screening program on a monthly and ongoing basis to the Department of Health for collation of the statewide data
<p>4. Management of babies with risk factors</p>	<ul style="list-style-type: none"> • Newborns identified as having risk factors for late onset or progressive hearing loss receive ongoing management of their hearing status • An audiological assessment is performed in the following circumstances: <ul style="list-style-type: none"> – Parental or professional concern about the infant’s hearing, development of auditory or vocal behaviour – Any craniofacial abnormalities • Family history of permanent sensorineural hearing loss (SNHL) from early childhood (in parents and siblings only) • NICU child who had intermittent positive pressure ventilation for more than 5 days • Jaundice or hyperbilirubinaemia requiring exchange transfusion • Neurodegenerative or neurodevelopmental disorders • Ototoxic drugs with levels outside the



Quality Standards	Target
	<p>therapeutic range</p> <ul style="list-style-type: none"> • Proven or possible congenital infection due to one of the following: <ul style="list-style-type: none"> – Toxoplasmosis – Rubella – Cytomegalovirus – Herpes
<p>5. Diagnosis</p>	<ul style="list-style-type: none"> • Audiological Assessment should be offered to all newborns who: <ul style="list-style-type: none"> – Receive a ‘refer’ result in either or both ears following the completion of the second screening event – Are unable to be screened due to screening exclusion criteria • Referrals for audiological assessment should be made by the SWISH Area Coordinator in consultation with the relevant paediatric audiologist
<p>6. Parent/Guardian Consent</p>	<ul style="list-style-type: none"> • Protocols developed for the documentation of refusals by parents/guardians for diagnostic audiology services • SWISH Area Coordinator requests the infant’s parent/guardian for consent to make a referral to diagnostic audiology and for information to be released, prior to a referral for audiological assessment • SWISH Area coordinator provides the audiological service with comprehensive referral information so that the audiological service can contact the family to organise an assessment appointment • Where further referral is required following audiological assessment the audiologist obtains consent for releasing the infant’s information to other clinical services and organisations (e.g. Australian Hearing) • Where a parent/guardian refuses audiological assessment the audiology service: <ul style="list-style-type: none"> – Provides information to the parent/guardian regarding the relevance and importance of audiological assessment and assessment re-offered, either in the immediate future or at a delayed interval • Where a parent passively refuses attendance, the family will be referred to the SWISH parent support (social worker) service to



Quality Standards	Target
	<p>evaluate if extra assistance is required for the family to attend diagnostic audiology services</p> <ul style="list-style-type: none">• The relevant SWISH Area Coordinator may also be contacted to determine if assistance to attend an audiological appointment can be offered by the SWISH Area Coordinator• Where a parent ultimately refuses to attend for diagnostic audiological assessment the infant should be referred back to the GP/Paediatrician for local monitoring and follow up if available





APPENDIX A – AUSTRALIAN AND INTERNATIONAL UNHS PROGRAMS

A.1 AUSTRALIAN UNHS PROGRAMS

This section provides a discussion of the evidence base for the implementation of UNHS programs in Australia and a brief description of the UNHS programs that have been implemented in Victoria, Queensland and South Australia. In addition we have provided a brief discussion of the proposed implementation of a National Framework for UNHS.

A.1.1 THE EVIDENCE BASE

In Australia there have been three published reports addressing the delivery of UNHS programs in Australia. The first report was published by the National Health and Medical Research Council in March 2002 which reviewed the evidence base for child health screening and surveillance. This report recommended a national approach to neonatal hearing screening, and identified the need to consider the logistics and quality of the testing system together with follow up systems for babies identified with hearing loss, before the implementation of a national neonatal hearing screening program.

The second report was published in 2008 by the Commonwealth Medical Service Advisory Committee²⁴ and addressed issues concerning the safety, effectiveness and cost-effectiveness of universal neonatal hearing screening. This report did not make recommendations for the establishment of a national neonatal hearing screening program.

The third report was published in March 2008 by the Screening Subcommittee of the Australian Population Health Development Principle Committee and assessed neonatal hearing screening against the Population Based Screening Framework²⁵. This framework is based on the World Health Organisation principles and was developed based on the available evidence and consideration of existing Australian population screening programs.

Australian UNHS programs have been progressively implemented by state and territory health jurisdictions with New South Wales being the first state to implement the program in 2002. The following sections provide a brief summary of the other infant hearing screening programs that have been implemented. Whilst acknowledging UNHS programs have been implemented across all states and territories, there is limited publicly available information and hence a summary of programs that have been implemented in Victoria, Queensland and South Australia is provided.

24 Medical Service Advisory Committee (2007) "Universal Neonatal Hearing Screening"
[http://www.health.gov.au/internet/msac/publishing.nsf/Content/8FD1D98FE64C8A2FCA2575AD0082FD8F/\\$File/ref17.pdf](http://www.health.gov.au/internet/msac/publishing.nsf/Content/8FD1D98FE64C8A2FCA2575AD0082FD8F/$File/ref17.pdf)

25 Australian Population Health Development Principal Committee, Screening Subcommittee (2008) "Population Based Screening Framework"
[http://www.health.gov.au/internet/screening/publishing.nsf/Content/pop-based-screening-fwork/\\$File/screening-framework.pdf](http://www.health.gov.au/internet/screening/publishing.nsf/Content/pop-based-screening-fwork/$File/screening-framework.pdf)

A.1.2 VICTORIAN INFANT HEARING SCREENING PROGRAM (VIHSP)

The Victorian Infant Hearing Screening Program²⁶ (VIHSP) was implemented in 1992. The program aims to detect bilateral moderate, severe or profound congenital hearing impairment and is not designed to reliably detect mild hearing loss (though some mild losses will be detected because of the screen). The screen will also detect unilateral losses (i.e. hearing loss in one ear, with normal hearing in the other ear).

In February 2003, the VicNIC program was established with weekday screening in the four neonatal intensive care units in Victoria. It aims to offer a pre-discharge hearing screen to all babies admitted to the neonatal intensive care or special care nurseries of the Royal Women's Hospital, the Mercy Hospital for Women, the Royal Children's Hospital and Monash Medical Centre. In the first 18 months of the program's operation, 2200+ babies were screened. 40 babies with a moderate or greater hearing impairment were identified through the program, with some only a few weeks old (corrected age) when diagnosed. These screens will continue as part of the expanded VIHSP. Infant hearing screening programs are also currently conducted by some regional hospitals in Victoria.

A.1.3 QUEENSLAND HEALTHY HEARING PROGRAM

The Healthy Hearing Program²⁷ in Queensland commenced in October 2004 at the major tertiary hospitals: the Royal Brisbane and Women's Hospital, the Mater Hospital, and the Townsville Hospital. Up to December 2006, the program was progressively rolled out across the state to both public and private birthing hospitals. In 2007, additional processes were put in place to ensure that parents of babies born outside of hospitals or unexpectedly at hospitals which do not usually offer birthing, were offered hearing screening.

The program aims to improve health outcomes for Queensland children through the earliest possible detection and management of permanent childhood hearing loss. Newborn hearing screening is the first stage of a comprehensive approach to communication development which includes further assessment and early intervention. The program aims to systematically monitor its performance and be alert and responsive to emerging evidence in this field.

A.1.4 SOUTH AUSTRALIA UNIVERSAL NEONATAL HEARING SCREENING PROGRAM (UNHSP)

South Australia commenced a pilot UNHSP program in August 2002 across three metropolitan hospitals and two country hospitals, establishing protocols for a state-wide UNHSP. In 2004 the South Australian Minister for Health announced that the UNHSP would be permanently funded and implemented across the state by the end of 2005. A state-wide rollout of the UNHSP was completed in February 2006, incorporating the 33 birthing and 12 non-birthing hospitals in South Australia.

The Program is a statewide service coordinated by the Children, Youth and Women's Health Service in South Australia. The Program provides free hearing screening to all new born babies to ensure early detection and implementation of intervention strategies for hearing loss.

A.1.5 NATIONAL FRAMEWORK FOR UNHS

Based on recent statistics published by the Department of Health and Ageing, approximately 75% of newborns are screened across Australia. This varies from over 95% in some states and territories to less than 40% in other states.

26 Victorian Infant Hearing Screening Program website http://www.rch.org.au/vihsp/info.cfm?doc_id=7684

27 Queensland Healthy Hearing Program Universal Newborn Hearing Screening Program website <http://www.health.qld.gov.au/healthyhearing/>

In Australia the need for a National Framework for universal neonatal hearing screening and early management of interventions has been widely acknowledged. This national approach was formalised in June 2009, with the Australian Government seeking a commitment from States and Territories to implement standardised Universal Newborn Hearing Screening in all states and territories for all Australian babies from 1 January 2011.²⁸

Under this initiative, work has been progressing at both National and NSW Health levels that have involved the development of draft national standards for screening and post screening follow up and a national quality and reporting framework that is supported by a national data collection system and clinical standards.

Staff from NSW Department of Health, Community and Government Relations Unit have been actively involved in the development of the national standards and have demonstrated a high level of commitment to the principles of best practice in implementing a universal newborn hearing screening program in NSW focusing on quality, monitoring and evaluation.

A.2 INTERNATIONAL UNHS PROGRAMS AND BENCHMARKS

This section provides a brief summary of the UNHS programs that have been implemented internationally and the associated best practice principles and performance benchmarks.

A.2.1 INTERNATIONAL BENCHMARKS AND PERFORMANCE INDICATORS

As previously discussed the JCIH through a series of regularly updated position statements provides international guidelines and an evidence base on benchmarking and quality indicators.

The following performance benchmarks represent a consensus of expert opinion in the field of newborn hearing screening and intervention and according to the JCIH, are the minimal requirements that should be attained in the delivery of high-quality UNHS programs.

QUALITY INDICATORS FOR SCREENING

- Percentage of all newborn infants who complete screening by 1 month of age; the recommended benchmark is more than 95% (age correction for pre-term infants is acceptable).
- Percentages of all newborn infants who fail initial screening and fail any subsequent rescreening before comprehensive audiological evaluation; the recommended benchmark is less than 4%.

QUALITY INDICATORS FOR CONFIRMATION OF HEARING LOSS

- Of infants who fail initial screening and any subsequent rescreening, the percentage who complete a comprehensive audiological evaluation by 3 months of age; the recommended benchmark is 90%.
- For families who elect amplification, the percentage of infants with confirmed bilateral hearing loss who receive amplification devices within 1 month of confirmation of hearing loss; the recommended benchmark is 95%.

QUALITY INDICATORS FOR EARLY INTERVENTION

- For infants with confirmed hearing loss who qualify for Part C services, the percentage for whom parents have signed an IFSP be no later than 6 months of age; the recommended benchmark is 90%.

28 Kevin Rudd Press Release (29 June 2009) "Hearing Screening for All Australian Babies"
http://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/E68U6/upload_binary/e68u60.pdf;fileType%3Dapplication%2Fpdf

- For children with acquired or late-identified hearing loss, the percentage for whom parents have signed an IFSP within 45 days of the diagnosis; the recommended benchmark is 95%.
- The percentage of infants with confirmed hearing loss who receive the first developmental assessment with the standardised assessment protocols for language, speech, and nonverbal cognitive development by no later than 12 months of age; the recommended benchmark is 90%.²⁹

A.2.2 EVALUATION OF UNHS PROGRAM PERFORMANCE – INTERNATIONAL COMPARATIVE STUDY

A study of UNHS programs in 46 countries was conducted that assessed the adherence of these programs to the JCIH published benchmarks.³⁰ 26 of these countries were classified as high income by the World Bank, 18 as middle income and 2 as low income.

The study also explored other factors of these programs including type, extent, delivery mechanisms, screening processes and the type of technology used which might impact on the ability of these countries to meet these benchmarks.

STUDY METHODOLOGY

The study methodology was based on data collected from a 2004 survey of early hearing detection programs; responses to a 2006 survey of audiologists undertaken by the authors; a literature review of 55 articles, reports and internet sources from 1995 to 2007; and one 2006 Market Research Report.

The criterion for undertaking the comparative analysis of the UNHS programs against the benchmarks set by the Joint Committee on Infant Hearing (JCIH) in 2007 was as follows:

- **Screening coverage.** At least 95% of all newborn infants should complete their hearing screening by 1 month of age (age correction for preterm infants is acceptable).
- **Referral rate.** Less than 4% of all newborn infants should get a refer result from their initial screening and any subsequent rescreening before being referred for comprehensive audiological evaluation.
- **Follow-up rate.** Of infants who get a refer result at initial screening and any subsequent rescreening, at least 90% should complete a comprehensive audiological evaluation by 3 months of age.

SUMMARY OF UNHS PROGRAM ANALYSIS

The analysis presented in Table A.1 below focuses on data from high income countries as it provides a more relevant comparison to the SWISH Program.

Table A.1: Summary of UNHS Program Analysis Relative to JCIH Performance Targets

Data Set	JCIH Benchmark	Achieved Result
National screening coverage (n=14)	95%	48%
Regional/local screening coverage (n=19)	95%	71%
Referral rate (n=17)	<4%	6%

²⁹ *Ibid* pp. 914-915.

³⁰ Tann, J., Wilson, W., Bradley, A., Wanless, G. (2009). "Progress towards Universal Neonatal Hearing Screening: A World Review" *The Australian and New Zealand Journal of Audiology*. 31(1), p. 3.

Follow-up rate (n=9)	>90%	75%
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This analysis shows that:

1. **Screening coverage.** Of the 14 high income countries where data on national screening coverage were available, the average coverage was 48% this was lower than the JCIH benchmark of 95% or more. In the 19 jurisdictions where data on regional or local screening coverage were available, the average coverage was 71% (JCIH recommends 95% or more).
2. **Referral rate.** Of the 17 high income countries in the study the referral rate was approximately 6% which are higher than the JCIH benchmark of less than 4%.
3. **Follow-up rate.** There were only 9 high income countries where follow-up data were available; the average follow-up rate was 75% which is lower than the average JCIH benchmark of over 90%.

These results highlight screening coverage and follow-up rate as the major inhibitors to the success of UNHS programs in many countries where UNHS programs have been implemented.

NEONATAL SCREENING COVERAGE

The UNHS study also identified the top five countries with neonatal screening coverage that are managed at the national level which are presented in Table A.2 below with respect to:

- Highest average coverage for neonatal screening at the national level
- Comparative regional coverage
- Characteristics of each program

Table A.2: Top 5 Countries with Neonatal Screening Coverage that are Managed at the National Level

Country	Average National Coverage	Comparative Regional Coverage	Program Characteristics
USA	95%	95%	Mandated, Regional, Universal, Hospital
Austria	90%	90%	Mandated, National, Universal, Hospital
Australia ³¹	77%	77%	Regional, Universal, Targeted, Hospital
Singapore	77%	77%	National, Universal, Hospital
UK	75%	90%	Mandated, National, Universal, Hospital & home visit

Whilst it is important to acknowledge that with the exception of the USA, these countries have not met the JCIH screening coverage benchmark of 95%, the common elements of these programs that may explain these higher coverage rates could be attributed to:

- 3 out of 5 countries have mandated screening, where screening is either supported by legislation or is common practice. Those countries with the lower screening coverage did not have mandated screening
- All countries offered universal screening to all babies, as opposed to only targeting ‘at risk’ babies

³¹ Based on our review of the published article the evaluators have not been able to identify the Australian data sources. The UNHS study findings are not representative of the performance of the NSW SWISH Program. Analysis of the performance of this program is presented in chapter 5.



- All countries were classified as high income countries and had hospitals from where screening was made available. The UK was the only country that made screening available outside of hospitals, which potentially could increase the coverage if babies are discharged without being screened

Possible explanations for why these screening numbers do not meet the JCIH benchmarks include:

- The variances observed between regional and national coverage has the potential to negatively skewed the national coverage data (e.g. in the UK)
- At the national coverage level, targeted screening programs for ‘at risk’ babies not aim to maximise coverage (e.g. in Australia)

REGIONAL SCREENING COVERAGE

Table A.3 below shows the screening coverage for the reported top five high income countries where programs are managed at the regional level with available data in terms of the:

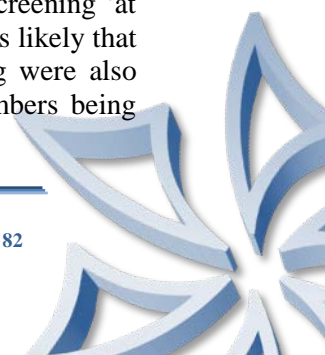
- Highest average coverage for neonatal screening programs implemented at the regional/local level
- Comparative national coverage
- Characteristics of each program

Table A.3: Neonatal Screening Coverage where Programs are managed at the regional level - from Top 5 High Income Jurisdictions

Country	Average Regional Coverage	Comparative National Coverage	Program Characteristics
Italy	99%	30%	Mandated, Regional, Universal, Targeted, Hospital
Ireland	96%	NA	Mandated, Regional, Targeted, Trial/Pilot, Hospital, Clinic
USA	95%	95%	Mandated, Regional, Universal, Hospital
Belgium	94%	54%	Mandated, Regional, Universal, Targeted, Clinic
New Zealand	94%	NA	Mandated, Regional, Universal, Targeted, Trial/Pilot, Hospital

The UNHS study identified that the regional screening covered for 3 of the 5 high income countries met or exceeded the JCIH screening coverage benchmark of 95% and the performance of the remaining 2 fell just below. Common attributes of these programs that may explain higher screening coverage included:

- All countries have mandated screening, where screening is either supported by legislation or is common practice.
- With the exception of Ireland (that run only targeted screening) a combination of universal and targeted screening programs has been implemented. It is important to note that the availability of targeted screening at the regional/local level may positively skew these figures, as screening ‘at risk’ babies greatly reduces the number of infants required to be screened and it is less likely that infants will miss screening. Additionally, 2 countries that offer targeted screening were also conducting their screening programs as trials, which again may lead to small numbers being screened, but high percentage of coverage.



- All of the leading countries were classified as high income countries and had hospitals or specialised clinics from where screening was made available. At the regional/local level, 3 of the 5 countries had screening programs available in hospitals, and the remaining 2 countries utilised screening clinics, which may have increased screening outreach.

REFERRAL RATES

Whilst the average referral rate for high income countries as a whole did not meet the JCIH benchmark (4% or lower), the five countries listed in Table A.4 below met and exceeded the JCIH benchmark. It is important to note that due to the management of the programs at regional/state in Australia and the USA, more than one type of technology and more than one screening program were used by the reviewers in the analysis.

Table A.4: Average Referral Rate for High Income Countries

Country	Technology Type	Screening Stages	Average Referral Rate
Singapore	AOAE & Automated ABR	2	0.6%
Australia	AOAE, Automated ABR or combination of both	2, 3	0.7%
Cyprus	AOAE & Automated ABR	3	2.0%
Netherlands	AOAE & Automated ABR	3	2.2%
USA	AOAE, Automated ABR, or combination of both	1,2	2.5%

Common attributes of these programs that may explain the achievement against the JCIH benchmark included:

- Excluding Australia and the USA due to the regional nature of the programs, the other countries utilised both Automated ABR and AOAE technology. Whilst the Automated ABR is generally recognised to yield lower referral rates, the AOAE testing is utilised for the initial screening, followed by the Automated ABR for rescreening to reduce the likelihood of a false positive.
- The multiple screening stages may have resulted in false positives being corrected.

FOLLOW-UP RATES

Based on the published literature there were only 9 of the 26 high income countries reported screening follow up rates. Table A.5 below summarises the top five countries with the highest average follow-up rates. We are unable to comment on specific issues relating to the follow-up rates such as the reasons for refer screening results requiring follow-up or the staff responsible for these processes as this information is not published.

Table A.5: Top 5 Countries – Follow Up Rates

Country	Average Follow Up Rate
Hong Kong	95%
Netherlands	94%
Italy	90%
Taiwan	89%
Germany	80%



There were 3 countries that met or exceeded the JCIH benchmark of 90%, whilst 2 countries did not achieve the target. Whilst the UNHS review did not directly assess the possible factors contributing to follow up rates, however possible explanations may include:

- Cultural and societal norms about attending hospital appointments
- Parents accepting testing
- Functional and efficient administrations systems
- Ability for people to travel to hospitals or have access to screening if they do not

LIMITATIONS OF STUDY FINDINGS

It is important to note that Tann et al acknowledged two significant limitations of the study findings. The first issue related to the incompleteness of the dataset as not all countries reported data against every criterion. The second related to the currency of the data (the analysis was based on data collected from 2003 to 2007, with the majority being dated from 2004 to 2005).

The reviewers considered that these limitations demonstrated the need for improved reporting requirements for all UNHS programs, as recommended by the JCIH (Joint Committee on Infant Hearing, 2007), to facilitate a more comprehensive review of UNHS programs.

A.3 INTERNATIONAL INFANT HEARING SCREENING PROGRAMS

Based on our review of the published literature UNHS programs have been implemented in 46 countries across North America, Europe, Asia, the Middle East, Oceania and Africa. The management of these programs vary (operating at national and regional/local levels) and have different screening delivery mechanisms (e.g. hospital, clinic, home based screening). In addition the published literature describing these programs varies and as a result comparison of the operations of these programs has not been possible. This section provides a summary of the four international UNHS programs that have been implemented including the:

- United States: Early Hearing Detection and Intervention (EHDI) Program
- England: National Health Service New Born Hearing Screening Programme (NHSP)
- Canada: Universal Newborn and Infant Hearing Program (UNIHP)
- New Zealand: Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)

A.3.1 UNITED STATES: EARLY HEARING DETECTION AND INTERVENTION (EHDI) PROGRAM

EHDI programs in the United States are managed at state or territory level and are designed to identify infants with hearing loss. Infants identified with hearing loss can then be enrolled in an early intervention program. Early intervention programs are designed to help infants and children develop communication skills needed to do well academically and socially. Communication skills can be learned through visual language, spoken language, or both.³²

EHDI LEGISLATION

In March 1993, the NIH Consensus Development Conference recommended that all babies be screened for hearing loss before being discharged from the hospital. At that time, only two states, Hawaii and Rhode Island, had legislative mandates, requiring newborn hearing screening for all babies

32 National Center for Hearing Assessment and Management <http://www.infantheating.org>

born in the state. As more newborn hearing screening programs were implemented and policy makers and the public became more aware of the benefits associated with such programs, legislative actions increased. Now there are 42 states (plus the District of Columbia and Puerto Rico) with universal newborn hearing screening statutes.

It is important to note that legislation outlines the minimum expectations of state policy makers, but does not necessarily define all that state newborn hearing screening programs are doing. For example, Rhode Island has one of America's best tracking and reporting systems, reports data to the Department of Health, and has an Advisory Committee, even though none of these issues are addressed in legislation.³³

EHDI GUIDELINES

As programs have evolved, States have developed information and guidelines to ensure that screening results are valid and that programs run efficiently and effectively. In addition the guidelines support the establishment and maintenance of the newborn hearing screening programs. A review of a number of state EHDI guidelines^{34,35,36} indicate there are some variations in the way programs operate, however there are minimal requirements for hospital based universal newborn hearing screening including the following:

- Each hospital or birthing centre should screen all births using a physiological hearing screening method prior to initial hospital discharge
- Each hospital should provide outpatient rescreening for babies who were missed or are referred from the initial screen. Outpatient screening should be scheduled at the time of the initial discharge and completed between 2-6 weeks of age
- When a baby is referred from the inpatient and outpatient hearing screening, the hospital or birthing centre's role should include linking the family to a medical home and appropriate audiological assessment
- Each hospital should develop collaborative partnerships with the local state program coordinators and the audiology and early intervention community

A.3.2 ENGLAND: NATIONAL HEALTH SERVICE NEW BORN HEARING SCREENING PROGRAMME (NHSP)

The NHS Newborn Hearing Screening Programme (NHSP)³⁷ was implemented by the Department of Health following a report in 1997 which demonstrated that the previous way in which early hearing impairment was detected missed a large number of children and that almost a quarter of children born deaf in the UK were not identified until they were three and a half or older. From March 2006, all eligible babies born in England are offered the screen.

This national program aims to identify moderate, severe and profound deafness and hearing impairment in newborn babies. The program automatically offers all parents in England the opportunity to have their baby's hearing tested shortly after birth. Early identification through screening, gives babies a better 'life chance' of developing speech and language skills, and of making the most of social and emotional interaction from an early age.

Newborn hearing screening is undertaken in a variety of settings, including hospital, the baby's home, clinic or surgery. It involves the use of specific equipment and liaison with parents, health

33 Vohr BR, Carty LM, Moore PE, et al. 1998. The Rhode Island Hearing Assessment Program: Experience with statewide hearing screening (1993-1996). *J. Pediatr.* 133:353-357.

34 Connecticut Department of Public Health (2008) "EDHI Guidelines for Infant Hearing Screening" http://ct.gov/dph/lib/dph/family_health/edhi/pdf/j_hosp_ehdi_guidelines.pdf

35 Massachusetts Department of Public Health "EDHI Guidelines" http://www.infanthearing.org/guidelines/guidelines_unhs_massachusetts.pdf

36 Arizona Department of Health Services Sensory Program "Arizona Hospitals' Universal Newborn Hearing Screening 2001 Guidelines" http://www.infanthearing.org/guidelines/guidelines_unhs_arizona.pdf

37 NHS Newborn Hearing Screening Programme website <http://hearing.screening.nhs.uk/>

professionals and other staff, in particular the midwifery and health visiting teams. The hearing screen is offered either in hospital prior to discharge home (75% of NHSP screening sites) or by the health visitor at about 10 days of age (25% of NHSP screening sites). Screening would usually take place while the baby is settled or in natural sleep.

QUALITY ASSURANCE AND RISK MANAGEMENT STRATEGY

The NHS has implemented a Risk Management Strategy for the period 2007-2010 that sets out a high level plan for addressing potential risks faced by the NHSP from both a national and local perspective and ensuring lessons from incidents are shared in order to prevent recurrence. This strategy acknowledges that whilst risk cannot be completely eliminated it can be minimised and managed. The key focus is on ensuring that the objectives of the programme are met.

RISK MANAGEMENT STRATEGY OBJECTIVES

This strategy focuses on risks that arise at a national level and/or best addressed at national level. It complements but does not supersede local risk management strategies and processes which are the responsibility of local management.

Following the national implementation of the NHSP, the Program Centre's primary focus was on the ongoing maintenance and improvement of the program. The performance of the NHSP is measured against national Quality Standards set by the Program Centre and managed through a national quality assurance and risk management framework. The framework aims to ensure minimum standards are met and exceeded by improving the performance of all aspects of hearing screening, diagnosis, management and early intervention for hearing impaired children and their families.³⁸

RISK MANAGEMENT ASSURANCE FRAMEWORK

The Risk Management Assurance Framework³⁹ has been developed that provides a model for reporting key information to the program Director, Quality Assurance Board and other key stakeholders. The framework identifies which of the organisation's objectives are at risk due to inadequacies in the operation of controls or where the organisation has insufficient assurance about them.

EVALUATION OF PARENT SATISFACTION

Information to evaluate the level of parent satisfaction with the screen program can be used for quality improvement purposes to develop better services, prevent program rejection and demonstrate the usefulness of a program. According to Bragadottir and Reed, parents who are satisfied with a health program will cooperate more effectively, show greater compliance with their child's treatment, and are more likely to return.⁴⁰

The JCIH advocates that quality intervention services should conduct annual surveys of parent satisfaction; there are no specific guidelines on how to evaluate screening programs. However, the rights of children and families feature prominently throughout the JCIH 2000 Position Statement and in order to ensure these are adhered to, an evaluation mechanism for screening needs to be in place.

To investigate the effectiveness of neonatal hearing screening programs and parent satisfaction, Mazlan et al developed the Parent Satisfaction Questionnaire with Neonatal Hearing Screening Program (PSQ-NHSP).⁴¹ Whilst the primary aims of the study were to conduct a comprehensive evaluation of parent satisfaction with neonatal hearing screening programs, it was recognised that there was no validated and reliable instrument available for such a comprehensive evaluation to take place. The PSQ-NHSP was developed through the following stages:

38 NHSP Program Centre. NHS Newborn Hearing Screening Program Quality Assurance Report 2006-2008. pp. 8-10.

39 NHSP Risk Management Assurance Strategy <http://hearing.screening.nhs.uk/cms.php?folder=1064>

40 Bragadottir, H., Reed, D. (2002). Psychometric instrument evaluation: the paediatric family satisfaction questionnaire. *Paediatric Nurse*, 28(5), pp 475-484.

41 Mazlan, R., Hickson, L., Driscoll, C. (2006). Measuring Parent Satisfaction with a Neonatal Hearing Screening Program. *Journal of American Academy of Audiology*, 17(4), pp. 253-264.

1. A literature review on parent perspectives of NHSPs was performed to identify relevant dimensions of satisfaction.
2. Four relevant dimensions of satisfaction were identified (information; personnel in charge of hearing testing; appointment activities; and overall satisfaction).
3. A twenty-eight item questionnaire was developed that incorporated Likert-type close-ended questions, multiple choice questions, open ended questions and relevant Client Satisfaction Questionnaire-8 (CSQ-8) questions.⁴²

The PSQ-NHSP was analysed for validity and reliability and reportedly demonstrated “excellent internal consistency reliability and excellent test-retest reliability.”⁴³ The authors drew attention to the low survey response rate (48%) and concluded that relying upon parents to return the survey via mail was a limitation and recommended that other survey distribution methods be trialled. Overall, the PSQ-NHSP was deemed a useful instrument for determining service deficits and was recommended for routine use in NHSPs.

- Training
- Funding and resource implications
- Health professionals’ perspectives
- Deaf professionals’ perspectives
- The perceived opportunities offered by the NHSP

A.3.3 CANADA: UNIVERSAL NEWBORN AND INFANT HEARING PROGRAM (UNIHP)

In Canada the UNIHP was initially introduced in Ontario in 2002. In response to growing interest in the field of early hearing and communication development (EHCD), the Health Surveillance and Epidemiology Division in Health Canada (now part of the Public Health Agency of Canada) established the Canadian Working Group on Childhood Hearing in September 2000. The Working Group was multidisciplinary and included representatives of national professional associations, a parent representative and experts in otolaryngology, audiology, speech-language pathology, deaf education, nursing, child health and public health from across Canada. Its mandate was to review and evaluate scientific evidence in areas essential to the development of EHCD programs, and to develop a report that could function as a resource document.⁴⁴

ONTARIO'S INFANT HEARING PROGRAM

Ontario’s UNIHP complements and substantially augments existing provincial services for Preschool Speech and Language Development. The key elements of the program include:

- Allocation of program specific funding to develop and deliver all necessary program services and supports
- Universal newborn hearing screening is conducted during the perinatal hospital admission and is augmented by follow-up community screening services
- Comprehensive services for confirmation of hearing impairment and diagnostic assessment are provided to inform medical and non-medical processes, as elected by the family
- Family psychological supports and provision of comprehensive, unbiased information about hearing and communication development options

42 Mazlan et al. (2006) *op.cit*

43 *Ibid.* pp 253

44 Canadian Working Group on Childhood Hearing (2005) “Early Hearing and Communication Development” http://www.phac-aspc.gc.ca/publicat/eh-dp/pdf/early_hearing_e.pdf

- High-quality services for provision of hearing aids and other assistive technologies
- Expanded provision of comprehensive and diverse communication development services
- Auxiliary sub-programs for detection of emergent hearing impairment in at-risk infants and in those who develop post-natal risk indicators for PCHI
- Educational and informational programs for families and hearing healthcare professionals

The key infrastructural elements that facilitate provision of high-quality, integrated services include, but are not limited to:

- Evidence-based protocols for screening, audiological assessment and provision of assistive technology
- Comprehensive information systems to ensure reliable tracking of infants and recording of outcomes
- Extensive training programs for personnel involved in screening, assessment
- Assistive device provision
- Family support and communication options provision, communications development for families and professionals
- Administrative systems to ensure necessary operations including supplies and services
- A substantial subprogram for evaluation and quality improvement

The overall screening model is based on centralised planning, development and quality management, combined with regionally adapted implementation that reflects local consumer needs and infrastructure.

A.3.4 NEW ZEALAND: UNIVERSAL NEWBORN HEARING SCREENING AND EARLY INTERVENTION PROGRAMME (UNHSEIP)

New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) was implemented as a national screening programme in 2007 and is scheduled to be completed in 2010. Once the programme is implemented; 21 District Health Boards (DHBs) will be offering newborn hearing screening to every eligible baby born in their area, whether they are born in hospital or at home, within a framework of nationally consistent policies, standards and guidelines.

The aim of the UNHSEIP is for 'early identification of newborns with hearing loss so that they can access timely and appropriate interventions, inequalities are reduced and the outcomes for these children, their parents and families/whānau, communities and society are improved. The program is not designed to identify babies with mild hearing losses. When the screening programme is fully implemented, it is estimated that between 80 and 120 babies each year will be identified with hearing losses of a sufficient degree to require Early Intervention Services funded by the Ministry of Education.

NATIONAL POLICY AND QUALITY STANDARDS

In January 2009, New Zealand developed National Policy and Quality Standards⁴⁵ that provide information about the UNHSEIP, to increase knowledge and understanding, and to assist Programme service providers to achieve minimum standards of good practice. These standards form part of the contract between the Ministry of Health and District Health Boards (DHBs), for the provision of newborn hearing screening services.

45 Ministry of Health, New Zealand (2009) "Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards"
http://www.nsu.govt.nz/Files/National_Policy_and_Quality_Standards_January_2009.pdf

The UNHSEIP National Policy and Quality Standards are intended to provide information about the Programme, to increase knowledge and understanding, and to assist all providers involved in the Programme to achieve minimum standards of good practice. It is also expected that all those involved in Programme provision will meet their professional and ethical standards as well as their legal obligations, including adherence to health legislation and any legislation related to the privacy of health information.





APPENDIX B – NHSP QUALITY STANDARDS AND TARGETS

	Standard	Target
1	Appropriately trained interpreters available when required	All
2	Parents to have written and verbal information on hearing screening in the ante natal period	All
3	Maternity notification to eSP	90% < 6 hours
4	Mother to have written & verbal info about the screen & data storage	All
5	Mother to be offered Newborn Hearing Screen	99%
6	Screen Started	98%
7	Screening tests completed within 4/5 weeks	95%
8	Decline screen	0.1%
9	No Clear Response rate	Varies dependent on stage of screen
10	Screening Outcomes set	99% < 3 months
11	Archiving screening data	All < 6 weeks
12	Screening data accuracy	98% electronic (Hosp); check data (comm.)
13	Checklists for appropriate language and auditory behaviour development	All – screening and audiology
14	Referral for audiological assessment and targeted follow up	All < 3 working days
15	Follow up of referrals with initial audiological assessment with exceptions for diagnostic reasons	All offered < 4 weeks; All offered < 9 months
16	PCHI cases confirmed and entered into eSP	80% by 6 months, 98% by 12 months
17	Explanation of assessment and result	Same day as assessment
18	Explanation of deafness and support mechanisms	Early support info given
19	Referral for aetiological Investigations and paediatric assessment	All with PCHI
20	Informing Education/Support Services	Education informed < 1 working day; education contact family < 1 working day; visit offered < 2 working days
21	Availability of early support	Explanation of support
22	Ongoing co-ordinated support	Main professional contact



	Standard	Target
23	Hearing aid fitting offered for confirmed cases of hearing loss	All offered < 4 weeks
24	Parents to be informed and supported with respect to developing early communication with their child	Full range of communication options
25	Access to family care support	Routine access for all
26	Support for children with complex needs	Complex needs responded to < 1 week
27	Children's Hearing Services Working Group (CHSWG)	Does one operate locally, and appropriately?



APPENDIX C – REVIEW OF INTERNATIONAL MONITORING SYSTEMS

C.1 REVIEW OF INTERNATIONAL MONITORING SYSTEMS

Having identified the issues relevant to designing and implementing a monitoring framework for the SWISH Program, HOI reviewed the program monitoring systems that have been implemented in four countries including the:

- USA: Early Hearing Detection and Intervention Program – Quality Assurance and Improvement
- UK National Health Service: Newborn Hearing Screening Programme – Quality Assurance Framework
- Canada: Early Hearing and Communication Development Program - Program Evaluation and Quality Improvement
- New Zealand: Universal Newborn Hearing Screening and Early Intervention Program

In considering these systems we have added comments about the possible application of a particular approach in the SWISH Program context.

C.1.1 USA: EARLY HEARING DETECTION AND INTERVENTION PROGRAM – QUALITY ASSURANCE AND IMPROVEMENT

The Resource Guidelines⁴⁶ for the National Center for Hearing Assessment and Management provide details regarding the quality assurance and improvement processes for the EHDIP. Program evaluation has been identified as an essential requirement for improving the effectiveness, cost efficiency, and overall sustainability of this Program. Outcomes are used to determine and improve clinical care, cost effectiveness, and sustainability. All states and territories in the US receiving EHDIP funding are required to undertake systematic annual evaluations of their programs to implement, expand, and improve the EHDI program.

EDHI PROGRAM EVALUATION

The state based EDHI program evaluations focus on the key elements of an effective EHDI program. There are seven major components and/or standards that have been described by the Joint Committee

⁴⁶ National Center for Hearing Assessment and Management “A Resource Guide For Early Hearing Detection and Intervention” <http://www.infanthearing.org/ehdi-ebook/>

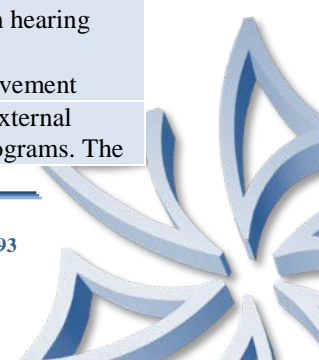
on Infant Hearing (JCIH). These components provide the minimum standard elements upon which evaluation of EHDI programs that focus on the following key performance measures:

- All newborns will be screened for hearing loss before 1 month of age
- All infants referred from screening will have diagnostic evaluations before 3 months of age
- All infants identified with hearing loss will receive appropriate medical, audiological, and educational intervention services before 6 months of age
- All infants with hearing loss will have a medical home
- Every state will have a complete EHDI Tracking and Surveillance System to minimize loss to follow-up
- All families will receive culturally competent family support
- Every state will do regular systematic monitoring and evaluation to improve the effectiveness of the EHDI program

EHDI EVALUATION PROCESSES

There are three key evaluation processes that are undertaken by each state as outlined below.

Hospital questionnaires	<p>Each hospital in the state is invited to complete a questionnaire regarding the newborn hearing screening program. Data is collected regarding:</p> <ul style="list-style-type: none"> • The hospital's screening protocol • Equipment and practice, follow-up, referral for diagnosis • Satisfaction with the program, obstacles that have been encountered, areas in which assistance is needed, and satisfaction with previous assistance and support provided by the state Department of Health <p>Prior to distribution, members of the state's newborn hearing screening advisory committee for suggested revisions may review drafts of the questionnaire</p>
Analysis of tracking data	<p>Hospitals in most states use an information management system to submit data to the state Department of Health regarding the:</p> <ul style="list-style-type: none"> • Number of babies born • Number of babies screened • Results of screening • Follow-up activities • Information about referral and diagnosis <p>An external evaluation team analyses these data to identify the strengths and weaknesses of the program. The analysis of tracking data is used to identify areas where additional technical assistance and training are indicated</p>
Questionnaires to parents	<p>Surveys are conducted of a random sample of parents whose babies were screened during a defined time period. The focus of the survey is to obtain the views of parents about:</p> <ul style="list-style-type: none"> • Their perceptions of the screening program • What they saw as the strengths and weaknesses • Suggestions for improving the program <p>The sample of parents include those who passed the inpatient screening, did not pass the inpatient screening but passed an outpatient screening, and did not pass either the inpatient or outpatient screening</p>
Questionnaires to physicians	<p>A random sample of physicians who are the primary health care provider for babies who are screened is also conducted. The focus of this survey is to collect data on:</p> <ul style="list-style-type: none"> • Physician attitude and knowledge about the universal newborn hearing screening program • The strengths, weaknesses and suggestions for program improvement
Onsite Hospital Visits	<p>Site visits to a sample of hospitals are conducted by a team of two external evaluators who are experienced with newborn hearing screening programs. The</p>



site visit include:

- Interviews with program staff (e.g., screeners, screening program manager, nursery coordinator, director of women's services)
- Observation of screening activities
- Review of records and program
- Policies
- Examination of materials for parents

C.1.2 UK NATIONAL HEALTH SERVICE: NEWBORN HEARING SCREENING PROGRAM

The National Health Service Newborn Hearing Screening Program (NHSP) consists of comprehensive care pathways that outline the routes infants may take from their initial neonatal hearing scan. There are 13 individual treatment pathways that are predicated upon a holistic approach to servicing infants with identified hearing impairments.

RISK MANAGEMENT STRATEGY

The NHS has implemented a Risk Management Strategy for the period 2007-2010 that sets out a high level plan for addressing potential risks faced by the NHSP from both a national and local perspective and ensuring lessons from incidents are shared in order to prevent recurrence. This strategy acknowledges that whilst risk cannot be completely eliminated it can be minimised and managed. The key focus is on ensuring that the objectives of the programme are met.

RISK MANAGEMENT STRATEGY OBJECTIVES

This strategy focuses on risks that arise at a national level and/or best addressed at national level. It complements but does not supersede local risk management strategies and processes which are the responsibility of local management.

Following the national implementation of the NHSP, the Program Centre's primary focus was on the ongoing maintenance and improvement of the program. The performance of the NHSP is measured against national Quality Standards set by the Program Centre and managed through a national quality assurance and risk management framework. The framework aims to ensure minimum standards are met and exceeded by improving the performance of all aspects of hearing screening, diagnosis, management and early intervention for hearing impaired children and their families.⁴⁷ The NHSP quality standards and targets are presented in Appendix A.

RISK MANAGEMENT ASSURANCE FRAMEWORK

The Risk Management Assurance Framework⁴⁸ (depicted in Figure C.1 below) has been developed that provides a model for reporting key information to the program Director, Quality Assurance Board and other key stakeholders. The framework identifies which of the organisation's objectives are at risk due to inadequacies in the operation of controls or where the organisation has insufficient assurance about them.

IDENTIFICATION OF PRINCIPAL OBJECTIVES

Given the diversity of potential risks involved across the multidisciplinary care pathway, there is a focus on the objectives that are deemed to be crucial to the achievement of overall program goals and these have been defined these as the principal objectives.

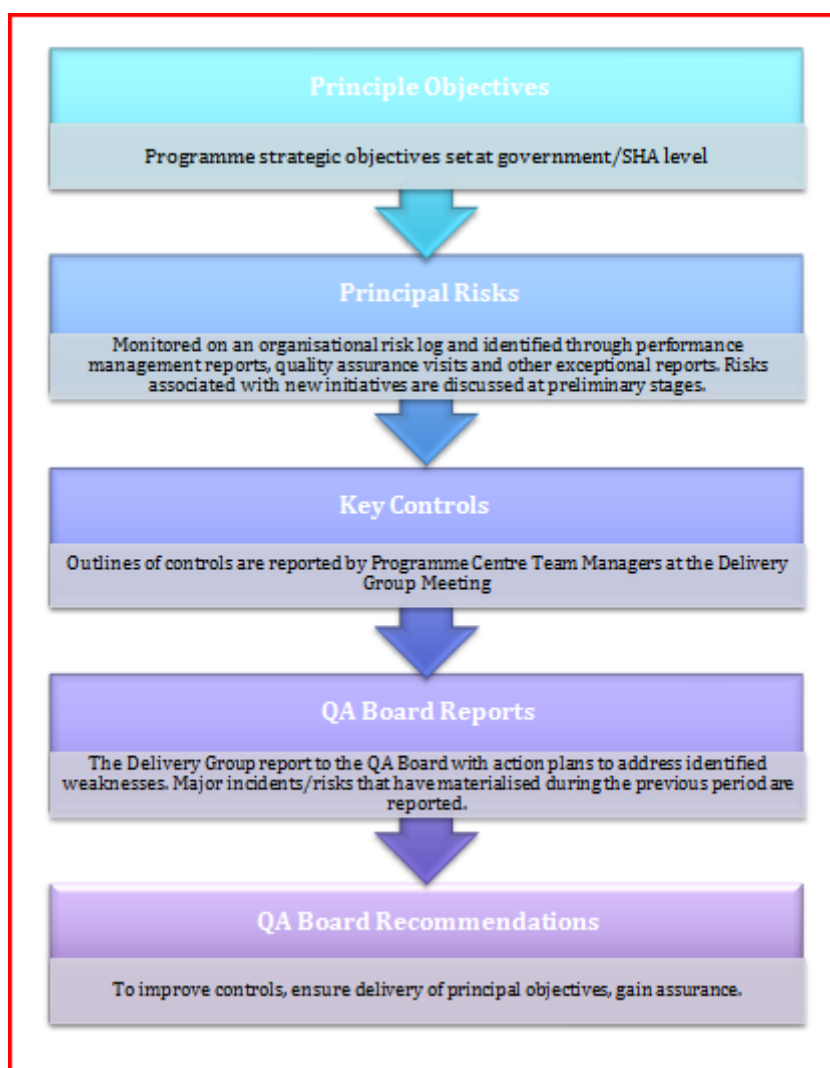
47 NHSP Program Centre. NHS Newborn Hearing Screening Program Quality Assurance Report 2006-2008. pp. 8-10.

48 NHSP Risk Management Assurance Strategy http://hearing_screening.nhs.uk/cms.php?folder=1064

IDENTIFICATION OF PRINCIPAL RISKS

Principal risks are defined as those that threaten the achievement of the organisation's principal objectives. It is essential that these potential principal risks are understood and appropriately managed, rather than reacting to the consequences of risk exposure. Key controls then developed to manage the principal risks as illustrated in Figure C.1 below.

Figure C.1: NHSP Risk Management Assurance Framework

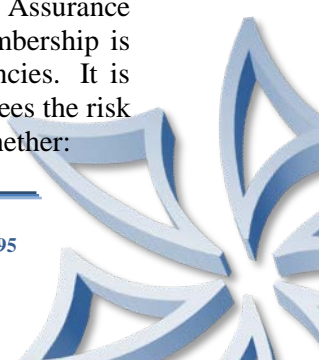


ACCOUNTABILITY AND REPORTING STRUCTURES

Responsibility and accountability are clearly defined components of the organisational structure of the Newborn Hearing Screening programme centre. Further, the programme centre is responsible for encouraging the essential managerial and governance arrangements for Newborn Hearing Screening programmes throughout England.

GOVERNANCE ARRANGEMENTS

On a national level the Quality Assurance programme is governed by the NHSP Quality Assurance (QA) Board, who are responsible for managing the Quality Assurance (QA) team. Membership is varied and includes representation from all provider sectors, parents and voluntary agencies. It is chaired by an independent, non-executive member of the public. The QA Board also oversees the risk management activity of the programme centre. The role of the QA Board is to determine whether:



- There is appropriate utilisation of local health, education and family support services to meet the needs of the local NHSP
- To ensure that all governance is well managed, particularly regarding arrangements for strategic partnership across services
- All elements of the care pathway are delivered within the parameters of the agreed Quality Standards and in a manner that is consistent with family friendly practice
- To promote a quality improvement organisational culture as a key element of the governance and performance management processes in all NHSPs

The Quality Assurance programme in each individual Programme Centre is ultimately the responsibility of the Programme Director. However, each Programme Centre also has a Delivery Group which consists of representatives of each specialist group involved in the Programme Centre and is primarily responsible for determining the risk management structure and activities of the Programme Centre.

PEER REVIEW PROGRAM

The peer review program (known as the QA team) is a key component of the quality assurance process and each local Newborn Hearing Screening program and its associated Audiology, Medical and Children's Services (particularly Education and Social Care Services) are visited by a multidisciplinary team of current practitioners. The role of the Quality Assurance Team is to determine whether:

- Commissioned services meet the needs of children and families
- Governance structures and strategic partnerships are in place
- The entire care pathway is delivered in line with Quality Standards and family friendly practice
- There is a quality improvement culture in place

The methodology adopted to collect information includes the review of self rating information; discussions with staff; visits to clinic settings; discussion with Commissioners and Public Health; and feedback from parents. At the end of each visit, good practice is acknowledged and recommendations for improvement submitted formally to the service provider through a written report. Services are required to submit action plans addressing the issues raised in the QA visit within 2 months of the report being finalised.

According to the 2006-2008 report, results from the first round of peer review visits show that this system is an effective and supportive mechanism for driving quality improvement. Where appropriate, local action was taken to improve quality and was subsequently reviewed by the Program Centre and good practice, emerging trends and risks to the program were analysed and fed back into the ongoing delivery of the program nationally

C.1.3 CANADA: UNIVERSAL NEWBORN AND INFANT HEARING PROGRAM

In Canada the Universal Newborn and Infant Hearing Program (UNIHP) was initially introduced in Ontario in 2002. In response to growing interest in the field of early hearing and communication development (EHCD), the Health Surveillance and Epidemiology Division in Health Canada (now part of the Public Health Agency of Canada) established the Canadian Working Group on Childhood Hearing in September 2000. The Working Group was multidisciplinary and included representatives of national professional associations, a parent representative and experts in otolaryngology, audiology, speech-language pathology, deaf education, nursing, child health and public health from across Canada. Its mandate was to review and evaluate scientific evidence in areas essential to the

development of EHCD programs, and to develop a report that could function as a resource document.⁴⁹

PROGRAM EVALUATION AND QUALITY IMPROVEMENT

In the Canadian EHCD Program guidelines specify that evaluation and quality improvement are essential components of program operations. The evaluation and quality improvement sub-program addresses structure, process and outcome elements of the entire EHCD program. The sub-program includes definitions for quantitative and realistic objectives for the EHCD program, as well as for each of the major program components. In addition, the sub-program includes clear and demonstrably effective mechanisms for EHCD program adjustment in response to observed deficiencies.

1. **Program Evaluation.** Program evaluation is a formal method by which the EHCD program directorate assesses the extent program goals and specific objectives of the program are being achieved. The results of the program evaluation are considered and where indicated program changes are implemented to ensure the achievement of all objectives.
2. **Quality Improvement.** Quality improvement initiatives are a related conceptual approach that incorporates ongoing and continuous assessment of the program components in order to determine proactively whether the program is functioning as effectively and efficiently as possible, and to determine when and where problems or concerns arise, so that the components can be maintained, addressed and, wherever feasible, enhanced.⁵⁰ It should be noted that this is consistent with the approach that has been adopted for the evaluation of the SWISH Program.

The sub-program has been designed in accordance with an evidence based health services evaluation conceptual framework and includes structural, process and outcome components that define the overall EHCD program.⁵¹ The structural elements of the EHCD program include but are not limited to:

- administration
- personnel training, performance management and continuing education
- information management, including tracking and reporting
- instrumentation procurement, calibration, maintenance and manufacturer liaison
- clinical protocol development, dissemination and updating
- family consenting, infant risk assessment; contact, screening and follow-up
- compliance procedures
- audiological assessment procedures
- communication development options provision
- family support provision, surveillance procedures, referral procedures, measurement procedures for outcomes and proxy outcomes
- quality management
- public and professional education
- Ongoing technology

49 Canadian Working Group on Childhood Hearing. Early Hearing and Communication Development: Canadian Working Group on Childhood Hearing (CWGCH) Resource Document. Ottawa: Minister of Public Works and Government Services Canada, 2005. http://www.phac-aspc.gc.ca/publicat/eh-dp/pdf/early_hearing_e.pdf

50 Donabedian A. Explorations in quality assessment and monitoring. Volume 1: The definition of quality and approaches to its assessment. Ann Arbor, MI: Health Administration Press; 1980.

51 Hyde ML, Riko K. Design and evaluation issues in universal newborn hearing screening programs. J Speech Lang Pathol Audiol. 2000; 24(3):102-18.

- evidence assessment

PROGRAM EVALUATION

The key elements of the EHCD program evaluation are as follows:

- Outcome measures for each sub-program component are defined and quantified
- Realistic indicators and benchmarks are developed for each of the outcome measures. These indicators are used to determine achievement of program performance targets
- The benchmarks are levels to which programs should aspire, in order to know that what is being achieved satisfies defined standards of care. They are important in EHCD programs to prove to health professionals and decision makers that EHCD is both beneficial and cost-effective

It is acknowledged that there is clear evidence of program improvement over time and that benchmarks might be difficult to achieve initially. However, the expectation is that performance benchmarks should be achievable in the second or third year of implementation. Failure to achieve benchmark performance is investigated and improvements are aggressively sought and documented.

OUTCOME MEASURES

The outcome measures to be achieved by the EHCD program are routinely quantified and documented. Measurements include both true outcomes and process events that may serve as proxies for true outcomes. The latter type of measurement is common in situations wherein true outcomes are difficult, expensive or impossible to obtain. The outcome measures are summarised below:

- The number and proportion of the overall target population successfully screened by 1 month of age, or within one month of discharge from the birth hospital admission
- The numbers and proportions of infants with a refer result from screening overall and broken down by screening site, screening personnel and risk status
- The numbers and proportions of screening referrals for whom audiological assessment is initiated by 3 months of age and within two months of the initial screening result
- The numbers and proportions of screening referrals with completed audiological assessments by 4 months of age and within one month of assessment initiation
- The numbers and proportions of the target birth, screened and referred cohorts of infants who have confirmed permanent childhood hearing impairment (PCHI) at 6 months of age, also broken down by ear and severity categories, risk status and assessment site/personnel
- The numbers and proportions of infants with PCHI who have been recommended for hearing aids by 6, 9 and 12 months of age
- The numbers and proportions of infants with PCHI who have received medical intervention for otitis media (OM) by 6 months of age
- Documentation of reasons for non-fitting of hearing aids by 6, 9 and 12 months of age, broken down by risk status
- The number of infants with confirmed PCHI at 12 and 24 months of age who passed newborn screening and were detected by surveillance and referral-in routes
- Family satisfaction with EHCD program processes

PERFORMANCE BENCHMARKS

The EHCD Program uses the above outcome measures to determine the achievement of specified benchmarks (these are aligned to the JCIH benchmarks⁵²)

- Within six months of program initiation, hospitals or birthing centres screen a minimum of 95% of infants during their birth admission or before 1 month of age
- The referral rate for audiological and medical evaluation following the screening process should be 4% or less within one year of program initiation
- The agency within the EHCD program with defined responsibility for follow-up documents efforts to obtain follow-up on a minimum of 95% of infants who do not pass the hearing screening
- Infants referred from universal newborn hearing screening (UNHS) begin audiological and medical evaluations before 3 months of age, or three months after discharge for neonatal intensive care unit (NICU) infants
- Infants with hearing impairments are enrolled in a family-centred early intervention program before 6 months of age

LONG-TERM OUTCOMES

A number of outcomes measures have been adopted as proxies for long-term outcomes at the sub-program level. For example, the UNHS component of an EHCD program exists solely in order to deliver all correctly identified infants with PCHI to appropriate follow-up services, with minimal delivery of false positives.

The EHCD program guidelines acknowledge the program's long term objectives are not to screen or to diagnose hearing impairment but to deliver effective interventions and communication development services. Therefore it is considered that the true measure of the success of this program lies in outcomes such as family satisfaction with services, improved hearing ability at an early age, and improved communication development over the long term. In order to achieve this objective there is an imperative to develop and apply valid and accurate measures that reflect these diverse outcome domains.

Given that randomised clinical trials of EHCD programs are unfeasible, the ultimate validations of the benefits of the EHCD Program are determined by comparing a range of outcomes with their historical controls. This approach has been strongly advocated in several critical evaluations of UNHS/ EHCD initiatives, including formal, evidence-based systematic reviews.

ECONOMIC EVALUATIONS

In addition to the outcome measures discussed above the guidelines advocate the conduct of economic evaluations of the EHCD to assess factors relating to Program:

- Accountability
- Sustainability
- Cost containment
- Opportunity costs of alternative health care programs

Given the functionality and sustainability of the EHCD Program is contingent on continued funding; economic data is required to be collected including capital and operating direct costs for the program structures and processes (including information systems). One of key challenges in undertaking this type of analysis is the need to attribute the actual cost of program delivery from other costs that are

52 Joint Committee on Infant Hearing. Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Am J Audiol.* 2000; 9(1):9–29.

associated with the health care environment within which the EHCD program operates. The difficulty lies in the fact that relevant quantitative data are frequently unavailable.

COST-EFFECTIVENESS ANALYSIS

Cost-effectiveness analysis (CEA) is commonly used for EHCD direct cost evaluation, where the overall cost per infant screened and the cost per infant identified with a PCHI are derived.⁵³ CEA is used to assess the comparative cost-effectiveness analysis of the program. For example, cost per infant identified has been shown to be dependent on the referral rates to audiological assessment; as a result this cost-effectiveness analysis is likely to produce a more valid outcome relative to using process proxies such as the raw referral rates.

COST-BENEFIT ANALYSIS

The guidelines acknowledge that a more cost-benefit analysis (CBA) is a more comprehensive approach that can be used to measure the benefits of the Program. This method requires the attribution of quantitative, monetary costs to long-term outcomes such as educational achievement, earning capacity and quality of life. In Canada area is under further investigation.

IMPACT ASSESSMENT OF EHCD

In 2007 a research project was conducted to investigate multi-dimensional aspects of development related to screening and early intervention in children with hearing loss. This study focused on communication skills during the preschool years (up to age 5 years) in children identified with hearing loss through either targeted or universal newborn screening and compare the outcomes with children who were not identified through screening.⁵⁴

Based on the findings of this research there was no conclusive evidence that there were significant improved outcomes for children as a result of the screening program. This was attributed to a number of to the:

- Challenges of quantifying program benefits
- Absence of evaluation studies that measure longitudinal benefits
- Various factors impacting on communication development which may not necessarily be attributed to the screening program

The study concluded there was a need to continue the conduct of long term program evaluation to identify the benefits of the program including multiple dimensions of outcome and parents' perspectives in order to provide further insights into the value of this population-based intervention.

C.1.4 NEW ZEALAND: UNIVERSAL NEWBORN HEARING SCREENING AND EARLY INTERVENTION PROGRAMME

New Zealand's Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) was implemented as a national screening programme in 2007 and is scheduled to be completed in 2010. Once the programme is implemented; 21 District Health Boards (DHBs) will be offering newborn hearing screening to every eligible baby born in their area, whether they are born in hospital or at home, within a framework of nationally consistent policies, standards and guidelines.

The UNHSEIP is not designed to identify babies with mild hearing losses. When the screening programme is fully implemented, it is estimated that between 80 and 120 babies each year will be

53 Keren R, Helfand M, Homer C, et al. "Projected cost-effectiveness of statewide universal newborn hearing screening". *Pediatrics*. 2002 Nov;110(5):855-64.

54 Elizabeth Fitzpatrick, Andree Durieux-Smith, Alice Eriks-Brophy, Janet Olds and Robin Gaines (2007) "The impact of newborn Hearing screening on communication development". *Journal of Medical Screening* Vol. 14 No.3 <http://jms.rsmjournals.com/cgi/reprint/14/3/123.pdf>

identified with hearing losses of a sufficient degree to require Early Intervention Services funded by the Ministry of Education.

In January 2009, New Zealand developed National Policy and Quality Standards⁵⁵ that provide information about the Programme, to increase knowledge and understanding, and to assist Programme service providers to achieve minimum standards of good practice.

QUALITY ASSURANCE AND RISK MANAGEMENT

The UNHSEIP has established a quality and risk management system that reflects continuous quality improvement principles, similar to those that are described in the NHSP. The requirements for quality and risk management include:

1. Programme providers maintaining written policies, procedures, guidelines, systems or plans that ensure compliance with these National Policy and Quality Standards, and all other relevant standards including:
 - Updating or formulating procedures and processes whenever it is found that there is an absence of documentation that could potentially affect the safety and/or quality of service delivery
 - Ensuring that staff are adequately informed and regularly updated of the content of these documents
2. Programme providers require a current documented quality management system that:
 - Clearly identifies the personnel that are responsible for ensuring the quality management processes are documented and implemented
 - Clearly identifies in detail all quality improvement processes and includes an internal audit plan
 - References the quality model or philosophy selected by the organisation
 - Is reviewed by the management at regular intervals to ensure compliance
 - Has the commitment and participation of management and staff, and enables consumer participation wherever appropriate
3. Programme providers are required to:
 - Implement regular assessment of all practices including management systems, policies, procedures and guidelines
 - Ensure that any changes in in practice are documented, communicated to, and implemented by all staff involved in service delivery
 - Ensure that quality improvement information is collected, analysed and evaluated and the results communicated to service providers and, where appropriate, consumers as part of the quality improvement process
 - Ensure that quality improvement information is relevant to the organisation's needs and its analysis is both accurate and unbiased
 - Ensure written evidence of routine quality assurance is available for audits and site visits
 - Ensure information and experiences regarding quality assurance processes are shared within the provider organisation and where appropriate to other UNHSEIP Programme providers

55 Ministry of Health, New Zealand (2009) "Universal Newborn Hearing Screening and Early Intervention Programme National Policy and Quality Standards"
http://www.nsu.govt.nz/Files/National_Policy_and_Quality_Standards_January_2009.pdf

C.1.5 SUMMARY OF INTERNATIONAL MONITORING SYSTEMS

Our analysis of the monitoring systems that have been implemented in the USA, UK, Canada and New Zealand demonstrates that for the most part there is a high level of commonality across all systems in terms of having a primary focus on:

- Quality assurance
- Program monitoring and reporting
- Program evaluation

The key distinguishing feature is the NHSP in the United Kingdom and the UNHSEIP in New Zealand monitoring systems is that they are based on a risk management approach to facilitate continuous improvement which is entirely different to the US and Canadian systems that are focused on conducting annual process, structure and outcomes evaluations.

