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Scoping Report

Evaluating UNHS Outcomes

Background

The Universal Newborn Hearing Screening (UNHS) programme has now been rolled out to all District Health Boards. Despite the full roll out, funding shortages have resulted in what is thought to be the screening of at best 70% of all children born. While the diagnosis of hearing loss is also not as clear cut as anticipated, deaf children are being diagnosed earlier than ever before.

Those children who meet the eligibility criteria are referred to the Ministry of Education. There has never been a better opportunity for the Ministry to provide effective early intervention for these children and measure its impact.

The Ministries of Health and Education have been working together to find ways to ensure that outcomes for these children are monitored up to the age of 5 or school entry. These outcomes are sought to better understand the efficacy of early identification and early intervention.

There is some urgency to this work being undertaken, as other participants in the project (National Screening Unit, Ministry of Health, Project Heidi and the University of Auckland) are anxious to get the reporting system fully operational.

Key challenges to achieving this include:

- It is not typical practice to aggregate assessment data on children within special education. An individual approach is taken for each child as opposed to a collective analysis.
- Changes in key personnel managing the project for Ministry of Education have meant that there has been some delays in progress towards being able to report on outcomes.
- There are multiple systems within the Ministry of Education involved: Early Intervention, Child Development Teams as well as Advisers on Deaf Children. Children with additional disabilities may also have other community organisations involved and a range of professionals. Deaf Education Centres and Cochlear Implant Programmes also have responsibilities for the early intervention of some children, and solutions need to take this into account. Transdisciplinary teams are supported by Advisers.

This scoping report has been requested to establish what needs to be done to make sure the Ministry of Education selects the right measures and systems to monitor an holistic range of outcomes for hearing impaired and deaf children accessing early intervention services.

It maintains that there is a sufficient amount of information to make decisions on key questions, that will allow the project to move forward.

The Issues

Current Data Requirements - UNHS

The current UNHS and Early Intervention Monitoring Framework requires three specific service measures:

1. The number of families and whanau eligible and referred to the Early Intervention education service from UNHS, who staff attempt to contact within 2 full working days of receipt of referral at a MOE Special Education office.

The number of families and whanau of children eligible for and referred to the Early Intervention education service from UNHS.

2. The number of children eligible for and referred to the Early Intervention education service from UNHS who began a service by one month following receipt of the referral at a district MOE Special Education office.

The number of families and whanau of children eligible for and referred to the Early Intervention education service following diagnosis by UNHS.

3. The number of children eligible for and referred to the Early Intervention education service from UNHS still receiving an education service at 3 years of age.

The number of families and whanau of children eligible for and referred to the Early Intervention education service through UNHS.

4. The number of children eligible for and referred to the Early Intervention education service from UNHS still receiving an education service at school entry.

The number of families and whanau of children eligible for and referred to the Early Intervention education service through UNHS.

These measures require the following information to be kept:

1. Child's NHI number
2. Date referral received from UNHS
3. Code that indicates that this is a specific cohort of children referred from UNHS.
4. Date of birth
5. Age at referral
6. Ethnicity
7. Number of days taken for AODC to attempt to contact the families following referral.
8. Number of days taken for the child to be enrolled in EI services following receipt of referral (i.e. Initial informed consent signed).
9. Early intervention service received at 3 years of age.
10. Early intervention service is received at point prior to school entry.

Current Practice - UNHS

The UNHSEI Referral and Monitoring Sheet is currently manually filled in by Advisers, but is not compiled nationally. It collects all the information above except:

1. Early intervention service received at 3 years of age.
2. Early intervention service is received at point prior to school entry.

Advisers also collect useful information on:

1. The degree of hearing loss.
2. Risk factors for hearing loss.
3. Additional issues – syndrome, medical condition or disability.
4. Families first language.

The current Te Pataka database system also collects on referral all the above information as well as a UNHS code (JHS), but does not collect:

1. Child's NHI number
2. The degree of hearing loss
3. Risk factors for hearing loss
4. Additional issues – syndrome, medical condition or disability.
5. Number of days taken for AODC to attempt to contact the families following referral.
6. Number of days taken for the child to be enrolled in EI services following receipt of referral (i.e. Initial informed consent signed).
7. Early intervention service received at 3 years of age.
8. Early intervention service is received at point prior to school entry.

The Te Pataka database is now under development, providing a perfect opportunity to maximise the efficiency and collection of data.

A specific code is already available on Te Pataka to identify UNHS (JHS) children as a subset of all children.

Data and reporting must align with the Ministry of Health in the longer term although the current MOH database is manually entered. Ministry personnel are eager to recommence regular meetings over a work programme with MOE.

"(Data collection) doesn't have to be high tech".

Christine Miller (Auckland MOE) is collecting data on young deaf children biannually and manually, in order to predict future impact on school and in particular, RTDs. She has been focussing on the Auckland area but has recently expanded this to Northland. She notes that the Te Pataka database is light on detail in the early stages of children's entry to the education system.

Current Requirements & Practice – Early Intervention

The UNHS criteria do not require specific educational or broader outcome measurements for children but it is well accepted among all people interviewed that agreement on specific assessment(s) will enable comparative information to be kept on the performance of deaf children over time.

MOE Monitoring Protocol

Advisors already use the Monitoring Protocol for deaf babies and children (up to 3 years). This is a criterion referenced checklist that describes development over 5 domains: communication; attending, listening and vocalisation; social-emotional; other developmental milestones; and play. This document has been based on a UK programme, Early Support, and accommodates different language preferences for children.

It is widely respected by Advisers and used with parents, although some informants suggested that the document is not being consistently used, and is sometimes just left with parents. There is some concern that MOE doesn't check on the performance of Advisors, in their assessment of children's performance and progress.

Advisers report that most parents like the Monitoring Protocol because it indicates the next stages of expected development for the child. In particular, articulate and highly literate parents use it well. The focus of it is for planning future work, rather than as an assessment at a specific period of time.

The cochlear programmes and Deaf schools are not currently using the Monitoring Protocol.

Advisers spoken to in this review would like to use this as a formal assessment partly because it is being used already and partly because it has a value for the child and whanau. Additional stand-alone assessments are seen as being of more benefit to the organisations involved than the child or family.

The University informants however, suggest that because this protocol is not norm referenced (i.e. based on a substantial and comparable sample of students) it would not be reliable enough to indicate age of performance. Preliminary checking suggests that this is true but could be further explored. If it is not norm referenced, could it be retrospectively. There will be distinct advantages to using a single existing document if it is possible, ensuring it is used consistently.

If it is not, specific norm referenced assessments are likely to be needed that provide measurement of expressive, receptive language including speech as well as social skills.

There is no comparative analysis of standardised assessments against the Monitoring Protocol. There is some comparable data available in NZ on speech assessments but overseas data would have to be probably be used as a source of comparison.

The LOCHI study in Australia is now reporting on a large population based study using specific measures and may be a point of comparison.

Other Assessments

There are 34 different assessments cited as being used by Advisers, Deaf Education Centres of the Cochlear implant programmes (see attached)

There is significant information within MOE personnel about available assessments, and in 2005, an international review was undertaken by Sally Robinson and Mark Douglas on best practice for early intervention, including an analysis around measuring outcomes.

Two assessments are already commonly used in Early Intervention services:

- Ages and Stages is used in Early Intervention services.
- Strengths and Difficulties, although this provides dichotomous data rather than a score.

There is some concern among Advisers about how additional assessment data will be interpreted collectively, given that there is huge heterogeneity of children. The high numbers of deaf children with other disabilities in particular needs to be considered.

Advisors have one paper in their training in which they complete standardised assessments, but they would need specific training around selected assessments.

Assessments are also likely to need interpretation assistance with children using Sign Language or other community languages.

Suzanne Purdy has a PhD student about to start some investigation of assessment needs of young deaf children.

The University could possibly help with assessments using research students, if funded. In Colorado, videos are sent to the university for analysis for example.

Parent Involvement

It is widely agreed that parents need to be involved in assessment, in the sense of tracking and supporting progress and in feeding back the level of satisfaction with the service. Parent evaluation is not occurring automatically with the screening process. Parent satisfaction surveys are provided by MOE on the cessation of early intervention services, although these are not collected or analysed in aggregate form either. Some systematic collection of satisfaction from parents over the entire screening and early intervention process is needed.

There are also issues around which professional groups see the parents first and sets up expectations around the type of service or technology offered.

Other Issues Mentioned

People with mild unilateral loss currently receive no service. Project Heidi advocates for their progress also to be tracked.

The University would like to see health and education providing a single programme operationally, with close connections.

Recommended next steps

1. Appoint a project leader within MOE who ideally has understanding of, or at least good access to information on both practice and policy around deaf children. This person would be expected to have an ongoing role until the project is well integrated into systems, and would also most likely be the new representative appointed to the new UNHS Advisory Board.
2. Explore further whether the Monitoring Protocol could meet assessment requirements.
3. Assemble an Advisory Group to MOE management to answer the following questions:
    a. What assessments are used?
    b. When should they be used?
    c. How should information be collected and aggregated?
    d. Who in MOE should be responsible for collecting, aggregating and analysing data?
    e. What training is needed?
    f. What information systems are feasible for collecting analysing parent satisfaction levels?

    Group membership suggestions include:

    a) Jo Davies as Practice Manager
    b) 1 Adviser from each region, possibly including
        a. Sally Robinson
        b. Diane Carly SLT (at least one SLT/EI should be included)
        c. Deaf Adviser

    Membership might also include representatives from the following organisations in order to align the decision as much as possible with related assessment systems.

    c) Deaf Education Centres
    d) Hearing House &/or Southern programme
    e) Suzanne Purdy from University of Auckland

    Buy-in to the final decision from Advisers will most likely be enhanced if contact is made to tell them about the above process and more importantly after the decision is made, with an opportunity for making comments.
4. Identify how the data can be collected efficiently and incorporated into the MOE database.

Informants for the Scoping Report

The following people were interviewed and asked what the key issues were around establishing monitoring systems for Newborn Hearing Screening and Early Intervention programmes:

Rose Cameron

Jo Davies

Sally Robinson

Mark Douglas

Joanna Carey

Raewyn Cantell

Christine Miller

Peter Thorne

Janet Digby

Suzanne Purdy

Vicky Rydz

Sarah Greensmith

THE RANGE OF ASSESSMENT TOOLS IN USE FOR CHILDREN WITH HEARING LOSS, BIRTH TO FIVE YEARS, IN 2007 BY THE DEAF EDUCATION SECTOR

Assessment Tools	Advisers On Deaf Children	Deaf Education Centres	Cochlear Implant Programmes
MacArthur Communicative Development Inventories – Words Gestures & Sentences	2	1	1
Listen Learn and Talk (Integrated Scales of Development and Listening Levels Checklist)	3		
Learn to Talk Around the Clock	2		
Van Asch Schedules of Development	7	1	
SKI-HI Checklists	6		
Early Support Monitoring Protocol	5		
McShane Pragmatics Schedule	1	1	
Video Assessment and Analysis	1	1	
Cottage Acquisition Scales for Listening, Language and Speech	2		
NZSL Assessment Tool (developed by KDEC)		1	
Rosetti Infant-Toddler Language Scale	1	1	
Pre-school Language Scale (PLS-4)	1	1	2
Clinical Evaluation of Language Fundamentals (CELF) Pre-school	1		2
REEL (Receptive-Expressive Emergent Language Test)			2
EI Assessment designed by Ann Locke and Magie Beech	1		
It Takes Two to Talk Checklists	1		
Carolina	2		
Infant-Toddler: Meaningful Auditory Integration Scale (IT-MAIS)			2
Meaningful Auditory Integration Scale (MAIS)			2
LittlEars			1
Clinical Evaluation of Language Fundamentals (CELF-4)			1
Peabody Picture Vocabulary Test (PPVT) Version 3			2
Expressive Vocabulary Test (EVT)			2
Goldman Friste: Test of Articulation 2			1
SKI-HI Language Development Scale		1	
Ages and Stages Questionnaire (ASQ)	1		
Boehm Test of Basic Concepts – Revised (BOEHM-R)			1
Learning Accomplishment Profile (LAP)			1
Wiig Assessment of Basic Concepts (WABC)			1
St Gabriel's Curriculum Checklists		1	
Rosenwinkel		1	
Reynell Developmental Language Scales		1	
Ling Phonological Charts and Phonetic Inventory Phonologic Level Speech Evaluation		1	
Auditory Skills Programme	1	1	