Engagement in Early Intervention Research

Queensland Hearing Loss Family Support Service
Overview

• How we developed the research question
• The literature
• The study
• Preliminary analysis
• Next steps
Development of the research question

• We do annual chart audits to measure our performance against national guidelines
• This is done with a small random sample – 35-40 charts
• The information obtained has suggested barriers to engagement with early intervention
• This anecdotal evidence has led to the development of a research question.
From our chart audits we already know:

Around 50% of children referred to QHLFSS through Newborn Hearing Screening show evidence of engagement in an EI service by 4 months of age.

Engaged in EI by 4 months of age

*NA = not at stage of decision-making yet
The Research Question

What are the factors that impact on the timing of engagement in early intervention services by children with permanent hearing loss and their families?
Timeline of the study

- Ethics approval
- Grant applications
- Preliminary data analysis
- Write-up
- NEAF (National Ethics Application Form)
- Literature review
- Data collection
- Statistical data analysis

WE ARE HERE
First, let’s look at the literature

Early identification and early intervention produce better language outcomes in children with hearing loss.

(A systematic literature review is beyond the scope of this project).
What does the literature tell us?

Family adjustment is significantly positively correlated with child outcomes across multiple studies.

1. Parental Involvement
2. Attachment
3. Stress and coping
What does the literature tell us?

How do these factors specifically relate to engagement in early intervention?
What does the Literature tell us about family involvement?

(Calderon, 2000; Moeller, 2000)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Intervention</th>
<th>Family involvement</th>
<th>Communication</th>
<th>Service use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Early</td>
<td>High</td>
<td>= More successful language outcomes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>High</td>
<td>= Increased use of EI services</td>
<td></td>
</tr>
<tr>
<td>Late</td>
<td>+</td>
<td>Low</td>
<td>= Poorer language outcomes at age 5</td>
<td></td>
</tr>
<tr>
<td>Late</td>
<td>+</td>
<td>High</td>
<td>= Best rate of catch up</td>
<td></td>
</tr>
</tbody>
</table>

Strong family involvement seems to buffer the effects of late enrolment → is family involvement just as important as early identification?

How do we encourage family involvement from our place outside the family?
What does the Literature tell us about Attachment?

(Ryan, 2012; Thomson et al, 2011; Miyamoto et al, 2005; Nicholas & Geers, 2007)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Timing of implantation</th>
<th>Communication</th>
<th>Attachment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td></td>
<td>More attachment behaviours in child consistent with hearing children</td>
<td></td>
</tr>
<tr>
<td>Earlier</td>
<td>=</td>
<td>Higher levels of infant-directed speech by mothers</td>
<td>Secure attachment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Critical period for language development</td>
<td>Critical period for attachment development</td>
</tr>
<tr>
<td>Earlier</td>
<td>=</td>
<td>More likely to catch up with hearing peers in spoken language skills by age 5</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Competent communication between parent and child (spoken or sign)</td>
<td>Secure attachment</td>
</tr>
</tbody>
</table>
What does the Literature tell us about Stress and Coping?

(Young & Tattersall, 2007; Sheeran, Marvin & Pianta, 1997; Meadow-Orlans, 1994; Ray 2012; Feher-Prout, 1996; Quittner et al, 2010; Pipp-Siegel et al, 2002; Asberg et al, 2008, Hintermair, 2006; Meadow-Orlans et al, 2004)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Grief</th>
<th>Social support</th>
<th>Stress</th>
<th>Coping</th>
<th>Attachment</th>
<th>Engagement with El</th>
</tr>
</thead>
<tbody>
<tr>
<td>Earlier</td>
<td>=</td>
<td></td>
<td>Higher</td>
<td>=</td>
<td>Impact on attachment?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td></td>
<td>Higher</td>
<td>Lower</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Higher</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unresolved</td>
<td>=</td>
<td>Higher</td>
<td></td>
<td></td>
<td>Insecure (19% had securely attached children)</td>
<td></td>
</tr>
<tr>
<td>Resolved</td>
<td>=</td>
<td>Lower</td>
<td></td>
<td></td>
<td>Secure (82% had securely attached children)</td>
<td></td>
</tr>
</tbody>
</table>

So unresolved grief might produce stress which impacts on coping which impacts attachment which reduces involvement which lowers levels of engagement with EI services which results in this negative cycle?
What does the Literature tell us about Stress and Coping?

(Hintermair, 2006; Meadow-Orlans et al, 2004; Pipp-Siegel et al, 2002; Young & Tattersall, 2007)

<table>
<thead>
<tr>
<th>Stress</th>
<th>Sources of stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patterns of stress in hearing parents of deaf children are mixed in different studies – higher, lower, no difference</td>
<td>Daily hassles; “context-specific” stress</td>
</tr>
<tr>
<td>Varies as a function of time, age, degree of hearing loss</td>
<td>Comparisons with trajectory of hearing children</td>
</tr>
<tr>
<td>More consistent patterns in deaf parents of deaf children – generally less stressed about their child’s hearing loss (but possibly more stress around daily hassles)</td>
<td>Striving for “normal” which is taken to mean “as if hearing”</td>
</tr>
</tbody>
</table>
What does the literature tell us?

• **We have looked at many of the intrinsic factors in families that can be barriers**

• **What extrinsic factors, particularly those involving services, hinder families or, alternatively, help them?**
What does the Literature tell us about stress and coping in chronic illness?

(Ray, 2003)

<table>
<thead>
<tr>
<th>Things that are difficult to navigate:</th>
<th>Things that are missing:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties with government or agency guidelines for eligibility for services</td>
<td>Lack of information on caring for the child or available resources</td>
</tr>
<tr>
<td>Negative attitudes among health professionals</td>
<td>Lack of funding for social services</td>
</tr>
<tr>
<td>Significant bureaucratic red tape</td>
<td>Lack of co-ordination among professionals and agencies</td>
</tr>
</tbody>
</table>
We know a lot about related factors but we don’t have a lot of information about the relationship between those factors and actual engagement with early intervention services.

- Early identification
- Parental Involvement
- Stress and Coping
- Attachment
- Communication Skills
- Engagement in Early intervention
This study: Dilemmas of what to measure

Lots we don’t know about and could choose to study

How do we decide what to measure?

What are our resources?

What data do we already have?

Engagement in Early intervention

We don’t know much about the factors that directly influence engagement with early intervention services

Children’s Health Queensland Hospital and Health Service
## Methodology

<table>
<thead>
<tr>
<th>Retrospective study of the data of children diagnosed with a permanent hearing loss between 2011 and 2013 in Queensland</th>
<th>Cases have been drawn from the Healthy Hearing database QChild and QHLFSS clinical charts for qualitative information</th>
<th>Includes all children diagnosed with a permanent hearing loss who received service from QHLFSS except deceased children and those who declined initial screen.</th>
<th>386 child records were identified as being eligible for inclusion in the study.</th>
</tr>
</thead>
</table>

<p>| Study does not require parent feedback or new data collection | Using data routinely collected by Healthy Hearing and QHLFSS between 2011 and 2013 | Additional exclusions are on variables where no data is recorded | Scheduled to be completed by end of 2016 |</p>
<table>
<thead>
<tr>
<th>The Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Developmental History</strong></td>
</tr>
<tr>
<td>Pregnancy</td>
</tr>
<tr>
<td>Birth</td>
</tr>
<tr>
<td>Comorbidities</td>
</tr>
<tr>
<td>Speech and language delay</td>
</tr>
<tr>
<td>Social support</td>
</tr>
<tr>
<td>Family mobility within 12 months of diagnosis</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<td></td>
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</tbody>
</table>

Plus demographic data: DOB, hospital of birth, diagnosing audiology service, HH/non-HH, referral process
What don’t we know?

We know that earlier diagnosed children have better outcomes – do they engage earlier with EI?

What about *time taken* to engage with EI - the amount of time between diagnosis and engagement?

The preliminary data analysis on this factor includes the data of 186 children out of 245 records to date from which data has been collected. 59 records were excluded due to missing data.
Preliminary Data Analysis:
Age of diagnosis

n=186

Age of diagnosis

Number of children

Age in months

2011 2012 2013
Preliminary Data Analysis:
Age of engagement

Age of engagement in EI

n=186
Age of diagnosis and age of engagement

Why is this group of children engaging so late?

Benchmark for diagnosis

Benchmark for engagement in EI

Children with PHL

n=186

Why are all these children engaging late?

Number of children

Age in months

Age of diagnosis

Age of engagement in EI

Children’s Health Queensland Hospital and Health Service
Understanding the cohort

- Total cohort: 386
  - Not yet analysed: 141
    - Excluded due to missing data: 59
      - Engaged with EI before 6 months of age: 90
        - Engaged with EI later than 12 months of age: 27
      - Engaged with EI between 6 and 12 months of age: 69
    - Engaged with EI between 6 and 12 months of age: 245
      - Engaged with EI before 6 months of age: 186

- Included in this analysis: 186
  - Engaged with EI later than 12 months of age: 27

The very late engaged group

Children with PHL who engaged with EI at 12 months+  

Benchmark for diagnosis

Number of children

Age of diagnosis in months

n=27

Children’s Health Queensland Hospital and Health Service
## The Factors

<table>
<thead>
<tr>
<th>Developmental History</th>
<th>Family History</th>
<th>Hearing status</th>
<th>Early intervention</th>
<th>Family Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnancy</td>
<td>Living arrangements</td>
<td>Hearing loss type</td>
<td>EI type</td>
<td>Transport type</td>
</tr>
<tr>
<td>Birth</td>
<td>Cultural identity</td>
<td>Hearing loss laterality</td>
<td>EI service</td>
<td>Domestic violence</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Language background</td>
<td>Hearing loss severity</td>
<td>Age at enrolment</td>
<td>Number of children</td>
</tr>
<tr>
<td>Speech and language delay</td>
<td>Housing type at time of diagnosis</td>
<td>Hearing loss severity - L</td>
<td>Frequency of attendance</td>
<td>Mother’s education level</td>
</tr>
<tr>
<td>Social support</td>
<td>Age at diagnosis</td>
<td>Regularity of attendance</td>
<td>Playgroup</td>
<td>Father’s education level</td>
</tr>
<tr>
<td>Family mobility within 12 months of diagnosis</td>
<td>Number of diagnostic appointments</td>
<td></td>
<td></td>
<td>Mother’s employment status</td>
</tr>
<tr>
<td></td>
<td>Cochlear implant status</td>
<td>Communication method - child</td>
<td></td>
<td>Father’s employment status</td>
</tr>
<tr>
<td></td>
<td>Hearing aid status</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Amount of time between diagnosis and EI enrolment

Plus demographic data: DOB, hospital of birth, diagnosing audiology service, HH/non-HH, referral process

Looks like our hunch was wrong!
Summary

• Where to from here?
  • Finish data collection
  • Analyse it on all factors
  • Prepare for publication
• The small matter of funding...
• We are also developing an app
References


References cont.


If you would like further information or a copy of these references please contact me:

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Children’s Health Queensland Hospital and Health Service