



## Engagement in Early Intervention Research

Great state. Great opportunity. **Trish McLean, M.Psych.Clin. Clinical Psychologist, Family Support Facilitator**  
**Queensland Hearing Loss Family Support Service**

# Overview

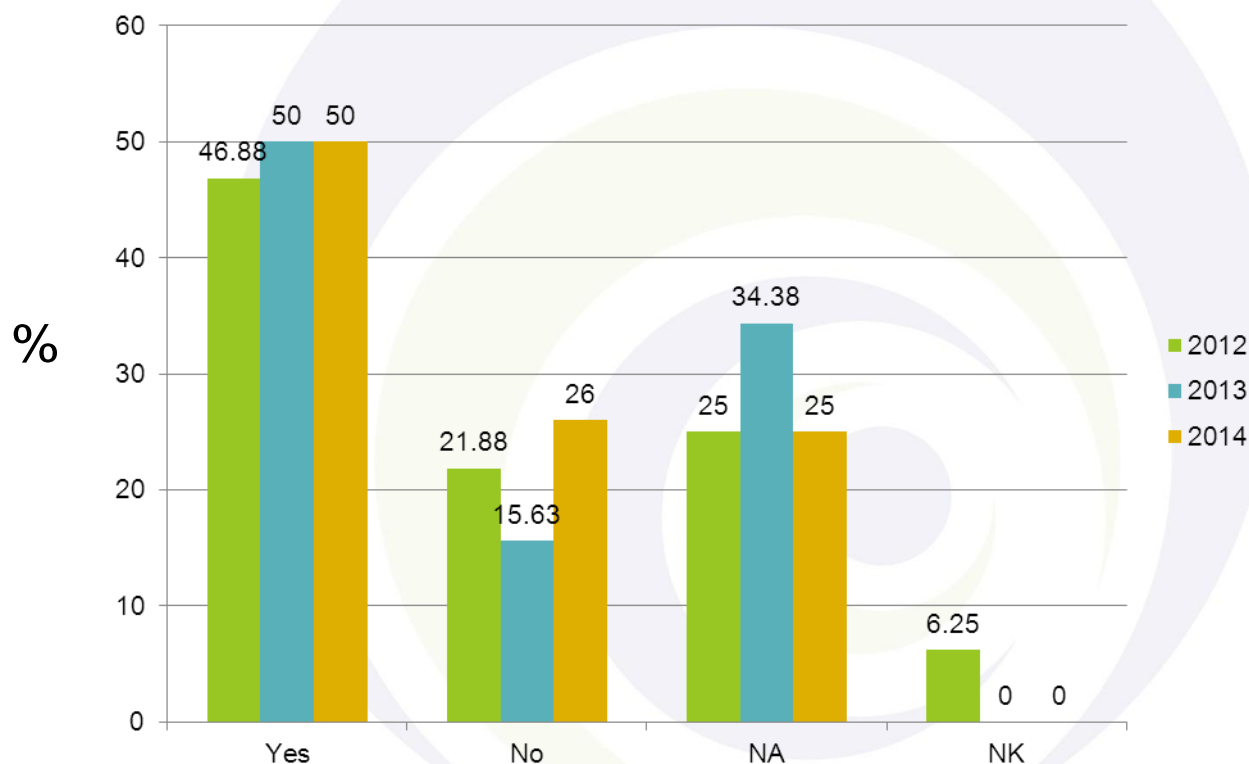
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- How we developed the research question
  - The literature
  - The study
  - Preliminary analysis
  - Next steps

# 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

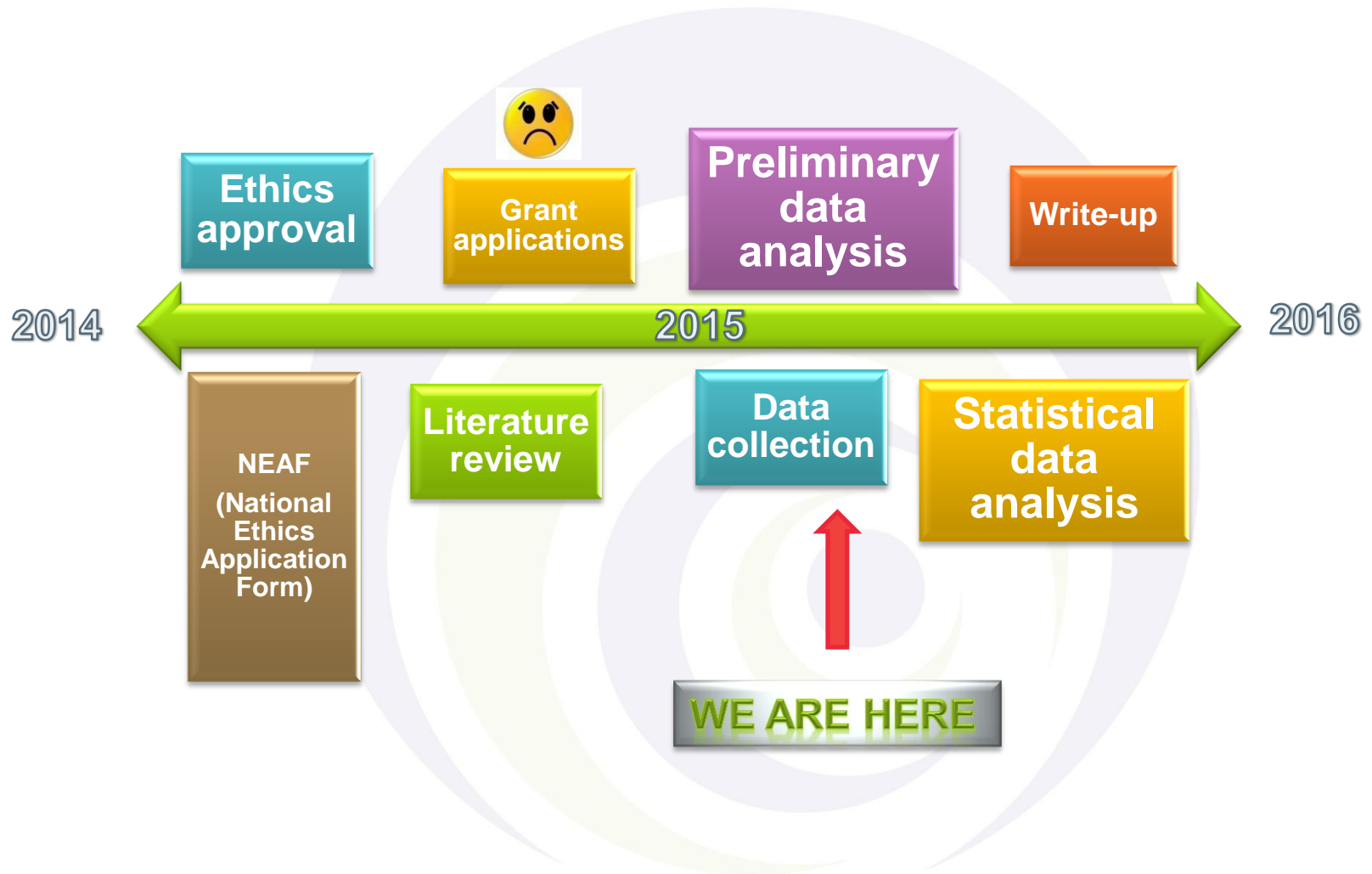


# The Research Question

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



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).

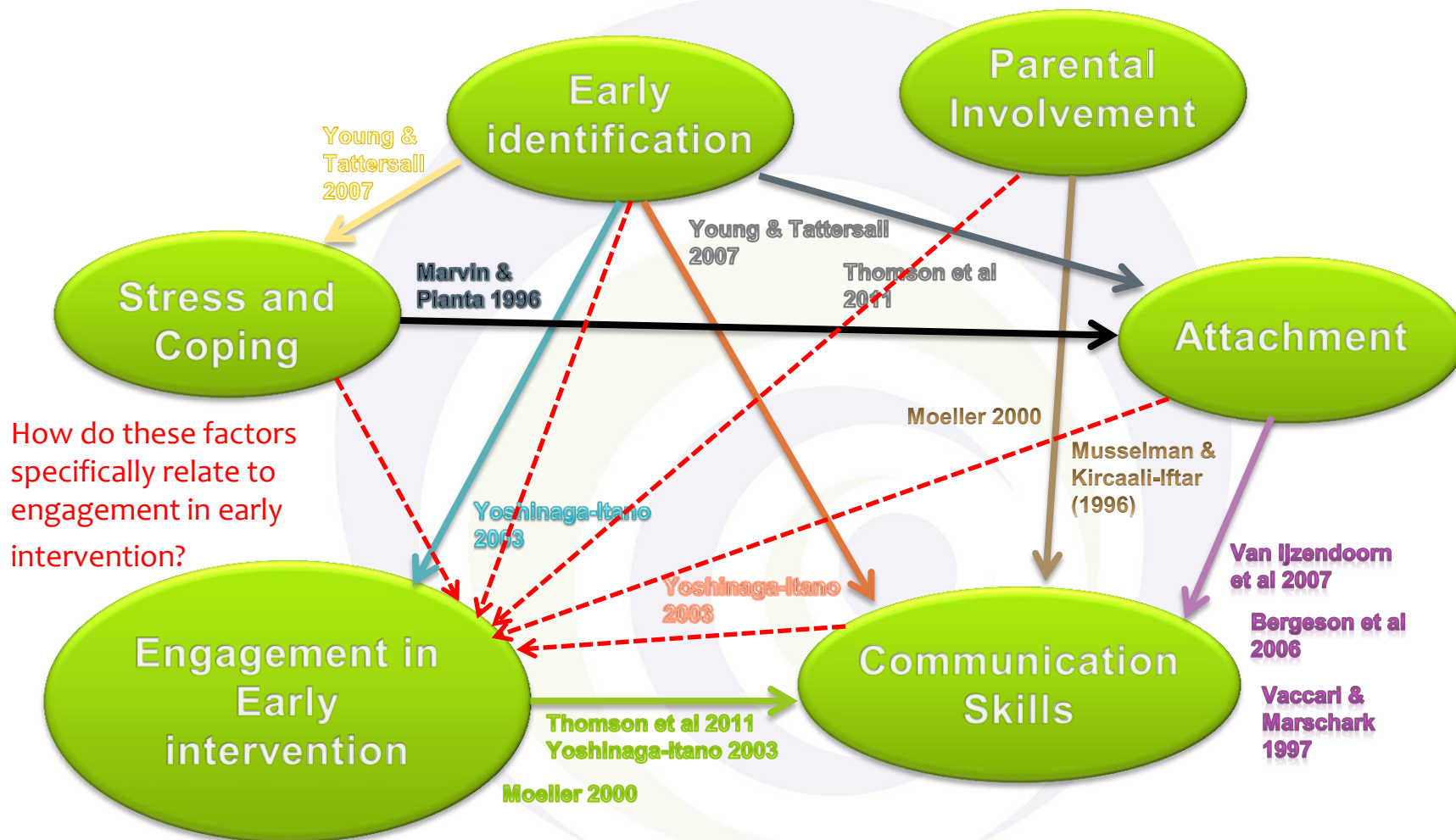
## What does the literature tell us?

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?



# What does the Literature tell us about

## Parental Involvement ?

(Calderon, 2000; Moeller, 2000)

Diagnosis		Intervention		Family involvement		Communication	Service use
Early	+	Early	+	High	=	More successful language outcomes	
				High	=		Increased use of EI services
				High	=	Better communication with children	
		Late	+	Low	=	Poorer language outcomes at age 5	
Late	+			High	=	Best rate of catch up	

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)

Diagnosis		Timing of implantation		Communication	Attachment
Early	=			More attachment behaviours in child consistent with hearing children	
		Earlier	=	Higher levels of infant-directed speech by mothers ?	Secure attachment
				Critical period for language development	= Critical period for attachment development
		Earlier	=	More likely to catch up with hearing peers in spoken language skills by age 5	
				Competent communication between parent and child (spoken or sign)	= Secure attachment

# 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)

Diagnosis		Grief		Social support		Stress		Coping		Attachment		Engagement with EI	
Earlier	=					Higher	=			Impact on attachment?			
				Lower		Higher							
				Higher	=	Lower							
		Unresolved	=			Higher				= Insecure (19% had securely attached children)			
		Resolved	=			Lower				= Secure (82% had securely attached children)			
		Unresolved	?			Higher	?	Lower	?	Impact?	?	Reduced	

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)

Stress	Sources of stress
Patterns of stress in hearing parents of deaf children are mixed in different studies – higher, lower, no difference	Daily hassles; “context-specific” stress
Varies as a function of time, age, degree of hearing loss	Comparisons with trajectory of hearing children
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)	Striving for “normal” which is taken to mean “as if hearing”



# 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 chronic illness?

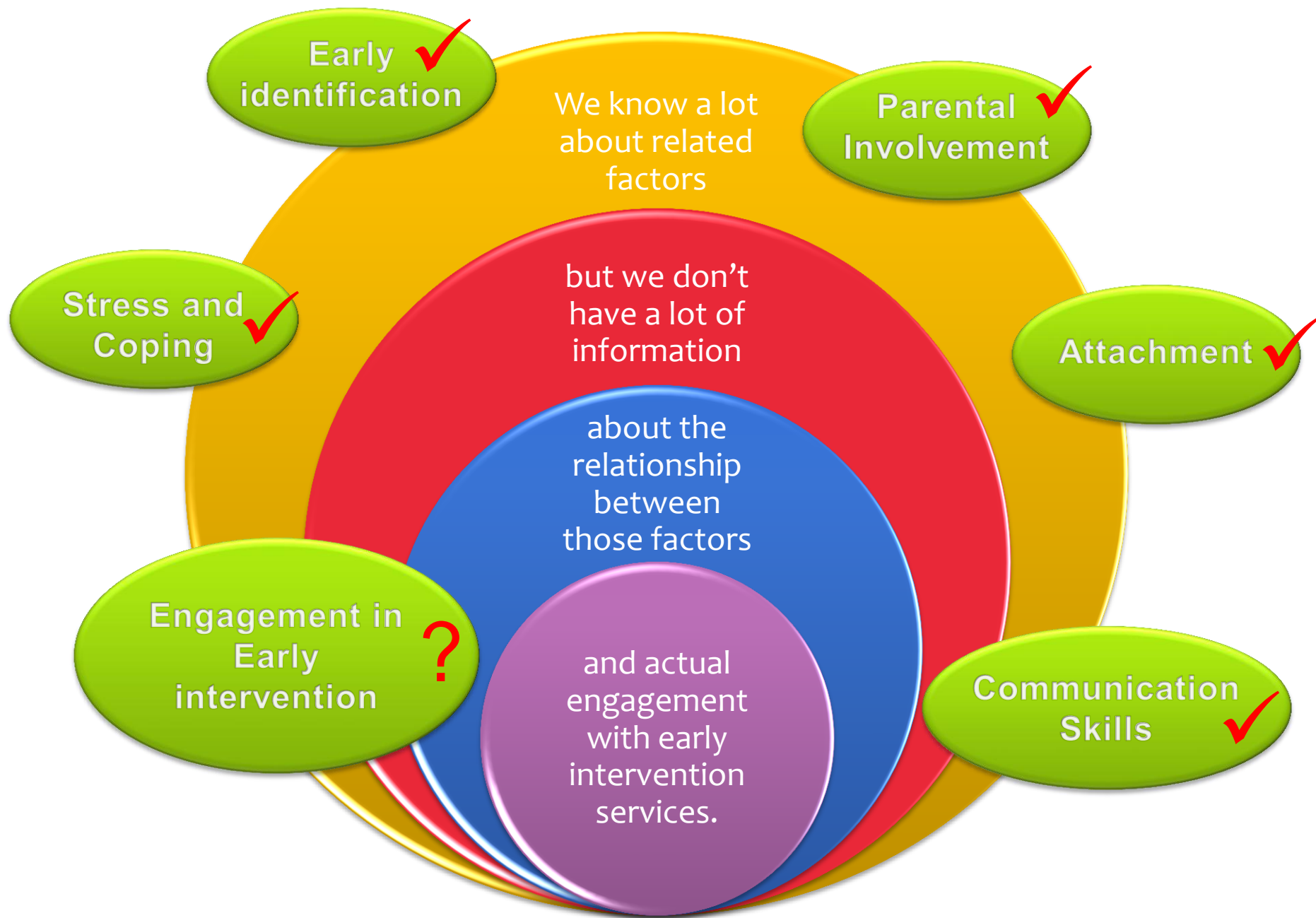
Stress and  
Coping

in

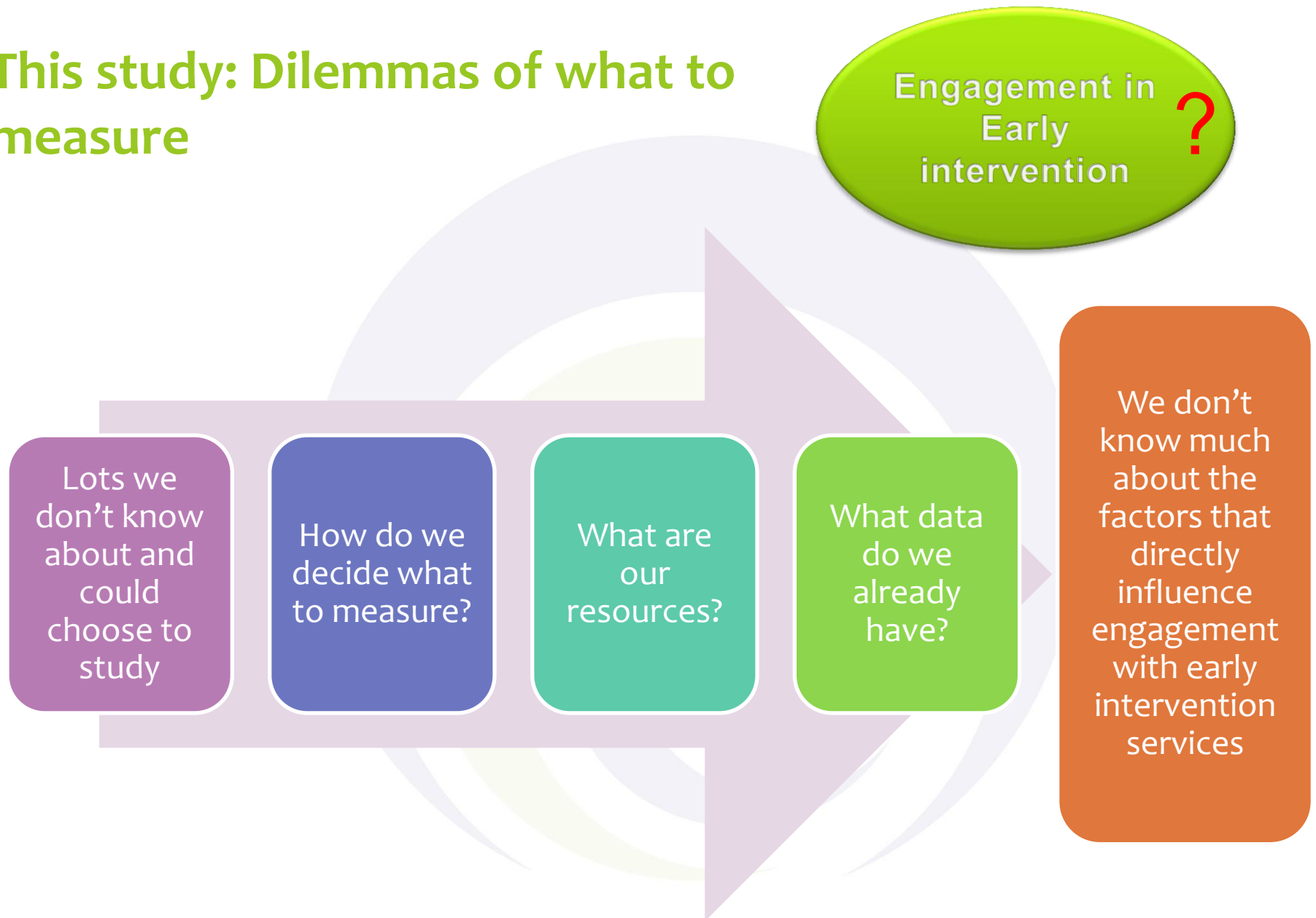
(Ray, 2003)

## Variables impacting negatively on stress levels and effective parenting in parents of children with chronic health conditions

<i>Things that are difficult to navigate:</i>	<i>Things that are missing:</i>
Difficulties with government or agency guidelines for eligibility for services	Lack of information on caring for the child or available resources
Negative attitudes among health professionals	Lack of funding for social services
Significant bureaucratic red tape	Lack of co-ordination among professionals and agencies



# This study: Dilemmas of what to measure



# Methodology

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





# The Factors

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

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

# What don't we know?

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

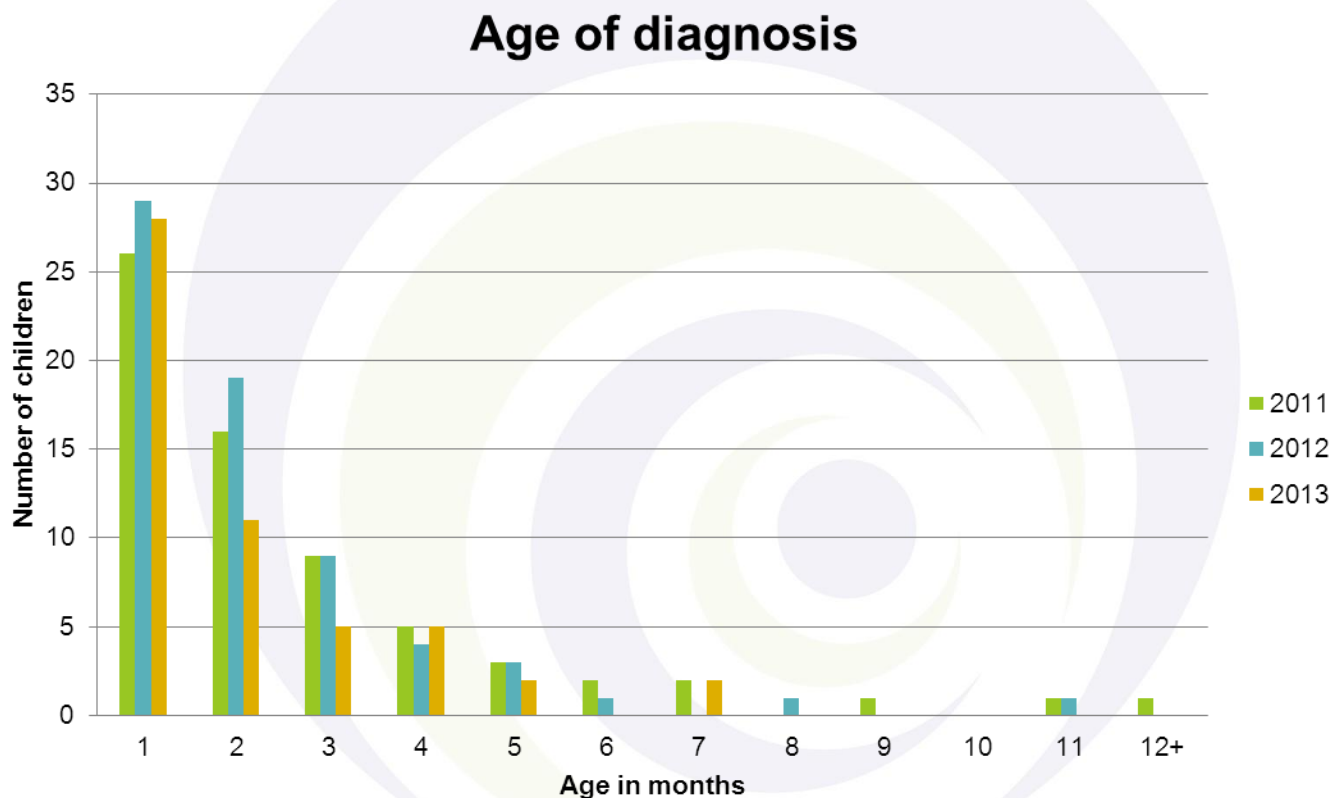
We know that earlier diagnosed children have better outcomes – do they engage earlier with EI?

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

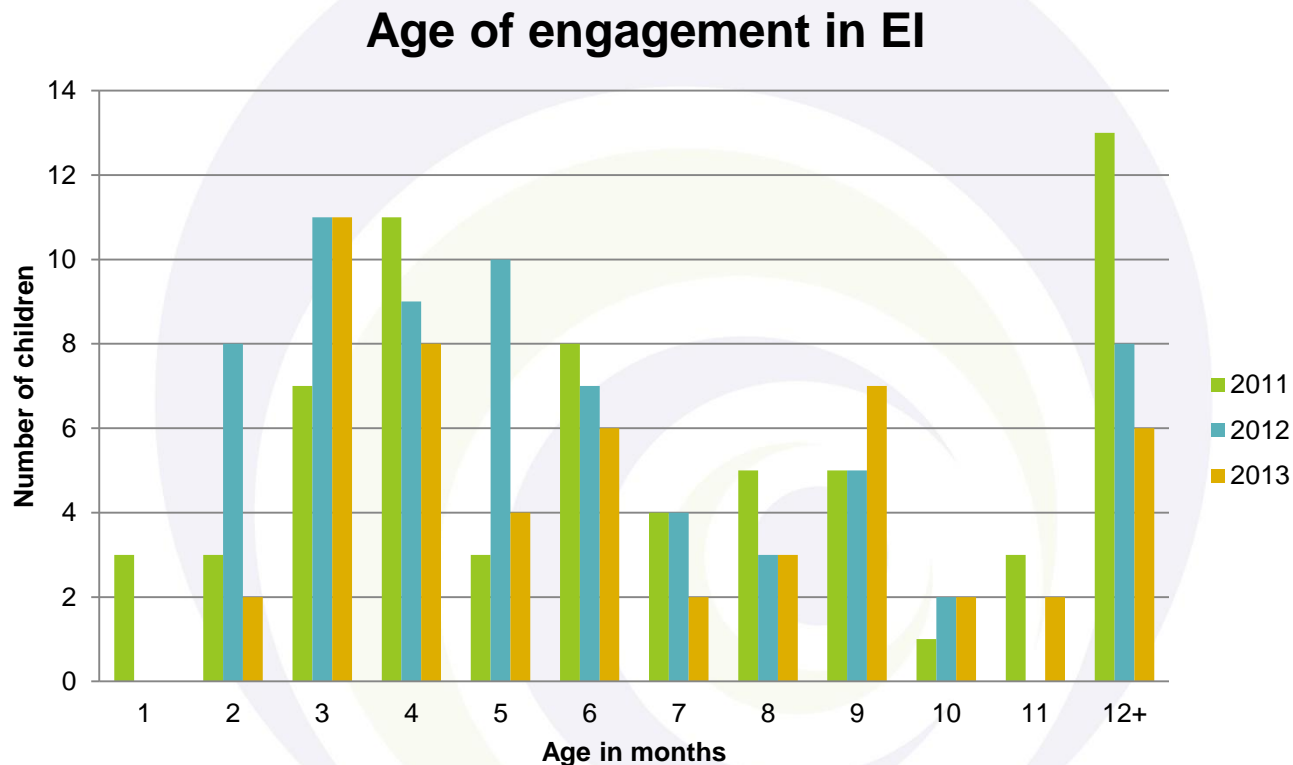
n=186



# Preliminary Data Analysis:

## Age of engagement

n=186



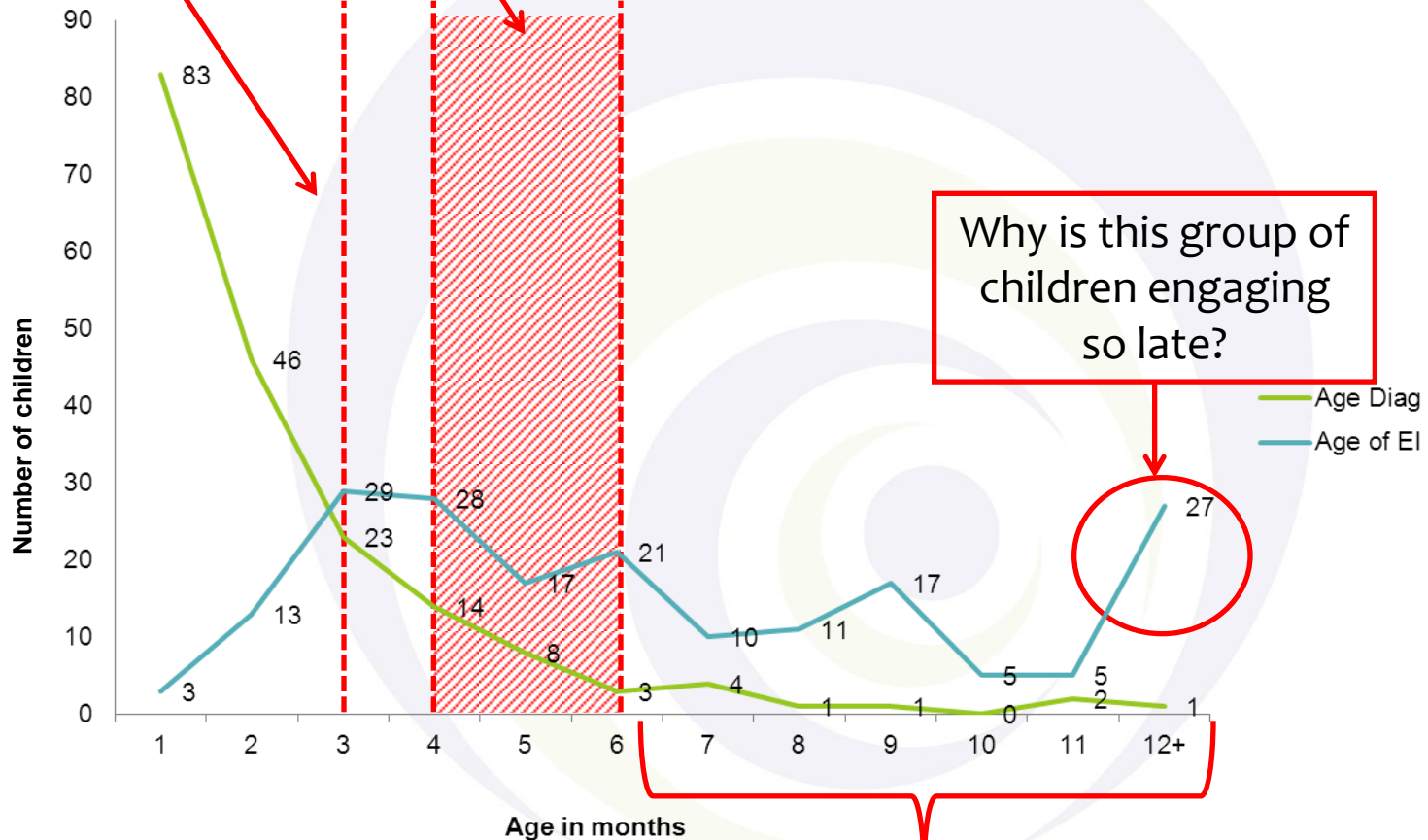
# Age of diagnosis and age of engagement

Benchmark  
for diagnosis

Benchmark for  
engagement in EI

Children with PHL

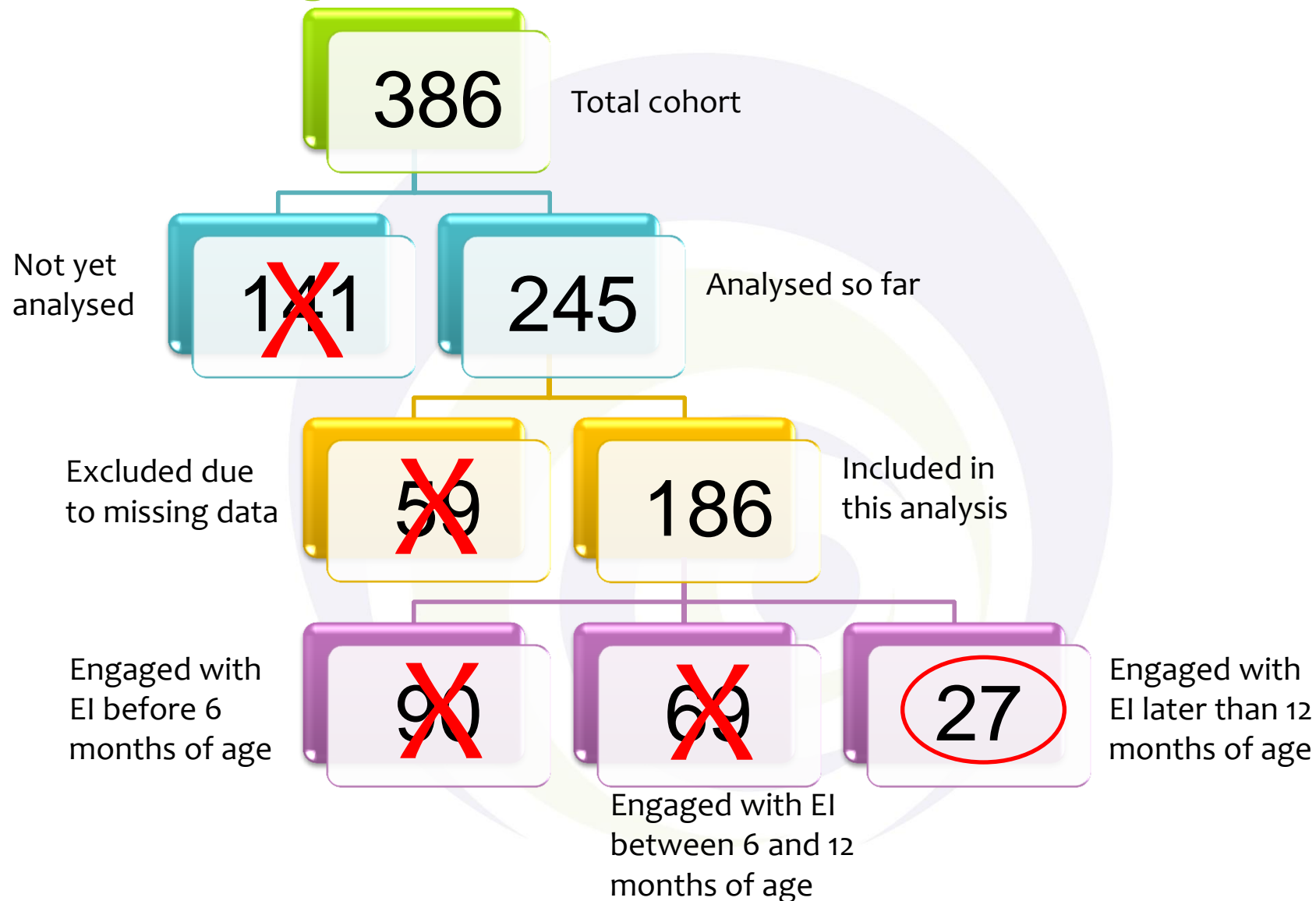
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Why are all these children engaging late?

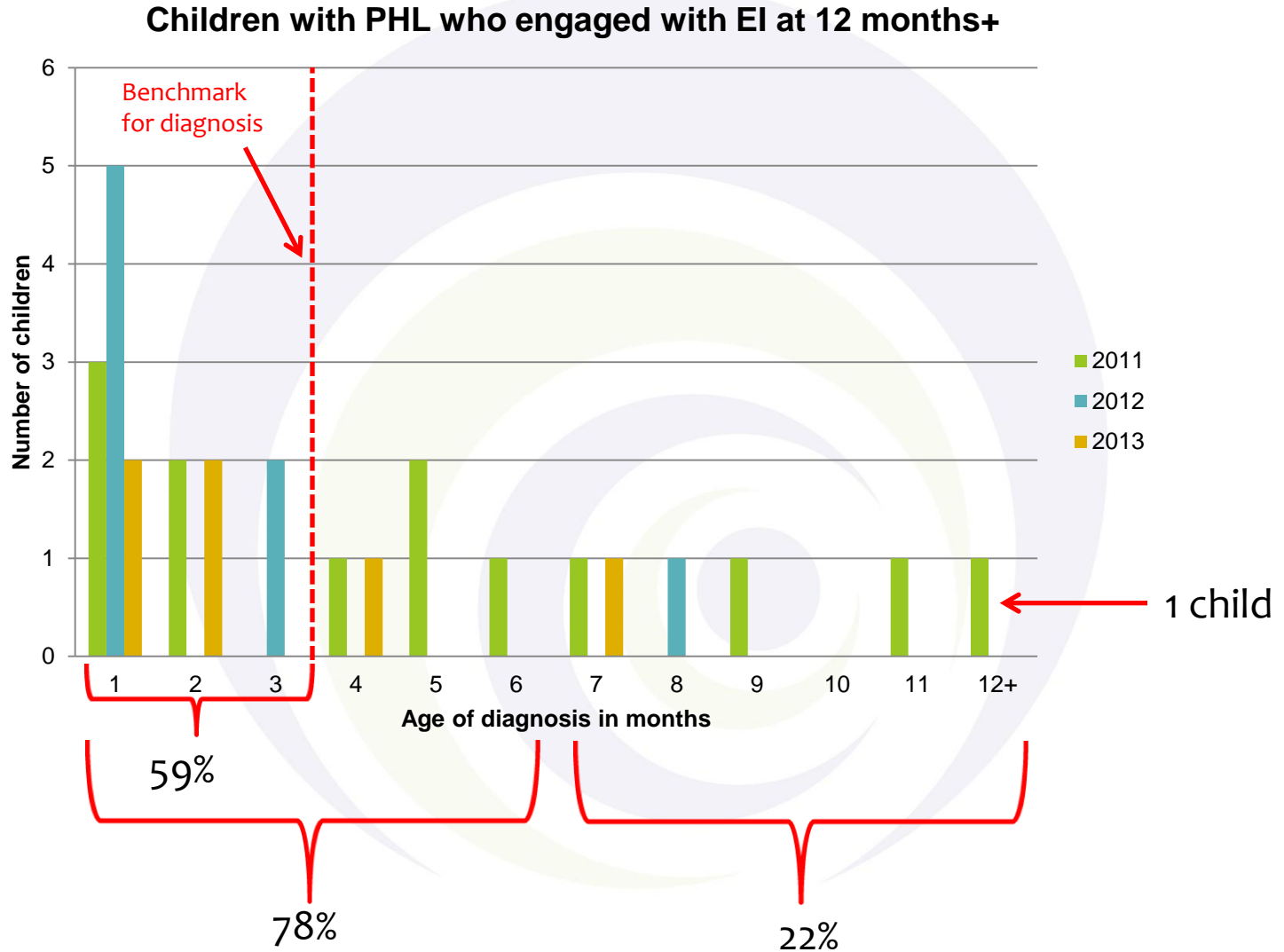


# Understanding the cohort



# The very late engaged group

n=27



# The Factors

Developmental History	Family History	Hearing status ?	Early intervention	Family Factors
Pregnancy	Living arrangements	Hearing loss type	EI type	Transport type
Birth	Cultural identity	Hearing loss laterality	EI service	Domestic violence ?
Comorbidities ?	Language background	Hearing loss severity	Age at enrolment	Number of children
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	Family mobility within 12 months of diagnosis ?	Number of diagnostic appointments	Playgroup	Mother's employment status
		Cochlear implant status	Communication method - child ?	Father's employment status
		Hearing aid status		
		Amount of time between diagnosis and EI enrolment		

Looks like our hunch was wrong!

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

# 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



# Questions?



## Contact Us

**Queensland Hearing Loss Family Support Service**

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

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