

**Investigating Developing Attachment Relationships:  
Infants with Hearing Loss and Complex Needs**

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## Errata Notice

### **PhD thesis by Samantha Claire Bernardo Woo: “Investigating Developing Attachment Relationships: Infants with Hearing Loss and Complex Needs”, 2020**

Author of notice: Jennifer Stanton

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Errata:

- p. 334 The title of a reference has been redacted to prevent identification of research participants.
- p. 389 A paragraph has been redacted to prevent identification of research participants. The name of the institution involved in the study has been redacted to prevent identification of research participants.
- p. 390 The name of the institution involved in the study has been redacted to prevent identification of research participants.
- p. 394 A paragraph has been redacted to prevent identification of research participants.
- p. 395 The name of the institution involved in the study has been redacted to prevent identification of research participants.
- p. 398 - 401 The date of birth and year has been redacted to prevent identification of research participants.
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## Statement of originality

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

This thesis has not been submitted for any other degree or purpose.

This thesis meets the University of Sydney's Human Research Ethics Committee (HREC) requirements for the conduct of research.

Samantha Claire Bernardo Woo

7<sup>th</sup> August 2020

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## Dedication Page

To my husband Yoakim who has supported me throughout this whole endeavour,

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To our two boys Benedict and Kolbe who have taught me all about attachment, and so much more.

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## **Abstract**

A key part of any child's development is forming a secure attachment relationship. Yet there is a scarcity in the research investigating attachment development in infants with hearing loss and complex needs (HL-CN). Such infants often receive varied services to support their learning and development. Parents of infants with HL-CN often experience higher amounts of stress, anxiety, depression, prolonged grief and trauma in comparison to parents of typically-developing infants. The current study proposed that an accumulation of risk factors may have an adverse impact on the attachment process, and that hearing loss alone was not a determinant for attachment insecurity. The study thus aimed to better understand how attachment develops in infants with HL-CN and their caregivers. It also asked whether the infant's early childhood intervention service provider could facilitate the development of attachment relationships. The study took a mixed-methods approach to a multiple-case study embedded design to explore these questions. It utilised interviews, self-report psychometric questionnaires, documentation, videotaped mother-infant interactions and service provider-infant interactions, during early childhood intervention therapy sessions. The CARE-Index and an original video-coding scheme were used to analyse the videotaped observations. Findings from the study revealed that in infants with HL-CN, the attachment process takes much longer, with an accumulation of risk and protective factors, including the presence of the service provider, influencing the likelihood of secure attachments. The implications of these findings are discussed, as well as future directions for attachment in infants with HL-CN.

## Chapter 1 Introduction

All children deserve a good start to life - to play, learn, grow and belong. Parents express desire for their child to experience quality of life through supporting their social, emotional and physical wellbeing (Brown & Brown, 2003; Colver, 2008). The most recent Australian research priorities have recognised the need to focus on “building healthy and resilient communities across Australia” (Australian Government, 2015, p. 4). This surely begins with the youngest of Australians, our children.

### Quality Start to Life for all Australian Children

Following a global movement to protect the rights and dignity of the child, the Australian government has seen an increase in research and policy in the field of early childhood, supporting this notion of a good start to life (Bowen, Zwi, & Sainsbury, 2005). The Department of Health put forward the *National Action Plan of Health of Children and Young People 2020-2030*, as “a national approach to improve and ensure the health and wellbeing of all Australian children and young people – providing them with the best start to life” (Commonwealth of Australia, Department of Health, 2019, p. 1). Specific to early childhood, *Belonging, Being and Becoming: The Early Years Learning Framework*, envisions that “all children have the best start in life to create a better future for themselves and for the nation” (Australian Government, Department of Education, Employment and Workplace Relations, 2009, p. 5). Its first principle, *Secure, Respectful, and Reciprocal Relationships*, is based on attachment theory and evidence-based practice that promotes the significance of such relationships to young children’s development (Australian Government, Department of Education, Employment and Workplace Relations, 2009, p. 12). It would appear that a crucial part of giving Australian young children the best start to life is by encouraging secure attachment relationships. Attachment is a “bi-directional relationship that develops from a set of interactional behaviours



between the infant and parent over time, usually established around 8 months of age” (Landy, 2009, p. 141). A secure attachment relationship is one where the infant’s attachment behaviours are reciprocated with sensitive caregiving behaviours, thus ensuring the infant’s needs are being met (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1969; Landy 2009).

All children have this right to the best start in life. As part of their national research priorities, the Australian government has sought to discover “better models of health care and services that improve outcomes, reduce disparities for disadvantaged and vulnerable groups, increase efficiency and provide greater value for a given expenditure” (Australian Government, 2015, p. 4). Children with disabilities and their families are included in these vulnerable groups, and indeed in the last decade, the landscape of disability in Australia has evidenced significant changes in its laws, policies and practices.

### **A National Agenda for People with Disability**

The Australian government is heading in a direction towards the social inclusion and participation of people living with disability. The United Nations *Convention on the Rights of People with Disabilities*, states that persons with disability have the right to “full inclusion and participation in all aspects of life” (The United Nations, 2006, art. 26). Inclusion can be defined as “enable[ing] all human beings to participate fully in society with respect for their human dignity” (Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010, p. 9). One major Australian development towards inclusion has been the National Disability Strategy 2010-2020. This Strategy outlined six policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and, health and wellbeing (Commonwealth of Australia, 2011). Its vision is “an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.” (p. 22).

Work towards upholding the principles of inclusion is also evident in the National Disability Advocacy Program’s (NDAP) objective, that: “People with disability have access to effective

disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation” (Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, 2013, p. 5). Government legislation, initiatives and policies such as the National Disability Strategy 2010-2020, the *Early Years Learning Framework*, the NDAP, and the National Disability Insurance Scheme (NDIS), reveal a deeper understanding of the experiences of children with disability, and their caregivers, and an increase in the support given. Moreover, under the National Disability Strategy 2010-2020’s policy area of health and wellbeing, is a policy direction that directly relates to young children with disability: “Timely, comprehensive and effective prevention and early intervention health services for people with disability” (Commonwealth of Australia, 2011, p. 61).

These initiatives show the complexities behind addressing the needs of children and families with disabilities. In particular, key objectives of the National Disability Insurance Scheme Act 2013, include “provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports” (Commonwealth of Australia, 2013, p. 4). Service users, including parents of young children with disabilities who access early intervention, are encouraged to take ownership of managing their child’s support needs. A closer examination of the NDIS shows that support for people with disability is taking a more individualised, self-determined and life-long approach. A key part of ensuring this approach are principles such as “the right of the participant to exercise control over his or her own life” and “people with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime” (Commonwealth of Australia, 2013, pp. 6, 34). It also includes a specific focus on early intervention and recognises how early intervention could mitigate the impact of disability on quality of life (Commonwealth of Australia, 2013).

The rollout of the NDIS has sought to combat previous issues in service delivery to families living with disability, including issues of access to funding and qualification for various services. A commission into the NDIS (Productivity Commission, 2017), revealed that “disability services were underfunded, inflexible, fragmented and built around the needs of the system rather than those of individuals” (Olney & Dickinson, 2019, p. 277). Consequently, individuals were not afforded the services they needed resulting in inequity within the system (Olney & Dickinson, 2019). However, implementation of the NDIS has been wrought with further challenges, with data and research on the NDIS trials revealing that service users - people with disability and their caregivers - have not all been able to exercise choice and control (Olney & Dickinson, 2019; Warr et al., 2017). For example, many service users reported that the administrative burdens of the NDIS, such as the completion of disability plans, being overly complicated, lengthy and time-consuming (Alexander, Frederico, Long, 2019; Olney & Dickinson, 2019) outweigh its benefits. Further problems stem from ICT issues, as well as communication issues with the NDIS (e.g., problems with the ICT infrastructure and extended delays in reaching support staff) (Olney & Dickinson, 2019).

For families with young children, one cost of managing their child’s supports was not returning to work, due to the time and effort required to navigate the NDIS and ensure their child’s service provision (Olney & Dickinson, 2019; Warr et al., 2017). Furthermore, while the NDIS pledged service users control and choice, options are limited by an analysis of the costs and benefits and an inability for the NDIS to engage with other government systems (Olney & Dickinson, 2019). One mother reported difficulties in trying to incorporate NDIS supports into her child’s activities - such as support from occupational therapists - resulting in her child being turned away from mainstream (i.e., education for children without disability) childcare centres (Warr et al., 2017). Clearly while the impetus behind the NDIS was to make service provision and delivery simpler and more effective for all Australians with disability, thus far it is facing challenges in meeting its goals. Such challenges only add to the difficulties many families of young children with disability face.

Across these different initiatives, programs and policies, what emerges is a focus on improving the quality of life of people with disability. However, underlying this move towards individualised yet nation-wide service provision and funding, is the reality that addressing the needs of people living with disability can be quite complicated. For example, support and intervention for people with disability needs to be accessible across multiple public and private sectors, such as housing, transport, education, and health. Currently, the NDIS has met some challenges in ensuring this type of accessibility. The issue may be further complicated when people live with multiple disabilities that require multiple health, social and emotional needs to be met, as is the case with young children with hearing loss and complex needs. It is within this context that the current research study is situated.

### **Young Children with Hearing Loss and Complex Needs**

In Australia, approximately 600 infants are identified each year with congenital hearing loss (Sung, Smith, Poulakis, Burt, Carew, Tobin, & Wake, 2019). Amongst this number, a percentage of infants are also diagnosed with additional needs. The term “additional needs” can be defined as any added disability, condition or impairment, for example, a child with hearing loss and autism, or a child with hearing loss and behavioural challenges (Edwards, 2007). However, for the Australian population limited data exist on children with additional needs. Difficulty in engaging a small and specific population to take part in research may account for the lack of current data. The most recently available Australian data are from a study by Birman and colleagues (2012) who found that in a cohort of 88 children with hearing loss, 33% were identified as having additional disabilities (Birman, Elliot, & Gibson, 2012). Literature on deaf children with additional needs from other countries is also either limited or dated. In North America, up to 40% of children diagnosed with hearing loss have additional needs (Gallaudet Research Institute, 2011). Holden-Pitt and Diaz’s (1998) study support this, reporting that 20-40% of children with hearing loss also have additional needs. Similarly, data from the U.K. attests that each year, 800 infants are born deaf, with 39% of that population also born

with additional needs, such as cognitive deficits, visual impairment and developmental delay (Davis, Bamford, Wilson, Ramkalawan, Forshaw, & Wright, 1997).

The crux of the issue is that the term ‘additional needs’ insufficiently encapsulates the reality of life for families. The lives of those families raising young children with hearing loss and additional needs, transform into lives that become complex as a result of the various factors that impact on their lives. A U.K. report entitled *Complex Needs and Complex Challenges* (McCracken & Pettitt, 2011), highlights that the term ‘additional needs’ does not fully describe the experiences of these children and their families, and instead uses hearing loss and ‘additional complex needs’ when referring to this population. Thus, with this realisation, this research aims to empower and support those families with young children with hearing loss and complex needs by coming to a better understanding of the experiences and needs of this specific population.

A child with a hearing loss and ‘complex needs’ (HL-CN) has multiple needs that span across social and healthcare issues, usually as a result of a disability, impairment, or illness, or a comorbidity of disabilities, that require varied support services (Hewitt-Taylor, 2010; Landy, 2009; McCracken & Pettitt, 2011; Rankin & Regan, 2004; Salisbury & Copeland, 2013). These services may be delivered by various service providers, including, but not limited to: occupational therapists, physiotherapists, special educators, speech pathologists, medical personnel, psychologists, social workers, audiologists, orthoptists, orientation and mobility instructors, and technology teachers (Cumming & Wong, 2012; Landy & Menna, 2006). Children with HL-CN may also have other needs if part of culturally and linguistically diverse families, single-parent families, families with mental health issues, low-income and/or rural families (Ziviani, Darlington, Feeney, Rodger, & Watter, 2014; McCracken & Pettitt, 2011). To summarise, the term young child with hearing loss and ‘additional needs’ falls short in describing the lives of these children and their families. Thus the term hearing loss with ‘complex needs’ has been deemed more apt as it better reflects the multitude of interacting complexities and challenges faced by such children and their families.

## **Complex Needs, Complex Service Provision**

McCracken and Pettitt (2011) noted that children with hearing loss and complex needs are often purposefully excluded from research studies, mostly due to the difficulty of researching a small subset of the population of children with hearing loss that includes a range of comorbid diagnoses. This is despite the significant challenges that their unique needs pose for families and services. This is problematic and perhaps suggests that there is a mismatch between the intervention and support that this population is receiving, and what they actually need. Their report stated that parents experienced a lot of stress gaining access to and interacting with services for their children (McCracken & Pettitt, 2011). Since young children with HL-CN have social and healthcare needs that require varied support services, one challenge for families is negotiating which need to focus on. Some parents describe difficulty in accessing services for all of their child's needs, with some needs being overshadowed by others (McCracken & Pettitt, 2011).

To help their child have a quality start to life, access to quality early childhood intervention (ECI) funding and programs is key. Frequently, these challenges come at a time of intense emotional stress, anxiety and grief, as the families attempt to come to terms with their child's multiple diagnoses and learn to cope with their situation (Fletcher, 2016; Granat, Gadassi, Gilboa-Schechtman, & Feldman, 2017; Green, 2007). Families living with disability are faced with an intricate, multi-faceted, and complex maze of early intervention providers, assessments, referrals, funding, and policies that they must navigate in order to provide their child with the best start to life (Moore, 2005). Fears about the future of their child plague the thoughts of parents (Landy, 2009). Doctors, service providers, relatives, the community and society, may have a lack of understanding, knowledge and empathy, therefore addressing the needs of families with young children with HL-CN can become an even harder task, than for families with children with solely a hearing loss (McCracken & Pettitt, 2011). Bowman and Virtue (1993) describe their experience: "caring for our daughters was made so much harder by lack of support, lack of information, lack of childcare, inadequate housing, living on a low income and struggling through the medical maze – all issues of public policy" (p. i). But despite

the assurances of the NDIS of ‘choice’ and ‘control’, parents still find themselves weaving through this maze (Olney & Dickinson, 2019).

### **Attachment and Young Children with Hearing Loss and Complex Needs**

Most parents want to give their children the best, to ensure their needs are being met, in order for them to have a quality life. A key part of attaining a quality life is having positive relationships with family and friends (Colver, 2008). The foundation of positive relationships for a young child is forming a secure attachment with their primary caregivers at an early age.

It is arguable that due to the stressful and emotional environment families with children with HL-CN find themselves in, the development of their attachment relationships are at risk. If an infant’s hearing loss and additional disabilities prevent them from interacting with their parents, how can young children engage and ‘woo’ their parents? If parents are too busy chasing service provision through the maze of policy and early intervention, where is the time to bond with their young child and form these crucial attachment relationships? If parents are experiencing depression or anxiety as a result of a lack of empathy and support, how can they have the psychological energy to provide the sensitive caregiving that such vulnerable infants need? The formation of an attachment relationship between a young child and their parents or carers and other significant persons has long-term implications for the child’s quality of life (Bowlby, 1973; Rolfe, 2004). Since ensuring the physical, social and emotional wellbeing of a child are all part of quality of life, this raises issues around the balance needed between the young child with HL-CN’s health care needs and social and emotional needs at the state and national level (Brown & Brown, 2003; Colver, 2008).

However, research has revealed a significant gap in the literature on attachment and young children with HL-CN, with little evidence surrounding this topic. A secure attachment is a major factor influencing a child’s social, emotional, physical and intellectual development (Sameroff, 2009; Shonkoff & Phillips, 2000; Sroufe, Egeland, Carlson, & Collins, 2005). For this reason, supporting secure attachments amongst those children arguably most at-risk of developing insecure attachment

relationships should be foremost in the national agenda. Children with HL-CN make up a small percentage of the population, and intensive, individualised intervention may offset possible detrimental long-term effects on society (Carter, Cummings, & Cooper, 2007; Landy, 2009; Landy & Menna, 2006). With little research specifically addressing attachment and children with HL-CN, the current study will contribute a greater understanding of the attachment process of young children with HL-CN to the body of research in the fields of attachment theory and ECI.

### **The Value of Early Childhood Education and Early Childhood Intervention**

Early childhood education encompasses education for young children aged 0 to 5 years of age and takes place before school entrance. Early childhood intervention provides specialised support and services for infants and young children with disability and/or developmental delay and their families to help their development, well-being and participation in family and community life (ECIA, 2016). Guidelines for early childhood education and early intervention models indicate the importance of early childhood education to a child's life. The Australian Children's Education & Care Quality Authority (ACECQA) works with all state and territory governments to provide guidance, resources and services to support the sector to improve outcomes for children. The ACECQA emphasises that "the early years are critical for establishing self-esteem, resilience, healthy growth and capacity to learn" (Australian Children's Education and Care Quality Authority, 2019). Through approved national learning frameworks, the ACECQA outlines practices that support and promote children's learning, starting from an early age. Australia's *Belonging, Being and Becoming: The Early Years Learning Framework* (Australian Government, 2009), emphasises the importance of providing children and families with a secure, safe and welcoming environment, in both physical and emotional dimensions. To ensure a positive emotional environment, early childhood educators should "support children's secure attachment through consistent and warm nurturing relationships" (Australian Government, 2009, p. 21).



The Australian national guidelines for best practice in ECI (Early Childhood Intervention Australia, 2016) recommend a focus on promoting responsive caregiving, and the strengthening of parent–child relationships, within families with children with disability. This is in line with current best practices in early intervention, including family-centred practice, strengths-based practice, inclusion, and engaging children in their natural environments (Bruder, 2000; Early Childhood Intervention Australia, 2016; Fordham, Gibson, & Bowes, 2012; Guralnick, 2005). In a recent article, Alexander and colleagues (2019) reference these guidelines of Early Childhood Intervention Australia, and have identified elements of the NDIS that may be counterproductive to fostering attachment security in children. They argue that attachment security should be a key consideration in the design and implementation of the NDIS, and propose improvement, including: easing access to the NDIS, reducing the stress of service providers, and, ensuring service providers are skilled and educated in ECI and attachment (Alexander et al., 2019).

Early childhood intervention that does not value the importance of secure attachments or does not adequately address attachment disorders may result in a child developing behavioural challenges, learning disabilities or mental illnesses (Landy, 2009; Landy & Menna, 2006). Without the foundation of a secure attachment, all subsequent therapies, interventions and even schooling that the child may go through will simply be playing ‘catch up’. It benefits the child’s preschool, primary and high school, workplace, community and indeed society as a whole, if young children are given the opportunity to form secure early attachments with those closest to them, enabling them to play, learn, communicate and share in social interactions with other members of society (Bruder, 2010).

Early childhood intervention models that support the caregiver or parent during the critical period of attachment by increasing caregiver sensitivity will have a greater likelihood of ensuring a secure attachment (Bakermans-Kranenburg, van IJzendoorn, & Juffer, 2003). The available literature on attachment and children with disability suggests that the caregiver, rather than the child, is more influential in developing the secure attachment (Atkinson, Chisholm, Scott, Goldberg, Vaughn, Blackwell, Dickens, & Tam, 1999; Feniger-Schaal & Joels, 2018). Important factors that have the

potential to affect caregiver quality include: stress, depression, anxiety and grief; caregiver sensitivity; social and family support (Belsky, 1984; Belsky & Jaffee, 2006; Fearon & Belsky, 2016). Implementers of early intervention models may have a crucial role in supporting attachment formation, hence their understanding of the various factors surrounding attachment, and how they enact this understanding when working with children and families, is worthy of investigation.

Therefore, if the ultimate goal of Australian research priorities and policies is to ensure and improve quality of life of all children, regardless of ability, then understanding the importance of attachment as foundational to the development and learning of a young child with HL-CN becomes a fundamental element of this agenda. The following section presents the study's theoretical framework as a way to better understand the significance of attachment relationships, and how it has been utilised within this study.

### **Theoretical Framework: Attachment, Parenting and Quality of Life within the Bioecological Systems Theory of Human Development**

A theoretical framework or lens guides the research study by providing a certain perspective through which different aspects of the study are shaped. One definition of theory is: "a set of interrelated constructs (variables)... that presents a systematic view of phenomena by specifying relations among variables, with the purpose of explaining natural phenomena" (Kerlinger, 1979, p. 64). In order to make sense of the phenomenon being studied within the current study, the researcher has pulled together the following theories: Quality of Life, Bowlby's (1958, 1969, 1973, 1980, 1982) attachment theory, Belsky's (1984) determinants of parenting model, and Bronfenbrenner's (1977, 1979, 1986, 2001) bioecological systems model of human development. Together they form the study's theoretical and conceptual framework, which has been used to guide the research study on attachment and infants with HL-CN. The following section describes the different constructs and theories that form the study's theoretical and conceptual framework. The theoretical framework is of importance as it "serves as the structure and support for the rationale for the study ... a grounding

base, or an anchor, for the literature review, and most importantly, the methods and analysis” (Grant & Osanloo, 2014, p. 12).

### *Quality of Life*

‘Quality of Life’ (QoL) has varied definitions (Brown, Bayer, & MacFarlane, 1989; Felce & Perry, 1995; Goode, 1994; Raphael, Renwick, Brown, & Rootman, 1996). It is a difficult concept to grasp; multidimensional with objective and subjective elements. QoL is objective in that it can be conceived in universal terms, as there are certain aspects of life that all people share and find important, such as satisfaction with one’s physical health, family, education, and employment. (Brown & Brown, 2003). It is also subjective in that QoL is different according to each individual’s experience of life (Brown & Brown, 2003). Most studies now agree on the subjective element, taking their definition of QoL from the World Health Organisation: “the individual’s perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (1997, p. 1). There are six dimensions of QoL that further explain the concept:

- Emotional wellbeing
  - Social wellbeing
  - Material wellbeing
  - Physical wellbeing
  - Self-esteem
  - Self-determination
- (Brown & Brown, 2003; Colver, 2008)

In studies on QoL and children with disability, the UN Convention on the Rights of the Child is often referenced, emphasising children with disability being entitled to a “full and decent life”, (United Nations, 1989, p. 7). Proponents of this view maintain that children have a right to a quality life, for the simple reason that they are children and human persons, regardless of their ability (Brown & Faragher, 2014; Colver, 2006, 2008; Dickinson et al., 2007). Dickinson and colleagues also argue

that children with disability are disabled by barriers in society and the environment, which places the focus on a disabling society rather than on disability as intrinsic to the child (Colver, 2006, 2008; Dickinson et al., 2007). These same studies have indicated that disability and impairment are not the major determinants of QoL.

One study is of particular significance to the current research. Colver (2008) suggested that on the whole, type or severity of the disability is not linked to QoL. Rather, the areas of social, interpersonal and family functioning have been identified as main determinants of QoL (Colver, 2008). Furthermore, a recent Australian study on quality of life stressed the importance of family quality of life, and the need to support families caring for a child with disability (Kyrkou, 2018). Therefore, to promote children's QoL there should be a focus on improving social and interpersonal relationships and family functioning. This highlights the QoL dimensions of emotional wellbeing and social wellbeing, in which positive and secure relationships play a major role (Brown & Brown, 2003).

The present study is framed by the concept of 'Quality of Life' and its relationship to attachment theory. Using QoL as part of the theoretical framework for the study, has allowed the researcher to consider the various needs of the child across the six dimensions that make up QoL, rather than focussing solely on the child's disability. Through an exploration of QoL in relation to children and disability, this study suggests important connections between QoL and attachment in infants with HL-CN. Furthermore, QoL directly links to current Australian policies around early childhood education and intervention and the Australian Government Strategic Research Priorities, which all point towards empowering families and enhancing the quality of life of all Australians, regardless of ability (Australian Research Council, 2012).

### ***Quality of Life and Attachment***

Attachment theory focuses on secure attachment relationships between young children and their caregivers as significant to a child's social and emotional development (Ainsworth, 1972; Bowlby,

1980; Landy, 2009). Attachment theory proposes that infants develop an attachment with their primary caregiver – usually their biological mother – through the quality of caregiving that the caregiver provides, and through early experiences within this relationship (Bowlby, 1969, 1973, 1980). Infants begin to develop this attachment relationship over the course of their first year of life, and well into toddlerhood (Bowlby, 1969). Caregiver sensitivity has a causal impact on attachment security (Ainsworth, Bell, & Stayton, 1974; Bakermans-Kranenburg et al., 2003; De Wolff & van Ijzendoorn, 1997). Less sensitive caregiving results in insecure or disorganised attachment relationships, therefore the quality of caregiver sensitivity that the infant’s primary caregiver can provide during the development of attachment is important (Ainsworth et al., 1978; Bakermans-Kranenburg et al., 2003; De Wolff & van Ijzendoorn, 1997). Since attachment security is part of the child’s social and emotional development, it would appear that focussing on early attachment security would improve QoL.

To conceptualise this theoretical framework, the following section discusses the current study’s conceptual framework. The conceptual framework “lays out the key factors, constructs, or variables, and presumes relationships among them” (Miles & Huberman, 1994, p. 440). The study’s conceptual framework is informed by Belsky’s (1984) determinants of parenting model, and Bronfenbrenner’s (1977, 1979, 1986, 2001) bioecological systems theory of human development.

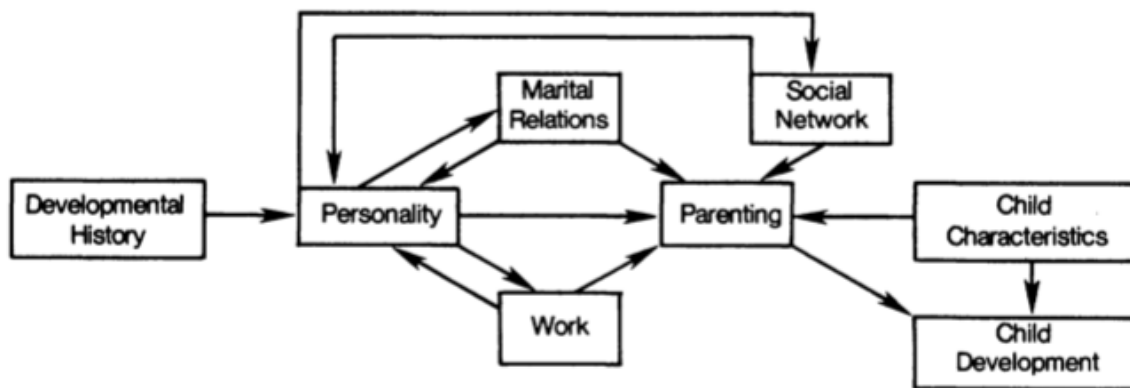
### ***Belsky’s Determinants of Parenting Model and Bronfenbrenner’s Bioecological Systems Theory of Human Development***

As stated, caregiver sensitivity impacts on the attachment relationship that develops between an infant and their caregiver (Ainsworth et al., 1978; Bakermans-Kranenburg et al., 2003; De Wolff & van Ijzendoorn, 1997). A caregiver’s psychological attributes influence their ability to parent and provide sensitive caregiving (Belsky & Jaffee, 2006). Belsky’s (1984) social-contextual model of the determinants of parenting outlines five domains that influence parenting: (a) the child’s characteristics; (b) the caregiver’s personality and psychological attributes; (c) the caregiver’s marital

relations; (d) the caregiver's occupation and socioeconomic status; and (e) the caregiver's social network. All five sources of influence reveal potential risk and protective factors that may determine how the child and caregiver's attachment relationship forms (Belsky & Jaffee, 2006; Fearon & Belsky, 2016). Figure 1.1 showcases the process model of the determinants of parenting, and how the various domains influence parenting, and consequently, child development (Belsky 1984, p. 84).

Figure 1.1

*A Process Model of the Determinants of Parenting (Belsky, 1984, p. 84).*



The following conceptual model (see Figure 1.2) displays the child-caregiver attachment relationship as influenced by Belsky's determinants of parenting. The five domains of influence on parenting are situated across Bronfenbrenner's bioecological systems model of human development. Bronfenbrenner's (2001) system describes how individuals develop within nested layers of environment, with the outermost layers affecting the innermost layers, and vice versa. In Figure 1.2, the individual is the child, and is positioned within the centre of the microsystem. The first direct parenting domain, child characteristics, is part of and directly related to the individual. According to Bronfenbrenner, the microsystem is the "complex of relations between the developing person and environment in an immediate setting containing that person (e.g., home, school, workplace etc.)" (Bronfenbrenner, 1977, p. 514). Therefore, in the conceptual model of this study, the child-caregiver attachment relationship lies within the microsystem. Child characteristics, the first of Belsky's parenting domains, is part of the developing individual. The domains of parenting influence that also

fall within the microsystem are the caregiver's personality, marital relations, and to an extent, social network (Belsky, 1984). For example, if the parents' marital relations are negatively affected (e.g., poor communication between spouses), this may have an impact on the child.

Surrounding the microsystem is the mesosystem. The mesosystem "comprises the interrelations among major settings containing the developing person at a particular point in his or her life" (Bronfenbrenner, 1977, p. 515). For example, connections between the child's home and early childhood intervention centre (ECIC) would include the relationship between the child's caregiver and service providers. The strength of these connections impacts on the influence of the microsystem on the child, for example, if the child's caregiver and health service providers have a strong relationship and communicate well, the child's attachment relationship with his primary caregiver may be positively impacted.

The environment around the mesosystem is the exosystem. The exosystem describes the larger social system that surrounds but does not impact directly on the child (Bronfenbrenner, 1977). For example, the child has no direct involvement in the parent's occupation, though may be influenced by his or her parent's work schedule. The parent may work part-time, limiting their availability to their child, and therefore being reliant on other persons, such as grandparents, childcare workers or service providers. Consequently, the child may likely develop attachment relationships with these persons which may serve to buffer any negative effects of the parent's absence. Thus, the exosystem impacts on the child's development by impacting on the nested microsystem. Both the parenting domains of social network and caregiver's occupation fall within the exosystem, having an indirect influence on parenting.

The outermost layer is the macrosystem. This system encompasses the attitudes, customs, ideologies and laws of the culture and society in which the child lives (Bronfenbrenner, 1977). The macrosystem has a flow-on effect on the inner layers. For example, if the culture values parents as being the primary caregivers of their own children, that culture would be less likely to provide resources for parents, such as childcare subsidy from the government. Subsequently, this affects

structures within the exosystem, for example, paid parental leave or childcare costs. This in turn affects structures in the microsystem, namely the parents' availability to their children and the development of their relationships.

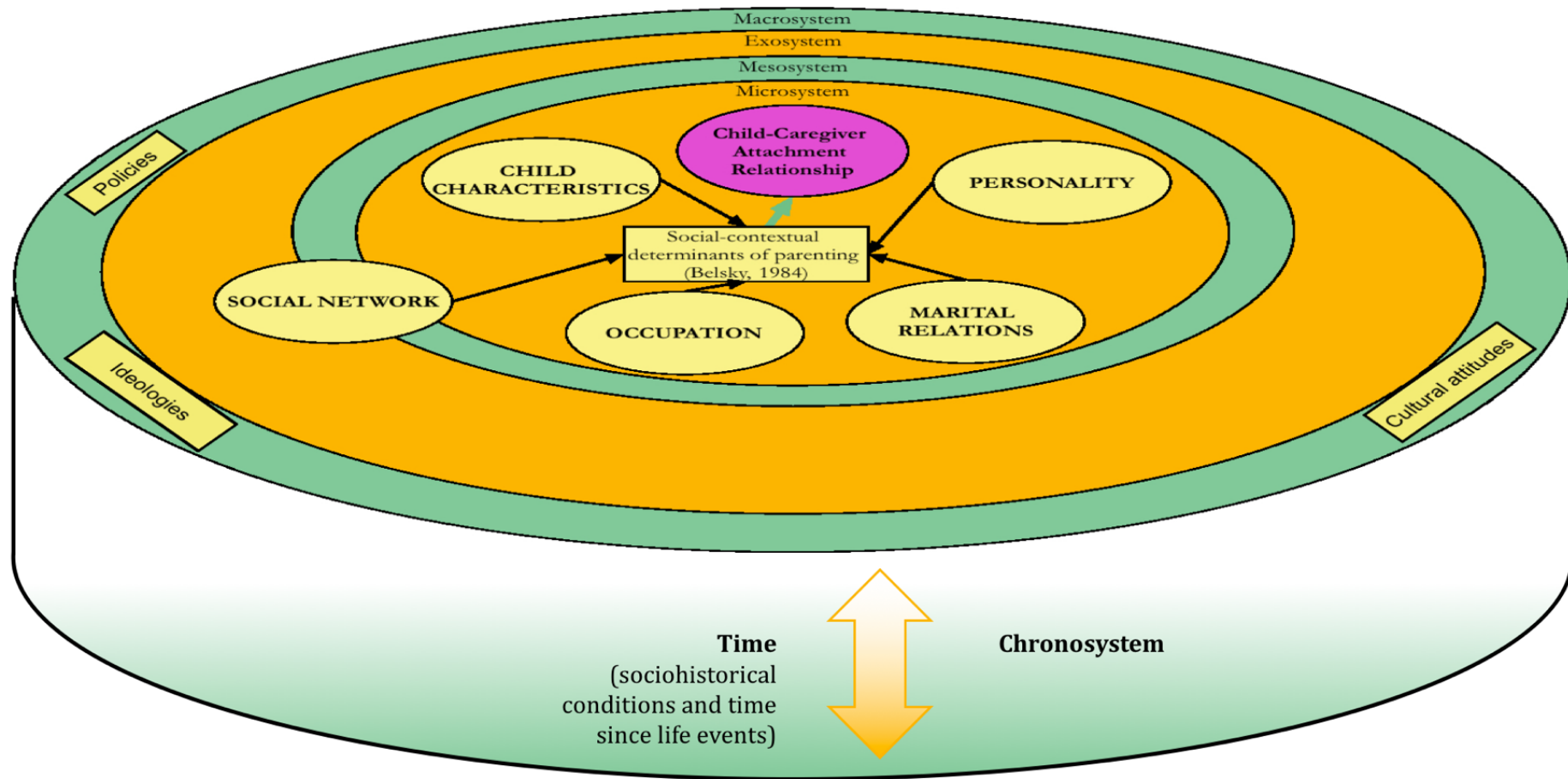
Finally, the chronosystem represents the dimension of time in relation to the other environments. It includes the social and historical conditions surrounding the individual's life events, for example, the aging of the child (internal life event), or a parent's death (external) (Bronfenbrenner, 1986; 2005). As time goes by, children are more able to understand how these nested environments influence their development and how they themselves can influence those same environments.

In sum, the current study sought to explore attachment relationships and the factors surrounding attachment development. It has used Belsky's determinants of parenting, and the five dimensions of 'child characteristics', 'parent's personality', 'social network', 'occupation', and 'marital relations', layered within Bronfenbrenner's bioecological systems theory.



Figure 1.2

*Attachment Relationship within Belsky's Determinants of Parenting and the Bioecological Systems Theory of Human Development.*



## Structure of the Study

The current study sought to better understand the attachment development of infants with hearing loss and complex needs. This exploratory study consists of two parts: 1) a pilot study that tested the methodological tools and research design; and 2) the main study, based on the outcomes of the pilot study.

The structure of the thesis begins with Chapter 1, *Introduction*, which has introduced this study, describing its significance within the current landscape of disability in Australia. The importance of a quality start to life for all Australian children was highlighted, in particular those with multiple disabilities. Furthermore, a quality start to life includes young children developing secure attachment relationships with their parents or caregivers. It concluded with presenting the study's theoretical framework, consisting of the concept of quality of life, attachment theory (Bowlby, 1958, 1969, 1973, 1980, 1982), Belsky's (1984) determinants of parenting model, and Bronfenbrenner's (1977, 1979, 1986 2001) bioecological systems theory of human development. The chapter then presented an operationalisation of this theoretical framework by presenting its conceptual model.

Chapter 2, *Literature Review*, begins with a review of the literature around attachment theory, its major components, attachment theory and disability, and finally attachment theory and infants with hearing loss and complex needs. The chapter ends with a section on methodological considerations and the presentation of the study's research questions.

Chapter 3, *Methodology*, considers the theoretical and methodological issues that surround an exploratory study on attachment and infants with hearing loss and complex needs. Firstly, the chapter details the study's research design and methodological approach. Purposive sampling methods highlight the study's small and unique population. A description of the study's mixed-methods approach and multiple-case study design is followed by a discussion of the reliability and validity of the study's chosen measures. The main qualitative tool was an original video coding scheme, and was used to analyse videotaped observations of the participants. This was supplemented by other tools as part of the study's case study research design, including psychometric self-report questionnaires,

interviews and documentation. A case study approach utilising two in-depth case studies was deemed most effective to obtain a deeper understanding of the factors surrounding the attachment development of infants with hearing loss and complex needs.

Chapter 4, *Case Study 1 (Pilot Study)*, presents the outcomes of the pilot case study. This chapter first describes the reliability and validity of the qualitative and quantitative tools used. Presentation of the results of the pilot case study are then made. This is followed by a discussion of several methodological considerations that arose out of the pilot study. Finally, the chapter concludes by presenting implications of these considerations of the research design and implementation for the next part of the study.

Chapter 5, *Case Study 2*, begins by discussing the revisions made to the study's research design and methodology as used in the second case study. It details the results of the second case study, presenting the results in chronological order based on the case study protocol. Results of the self-report questionnaires administered to the infant's primary caregiver, are triangulated with the interview responses from the primary caregiver, secondary caregiver, and service provider. This is followed by results of the videotaped observations analysed qualitatively and quantitatively. These results are triangulated with the documentation gathered, the researcher's logbook, as well as the follow-up interviews. The chapter concludes with a summary of the second case study's results, presented using Belsky's (1984) determinants of parenting model.

Chapter 6, *Discussion*, uses a cross-case analysis of the two case studies to provide a response to the study's research questions. This analysis draws upon the study's several databases: psychometric data, interview responses, video-recorded observations, and documentation, as well as its theoretical framework and the current research literature on attachment and infants with HL-CN. The chapter will conclude with a response to the study's theoretical framework, limitations, and implications for future research.

## Chapter 2 Literature Review

This literature review will begin by presenting a detailed review of attachment and factors surrounding its development, followed by a review of the literature specific to attachment in infants with hearing loss and complex needs (HL-CN). The chapter will conclude with a discussion of early childhood intervention (ECI) addressing attachment relationships and infants with HL-CN, and their caregivers. Finally, the chapter will present the study's research questions in light of the review of literature.

### Attachment Theory

Attachment theory is a theory that impacts on the overall wellbeing, growth and development of a person (Bowlby, 1969, 1973, 1980). Since its conception, attachment has become fundamental in understanding child development. It is known that in order for a child to optimise opportunities to grow and develop into a balanced, purposeful member of society, forming a secure attachment with their primary caregiver – usually their biological mother – at a very early stage in their life is important (Ainsworth, 1972; Bowlby, 1980). The primary caregiver can also be their biological father, adopted mother or father, other relatives, or caregivers providing the child with regular care. For convenience, the female pronoun will be used when discussing the primary caregiver, whilst acknowledging primary caregivers can be male.

The basic tenet of attachment theory is that social and emotional development is connected to a child's early relationships with their primary caregiver (Ainsworth, 1972; Bowlby, 1980; Sroufe et al., 2005; Thompson, 2016; van der Voort, Juffer, & Bakermans-Kranenburg, 2014). Unlike other mammals, human babies do not instinctually attach themselves to the first living being they are exposed to. Instead, they become attached to the person who takes care of them most regularly during the first few months of life (van Rosmalen, van Ijzendoorn, & Bakermans-Kranenburg, 2014). An infant encourages this individual to feel responsible for caring for them by specifically directing

attachment behaviours (e.g., crying, seeking proximity) to this person, in times of fear or distress (Bowlby, 1969). What develops is a reciprocal, bi-directional relationship, with infant and caregiver responding to each other's behaviours (Landy, 2009). This is what distinguishes attachment from bonding, a one-way emotional bond from mother to infant that usually develops soon after a mother has given birth to her baby (Landy, 2009).

According to Bowlby (1969), there are four phases in an infant's development of attachment:

Phase I: Orientation and Signals with Limited Discrimination of Figure

(shortly after birth to first few months of life) – orientation towards people without differentiating between them. Preference of the infant for the human smell, the sound of the human voice, and the rough outlines of the human face.

Phase II: Orientation and Signals Directed towards One (or More) Discriminated Figure(s) (6 to 12 months of age) – infant focusses on people it sees regularly and becomes familiar. Infant develops a preference for one or a few specific people to whom they become attached during the third phase.

Phase III: Maintenance of Proximity to a Discriminated Figure by means of Locomotion as well as Signals (begins between 6 and 7 months through to 3 years of age) – infant wants to be around these attachment figures when frightened or stressed. Attachment to the primary caregiver – usually the mother – has been established. The primary caregiver is used as a base from which to explore. Strangers are treated with caution and likely evoke alarm.

Phase IV: Formation of a Goal-corrected Partnership (3 years onwards) – child can form a perspective of the attachment figure. Attachment in this phase has developed from a solid behavioural pattern aimed at proximity, to a mental representation of a caregiver.

By this fourth stage, Bowlby (1969) proposed that the child has formed, what he termed, an *internal working model* (IWM), that is, a model of the child's representations for themselves, their behaviours, the environment, as well as the person these behaviours are directed towards. These IWMs are flexible and are used to understand and predict what the child's relationship is with their

environment, and how to plan series of behaviours to achieve certain outcomes (Bowlby, 1969; Marvin, Britner, & Russell, 2018). IWMs continue to change and develop throughout a person's life (Bowlby, 1969).

Interestingly, the phases of attachment (Bowlby, 1969) appear to match the sensorimotor stage of Piaget's theory of cognitive development, with the development of object permanence (i.e., the ability of the child to understand that objects continue to exist, though they cannot be seen or heard) playing a key role in a young child's establishment of an attachment relationship with their caregiver (Piaget, 1962).

Ainsworth (1972) observed these attachment phases in her research of mothers and infants in Uganda, within naturalistic settings. Along with her colleagues, she went on to develop the *Strange Situation Procedure* (SSP), the gold standard in measuring attachment security (Ainsworth et al., 1978). The SSP is a laboratory procedure designed to assess the attachment and exploratory behaviour of an infant (12 to 20 months), under conditions of increasing yet moderate stress. It consists of seven 3-minute episodes, including a play period where infant and their adult attachment figure are present, separations and reunions between them, and episodes wherein a strange adult is present, with and without the attachment figure. Infant and adult caregiver interactions are observed and recorded, as well as the infant's response to separations, reunions, and the unfamiliar adult. Ainsworth and her colleagues (1978) used four scales of infant-caregiver interaction in the process of classification:

- proximity seeking
- contact seeking
- avoidance, and
- resistance to contact and interaction.

From these observations, Ainsworth and her colleagues (1978) derived three main attachment classifications:

1. insecure-avoidant
2. secure

### 3. insecure-resistant/ambivalent

A fourth classification was later identified by Main and Solomon (1986, 1990) and termed disorganised/disoriented. Infants in this group exhibit a diverse set of behaviours, characterised by a lack of an observable goal, as seen in the immediate situation. This suggests that the child does not have an organised attachment strategy with respect to their attachment figure (Main & Solomon, 1990).

Attachment security is present throughout a person's life, with adult attachment styles measurable through other instruments. One such instrument is the *Adult Attachment Interview* (AAI) which assesses an adult's 'state of mind' in regards to attachment (George, Kaplan & Main, 1984, 1985, 1996). The focus is on the coherence of the person's responses, rather than their actual life story (Main, 2000). For example, bad events can still leave a person able to have warm, loving relationships. Information is recorded on two levels: 1) how a person remembers their caregiver, and 2) the way the person discusses past events. Participants are classified into four categories:

- autonomous/secure,
- dismissing/detached,
- preoccupied/entangled, or
- unresolved.

The reliability and validity of the AAI has been researched and shown to be consistent and meaningful (Bakermans-Kranenburg & van Ijzendoorn, 1993; Crowell, Waters, Treboux, O'Connor, Colon-Downs, Feider, Golby, & Posada, 1996; Hesse, 2016; Sagi, van Ijzendoorn, Scharf, & Koren-Karie, 1994; van Ijzendoorn, Kranenburg, Zwart-Woudstra, & Van Busschbach, 1991). An adult's mental representation of their own early attachment experiences can have a significant impact on their own caregiving (Feeney & Woodhouse, 2016; Rolfe, 2004). In fact, it has been consistently shown that the AAI categories correlate with parenting behaviour and the quality of attachments developed with their own children (van Ijzendoorn, 1995; Verhage, Schuengel, Madigan, Fearon, Oosterman, Cassibba, Bakermans-Kranenburg, & van Ijzendoorn, 2016).

Another instrument used to measure adult attachment styles, is the *Experiences in Close Relationships Scale* (ECR) (Fraley, Waller, & Brennan, 2000). The ECR assesses the quality of a person's romantic relationship, based on attachment propositions. This is significant since a person's adult attachment style – including their romantic attachment style – has a bearing on the quality of caregiving that that person is able to provide to his or her own child (Feeney & Woodhouse, 2016; Jones, Cassidy, & Shaver, 2015; Rholes, Simpson, & Friedman, 2006; Simpson & Rholes, 2015). Therefore, if a person falls towards the anxious or avoidant dimensions of attachment in regards to their romantic partner, it is likely that the caregiving they provide to their child is also either insecure-anxious or insecure-avoidant (Rholes et al., 2006).

Not only is their adult attachment style a determinant of their infant's attachment security, but the adult's caregiving behaviour is as well. Results from two meta-analyses confirmed this link between caregiver attachment representations and child-caregiver attachment, identifying this construct as the intergenerational transmission model of attachment (van Ijzendoorn, 1995; deWolff & van Ijzendoorn, 1997). Based on this model, a parent's internal working models of attachment motivate their parenting behaviours, which subsequently shape the quality of the child's attachment to that parent (Berlin, Zeanah, & Lieberman, 2016; van Ijzendoorn, 1995). In other words, the psychological and environmental factors surrounding a person's attachment experiences throughout their life, influence the subsequent development of their attachment relationships with their children (Verhage et al., 2016).

Regarding the adult attachment figure's caregiving behaviour, four highly intercorellated variables have been identified (Ainsworth et al., 1978):

- sensitivity (defined as prompt and appropriate responsiveness to the infant's signals),
- acceptance (versus rejection),
- cooperation, and
- psychological accessibility



As explained, a young child will develop an attachment with their primary caregiver, regardless of the quality of caregiving. Insecure (avoidant/resistant) or disorganised attachments will develop if a child's attachment behaviours are met with poor caregiving behaviours, such as rejection, hostility or anxiety (Ainsworth et al., 1978; Main & Solomon, 1986, 1990). Therefore, it is the quality of these attachments, formed through the reciprocity of the infant's attachment behaviours and the caregiver's behaviours, that are of significance. The essence of the attachment quality involves both caregiver and child being attuned to each other's emotional and behavioural agendas, thus the ability to communicate such needs becomes important (Landy, 2009). The main construct that has been found to influence attachment security is caregiver sensitivity. Caregiver sensitivity will be discussed in detail below.

### ***Caregiver Sensitivity***

The research of Bowlby, Ainsworth, and subsequent attachment theorists, has attested that 'caregiver sensitivity' is a major factor influencing the attachment quality between caregiver and infant (Bakermans-Kranenburg et al., 2003). It has been defined as a caregiver's ability to respond to an infant's signals promptly and appropriately (Ainsworth et al., 1974; Solomon & George, 1999). A substantial body of evidence has shown that quality caregiver sensitivity, throughout early childhood, is beneficial to a child's language, cognitive, emotional and social development (Laible & Thompson, 1998; Murphy & Laible, 2013; Ontai & Thompson, 2002; Thompson, 2016; van der Voort et al., 2014). Through her Baltimore study, Ainsworth and colleagues (1978) identified sensitivity as a construct pivotal to secure attachment formation. This conclusion was also found in a meta-analysis of 66 studies exploring the association between attachment and sensitivity (De Wolff & van Ijzendoorn, 1997). A more recent meta-analysis reviewing interventions that aimed at improving sensitivity and attachment by Bakermans-Kranenburg and colleagues, has demonstrated the causal relationship between sensitivity and attachment (Bakermans-Kranenburg et al., 2003). This was achieved by evaluating several interventions on parental sensitivity, and determining the effect sizes

of these interventions (Bakermans-Kranenburg et al., 2003). They found that those interventions that were particularly aimed at enhancing sensitivity (and not focussed on providing social support or changing the parents' mental representations), were able to significantly affect infant attachment security, with an effect size of 0.39 (Bakermans-Kranenburg et al., 2003). It must be noted that in studying the link between sensitivity and attachment, a transmission gap has been found, where sensitivity only accounts for a small portion of the link between parenting behaviour and child development (Fearon & Belsky, 2016; Berlin et al., 2016; Feeney & Woodhouse, 2016; van Ijzendoorn, 1995). This transmission gap refers to the intergenerational transmission model of attachment (van Ijzendoorn, 1995; DeWolff & van Ijzendoorn, 1997), and the fact that caregiver sensitivity does not fully account for the link between a parent's own state of mind towards attachment, and the infant's attachment security, (van Ijzendoorn, 1995). For example, research findings on the correlation between the parental characteristic of reflective functioning and attachment quality has prompted attachment theorists to see this as one characteristic that can bridge the transmission gap (Fonagy & Target, 2005; Slade, Grienenberger, Bernbach, Levy, & Locker, 2005). Reflective functioning will be discussed further in the sections to follow.

The meta-analysis by Bakermans-Kranenburg and colleagues (2003) included 81 studies, with 24 of those measuring sensitivity and attachment outcomes. The studies included a wide range of groups, including: low-SES, middle class mothers, single mothers, highly anxious mothers, mothers with clinical depression, preterm infants, adolescent mothers, internationally adopted infants, infants with developmental disabilities, as well as multi-risk or multi-problem families (Bakermans-Kranenburg et al., 2003). Data analysis showed that attachment insecurity was more difficult to change than parental insensitivity, however, in interventions successful in improving sensitivity there was a parallel positive change in attachment security (Bakermans-Kranenburg et al., 2003). They concluded that relatively short-term interventions (i.e., five to 16 sessions) that focussed on enhancing parental sensitivity through behaviour were the most effective in enhancing attachment security in infants (Bakermans-Kranenburg et al., 2003). When looking at studies of groups with multiple risks

or multiple problems, the authors found that short-term intervention was also the most effective for this population. The presence of multiple problems did not appear to be a major factor in the effectiveness of the intervention, although the authors recognised that in the clinical groups, intervention was often focussed on one problem area (e.g., maternal depression, or anxious infants) that the interventionists were able to handle. This poses a concern about the efficacy of single-focussed interventions in families with multiple problems across more than one area, as was the case with the present study.

According to Ainsworth's original definition of sensitivity, its core elements or indicators included: signal perception, correct interpretation, prompt reaction, and appropriate reaction (Ainsworth et al., 1978; Mesman & Emmen, 2013). A more recent study reviewing instruments measuring sensitivity in relation to attachment security support that the above elements are key to assessing caregiver sensitivity (Mesman & Emmen, 2013). Mesman and Emmen (2013) aimed to review the most common observational instruments measuring parental sensitivity, in comparison to Ainsworth's *Sensitivity-Insensitivity to Infant Signals and Communications* observational scale, which is part of the *Maternal Care Scales* (Ainsworth et al., 1978). The researchers concluded that the instruments most similar to Ainsworth's original sensitivity scales were the *Global Ratings of Mother-Infant Interaction* and the *National Institute of Child Health and Human Development study of Early Child Care and Youth Development (NICHD-SECCYD) Sensitivity Scales* (Mesman & Emmen, 2013). Both used a single global rating scale to assess sensitivity, similar to Ainsworth's sensitivity scale, as opposed to the other instruments, which used composite scales (Mesman & Emmen, 2013). Also, the *NICHD-SECCYD Sensitivity Scales* did not include positive affect or warmth, therefore did not add new elements to the original sensitivity construct as defined by Ainsworth (Mesman & Emmen, 2013). Through research studies, both the *Global Ratings of Mother-Infant Interaction* and the *NICHD-SECCYD sensitivity scales* have been found to detect improvements in sensitivity following interventions (e.g. Feeley, Zelkowitz, Shrier, Stremler, Westreich, Dunkley, Steele, Rosberger, Lefebvre, & Papageorgiou, 2012; Ravn, Smith, Lindemann,

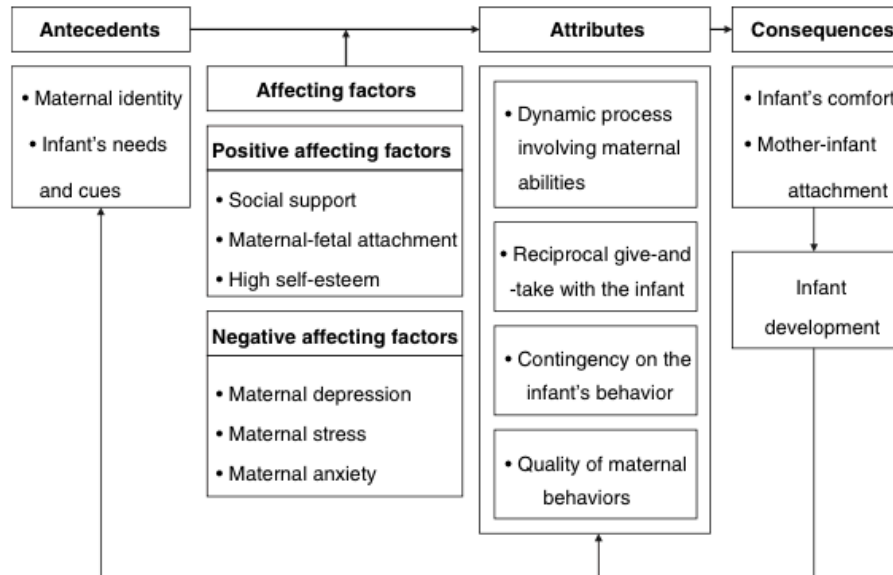
Smeby, Kyno, Bunch, & Sandvik, 2011), and were found to be related meaningfully to infant attachment security (Tomlinson, Cooper, & Murray, 2005; McElwain & Booth-LaForce, 2006; NICHD Early Child Care Research Network, 2006).

Limitations of these two instruments, and the interventions and instruments that sought to improve or measure sensitivity as reviewed by Mesman and Emmen (2013), are that their focus population was not necessarily families with children with disabilities. Although one can argue that studies on mothers and their premature children can be likened to mothers and their children with disability, owing to the reduced ability of mothers to read the subtle and atypical signals and behaviours characteristic of both infants born prematurely, and infants with developmental disability (Feeley et al., 2012; Ravn et al., 2011; Warren & Brady, 2007). Nevertheless, such instruments would be valuable in assessing the sensitivity of caregivers in parent-child dyads at most risk of developing insecure/disorganised attachments.

A concept analysis reviewing the literature on sensitivity since Ainsworth's work identified that maternal sensitivity has four critical attributes: "dynamic process involving maternal abilities, reciprocal give-and-take with the infant, contingent on the infant's behaviour and quality of maternal behaviours" (Shin, Park, Ryu, & Seomun, 2008, p. 311). The authors also noted that maternal sensitivity involves "complex relationships with multiple variables" and further research should consider personal, relational and contextual factors (Shin, et al., 2008, p. 311). Acknowledging that mother-infant attachment is a consequence of maternal sensitivity, Shin and colleagues presented a conceptual structure (Figure 2.1) displaying the relationships between the antecedents and factors of the four critical attributes of maternal sensitivity (2008, p. 306). Moreover, they maintained that a solid understanding of maternal sensitivity would assist in developing better measures of mother's sensitivity (Shin et al., 2008). Clearly, as evidenced from the two in-depth studies on sensitivity (Mesman & Emmen, 2013; Shin et al., 2008), a critical understanding of caregiver sensitivity and its relationship to attachment is important in exploring and measuring attachment between parents and their children.

Figure 2.1

*A Conceptual Structure of Maternal Sensitivity Identifying Antecedents, Affecting Factors, Attributes, and Consequences (Shin et al., 2008, p. 306).*



As evident in Figure 2.1, key attributes of caregiver sensitivity include reciprocity with the infant, and maternal behaviours that are contingent and attuned to the infant's behaviour. Affect attunement can be defined as "expressing the quality of a shared affect state but without imitating the exact behavioural expression of the inner state" (Stern, 1985, p. 251). In other words, the caregiver is able to signal to the infant that he or she understands and shares the infant's affective state, as distinguished from the infant's behaviours, in a way that allows the infant to understand that the caregiver shares the same affective state (Stern, Hofer, Haft, & Dore, 1985). For example, the caregiver might name the infant's emotion, or mirror the infant's facial expressions. This attunement between caregiver and child plays a significant part in the development of a secure attachment. Misattunement may be detrimental to the developing attachment (Stern et al., 1985). Repetition and familiarity of attachment and caregiving behaviours contributes to the formation of an infant's IWM of attachment (Bowlby, 1973). Eventually, the infant is able to reach 'attachment security' which is the state of being secure or untroubled about the availability of one's attachment figure (Ainsworth et al., 1978).

While much of the literature on caregiver sensitivity and attachment has been based on studies of mothers and children, there is also a substantial amount of research on father-infant attachment. Belsky and Jaffee (2006) attest that fathers' psychological health and well-being – not just that of mothers – affect the quality of care and sensitivity that parents provide. Moreover, findings from a study by Brown, Mangelsdorf, and Neff (2012) have shown that the anticipated adverse effect of low parental sensitivity decreased when father involvement was high. A meta-analysis on infant-father attachment has also shown that higher levels of paternal sensitivity were associated with more father-infant attachment security (Lucassen, Tharner, van Ijzendoorn, Bakermans-Kranenburg, Volling, Verhulst, Lambregtse-van den berg, & Tiemeier, 2011). While the small number of studies in this meta-analysis is a weakness of the study, the authors were nonetheless able to build on the meta-analysis conducted by De Wolff and van Ijzendoorn in 1997, providing an update of studies on paternal sensitivity and attachment security (Lucassen et al., 2011). Thus, the sensitivity of fathers is also a predictor of infant attachment security, as is the case with mother-infant attachment.

Regarding improvement of the interactional synchrony of the caregiver-child dyad, Tryphonopoulos and colleagues (2014) stated that it is best assessed early on in the child's development. Their study also suggested that service providers wishing to support such families can use measurement and assessment tools that evaluate different aspects surrounding the attachment relationship (Tryphonopoulos, Letourneau, & Ditommaso, 2014).

The use of video observations and video feedback to enhance mother-infant interaction and caregiver sensitivity, and therefore the child's attachment security, is evident in several studies (e.g., Beebe, 2003; Fiamenghi, Vedovato, Meirelles, & Shimoda, 2010; Hoffman, Marvin, Cooper, & Powell, 2006; Poslawsky, Naber, Bakermans-Kranenburg, de Jonge, van Egeland, & van Ijzendoorn, 2014). In Hoffman and colleagues' (2006) use of video feedback intervention, caregivers and their child were videotaped during playful interactions at the beginning of the intervention. Having analysed the videotapes for problematic interactive patterns between caregiver and child, the psychotherapists would then commence the intervention. The psychotherapist watched the

videotaped interactions with the caregiver and helped the caregiver reflect on their interactions, and also helped them improve ways to read and respond to their child's cues. The intervention lasted for 20-weeks with pre- and post-measures of attachment classification taken to mark improvement (Hoffman et al., 2006). Another video feedback intervention was designed for parents and their children with autism (Poslawsky et al., 2014). This Dutch intervention, namely the *Video-feedback to promote Positive Parenting for Children with Autism* (VIPP-AUTI), uses videotaped daily interactions of a parent and child with autism taken at home, to help enhance parents' sensitivity to the child's autistic traits. These videotaped interactions are used during the five sessions that focus on themes such as attachment, sensitivity, and sharing emotions. Poslawsky and colleagues (2014) found that in a randomized control trial with the VIPP-AUTI, the 40 parents who completed the VIPP-AUTI, reported higher levels of parenting competence. Parents also expressed greater understanding of what lay behind their child's behaviour, and thus greater sensitivity and awareness of their own behaviour (Poslawsky et al., 2014).

A conclusion from these studies is that, caregiver sensitivity maintains its place as a strong determinant of attachment security. Other constructs have also been investigated that influence attachment. These include mind-mindedness and reflective functioning, and are discussed in the following section.

### ***Attachment, Reflective Functioning and Mind-mindedness***

Academic literature has identified other constructs that influence attachment security, namely mind-mindedness and reflective functioning. Notably, both these constructs are related to parent's psychological attributes, one of the five domains in Belsky's determinants of parenting model (1984).

Mind-mindedness is the ability for a parent to "treat her infant as an individual with a mind rather than merely as a creature with needs that must be satisfied" (Meins, Fernyhough, Fradley, & Tuckey, 2001, p. 638). Meins and colleagues (2001, 2012) proposed that mind-mindedness is necessary in facilitating caregiver sensitivity. Studies have shown that mothers of secure infants make

appropriate mind-minded comments during interactions with their infants, much more so than mothers of infants with insecure attachment (Laranjo, Bernier, & Meins, 2008; Lundy, 2003; Meins et al., 2001). An example of a positive mind-mindedness comment would be if the mother voiced what toy the infant was interested in, and the infant's current behaviour matched the mother's comment (Meins et al., 2001). It has also been identified as a construct separate from caregiver sensitivity in determining secure attachments (Meins et al., 2001; Meins, Fernyhough, de Rosnay, Arnott, Leekam, & Turner, 2012).

Another important construct influencing attachment security is reflective functioning; the ability of the caregiver to understand that his or her own and others' behaviours are related to one's feelings, desires and thoughts (Fonagy, Steele, Steele, Moran, & Higgitt, 1991; Fonagy, Gergeley, Jurist, & Target, 2002; Slade, 2005). High parental reflective functioning has been identified as a predictor of children's attachment security (Fonagy et al., 1991). Moreover, improved reflective functioning has also been linked to improved parenting (Suchman, DeCoste, Leigh, & Borelli, 2010). A recent study has also supported the link between reflective functioning and sensitivity (Riva Crugnola, Ierardi, & Canevini, 2018).

It is therefore not only the caregiver's behavioural capacity to regulate the infant's distress or fear, but also her display of self-regulation, that serves as a model for the infant who gradually learns to regulate their own emotions (Grienenberger, Kelly, & Slade, 2005). In other words, both the ability of the caregiver to use reflective functioning, and to regulate her own emotions, is significant to the infant's mastery of self-regulation. However, "when mothers respond in ways that disrupt mother-infant communication, via behaviours that are frightening or fearful, hostile or withdrawn, or more generally misattuned, child disorganisation and insecurity ... result" (Grienenberger et al., 2005, p. 307). On the other hand, when mothers are capable of reflective functioning, it can act as "a buffer against breakdowns in affect regulation during times of infant distress" (Grienenberger et al., 2005, p. 306). For instance, in the presence of a stranger, an infant often experiences distress and turns towards their mother, seeking comfort and security. A study on clinically depressed and anxious



mothers and their infants explored the effect of maternal psychopathology on the infant's emotion regulation (Granat, Gadassi, Gilboa-Schechtman, & Feldman, 2017). Results indicated that while anxious and controlling mothers acted as buffers during infant distress, the presence of depressed mothers failed to provide this same role to their infants (Granat et al., 2017). Moreover, infants of mothers who were anxious, tended to increase their self-regulation during moments of joy. The authors proposed that this may have been a consequence of the mother's overly-stimulating and intrusive parenting style, leaving infants to learn self-soothing strategies in order to defend themselves from the overstimulation of their mothers (Granat et al., 2017). Reflective functioning clearly can have both a negative and positive impact on the attachment relationships between mothers and infants.

Granat and colleagues (2017) also emphasised the importance of touch and gaze synchrony to the development of emotion regulation in infants. Their findings support existing evidence that depressed mothers and their infants showed lower levels of synchrony (Murray, Arteche, Fearon, Halligan, Goodyer, & Cooper, 2011). In contrast, anxious mothers and their infants, displayed higher levels of touch and gaze synchrony, also consistent with research that links maternal anxiety with intrusiveness (Beebe, Steele, Jaffe, Buck, Chen, Cohen, Kaitz, Markese, Andrews, Margolis, & Feldstein, 2011). Parents have the potential to act as a protective factor and a risk factor in the formation of their infants' emotion regulation.

Reflective functioning can facilitate emotion regulation (Grienenberger et al., 2005; Rutherford, Wallace, Laurent, & Mayes, 2015). One definition of emotion regulation is an individual's capacity to control and modify their emotional reactions, in order to maintain a manageable level of arousal (Cole, Martin, & Dennis, 2004). In the infant's first years of life, emotion regulation emerges, with parents playing a vital role in facilitating these developing emotion regulation skills (Eisenberg, Spinrad, & Eggum, 2010; Feldman, 2009). Indeed, a number of attachment theorists have proposed that early attachment relationships help infants develop emotion regulation (e.g., Cassidy, 1994; Isabella, 1993; Sroufe, 1979; Sroufe & Hoffmann, 2000; Thompson,

2016). Mothers who accept a wide range of emotional expressions from their infants, help them to learn flexible self-regulation strategies in the face of negative emotion, and thereby develop secure attachment relationships (Cassidy, 1994; Sroufe et al., 2005). Meanwhile, parenting that is intrusive and overwhelming, increases dysregulation and negative affect in the infant (Eiden, Edwards, & Leonard, 2007; Granat et al., 2017; Johnson, Morrow, Accornero, Xue, Anthony, & Bandstra, 2002; Wood, 2006). Infants are thus reliant on their primary caregiver to make sense of their affective states, through the caregiver's contingent and sensitive behavioural responses to infant distress (Bernier, Carlson, & Whipple, 2010; Cassidy, 1994; Feldman, Greenbaum, & Yirmiya, 1999; Halligan, Cooper, Fearon, Wheeler, Crosby, & Murray, 2013; Kim & Kochanska, 2012; Kochanska, Aksan, Prisco, & Adams, 2008). Dyadic emotion regulation develops into the infant's self-regulation. Emotion regulation during parenting is of significance, with emotion regulation being critical to both the parent and child development (Rutherford et al., 2015).

Overall, the research shows the critical role parents have in developing their infants' emotion regulation. Parents need to maintain their own emotion regulation, through the ability to reflect on their own and others' mental and affective states, and use this knowledge to provide the optimal level of synchrony during interactions with their infant. Those parents who find it hard to regulate their emotions may struggle with the challenges of parenting (Simpson & Rholes, 2015).

### ***Attachment and Child Development***

Research in childhood development attests a holistic understanding that considers a child's physical and cognitive development, as well as their social and emotional development (Landy, 2009; Landy & Menna, 2006; Shonkoff & Phillips, 2000). This development is nonlinear, involving a number of reorganisations allowing a child to adapt to their environment (Spencer, Clearfield, Corbetta, Ulrich, Buchana, & Schoner, 2006). Moreover, it has been found that children need to resolve particular developmental stages and attain various capacities, in order to lay the foundation for later positive emotional and social development (Greenspan & Wieder, 1998; Masten & Gewirtz,

2006). It has been argued that children's social or emotional intelligence, their ability to recognise and control their own feelings (self-regulation), as well as to read and respond to the feelings of others (empathy), significantly influences later developmental stages and success in life (Erikson, 1963; Gardner, 1983, 1999; Greenspan & Wieder, 1998; Shonkoff & Phillips, 2000). Therefore, in social and emotional development, and thus a child's overall development, the formation of an attachment plays a crucial role.

In their first year, once an attachment begins to be established with one or more primary caregivers, a child is able to use these individuals as their 'secure base', allowing the child to explore their world with confidence, and as a 'safe haven' in times of stress (Cummings & Cummings, 2002; Sroufe et al., 2005). By the child's second year, they become interested in imaginative play and symbolisation, seen as most influential to social and emotional development (Landy, 2009). Play is also essential for children as it contributes to their cognitive, physical, emotional, and social development (Burriss & Tsao, 2002; Ginsburg, 2007; Milteer & Ginsburg, 2011; Stagnitti, 2004). Play is "an activity that is engaged in voluntarily and in which the child directs what happens" (Landy, 2009, p. 213). Though there has been a diversity of theories towards play, all modern theorists of children and play (e.g. Erikson, 1963; Piaget, 1962; Vygotsky, 1966, 1978) agree on the importance of play to various areas in a child's development (see Burriss & Tsao, 2002, and Stagnitti, 2004, for reviews).

A child develops and learns best through playful, affective, social interactions, with their primary caregivers (Ginsburg, 2007; Milteer & Ginsburg, 2012; Shonkoff & Phillips, 2000). Within this context of mother-infant playful interaction, it is proposed that attachment be promoted as necessary for a child's social-emotional, cognitive, physical and educational development. From the literature it is evident that a typically-developing child, having formed secure attachments with a few primary caregivers, is able to play, and to explore their environment leading to communication, language and learning (Bowlby, 1980; Landy, 2009; Landy & Menna, 2006; Shonkoff & Phillips, 2000).

In summary, focussing on the significance of forming secure attachments to a child's long-term social, emotional, cognitive, physical and educational development is important. What appears to be of crucial importance to a young child's overall development, is the quality of the attachment formed, as influenced by the responsiveness of their primary caregivers (Ainsworth et al., 1978; Bowlby, 1969; Fiamenghi et al., 2010; Landy, 2009; Pauli-Pott & Mertesacker, 2009; Sroufe, Carlson, Levy, & Egeland, 1999).

The previous sections of this review have discussed factors surrounding the attachment of typically-developing infants and their caregivers. The following sections will discuss the impact of disability on the infants' developing attachment relationship.

### **Attachment and Children with a Disability**

An important determinant of parenting, one that also impacts on attachment formation, is a child's characteristics. Disability is one characteristic that has been extensively researched in the attachment literature. A large body of research supports the notion that children with disabilities are more likely to form an insecure or disorganised attachment than children without disabilities (e.g., Clements & Barnett, 2002; Fletcher, Flood, & Hare, 2016; Howe, 2006; Naber, Swinkels, Buitelaar, Bakermans-Kranenburg, van Ijzendoorn, Dietz, van Daalen, & Engeland, 2007; Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004; van Ijzendoorn, Schuengel, & Bakermans-Kranenburg, 1999; van Ijzendoorn, Rutgers, Bakermans-Kranenburg, Swinkels, van Daalen, Dietz, Naber, Buitelaar, & van Engeland, 2007). Studies originating from the United States of America and the Netherlands, for example, demonstrate that compared to 65% of the general population, worldwide less than 50% of children with a disability develop a secure attachment (Clements & Barnett, 2002; Naber et al., 2007; van Ijzendoorn & Kroonenberg, 1988; van Ijzendoorn et al., 1999; van Ijzendoorn et al., 2007).

However, studies have also shown that children with disabilities form secure attachments with their primary caregivers. For example, in a recent study on children with intellectual disability,

Feniger-Schaal and Joels (2018) found that 40% of the participants in the study were classified as secure. In a study on children with Down syndrome, 40% of the participants were also classified secure (Atkinson, Chisholm, Scott, Goldberg, Vaughn, Blackwell, Dickens, & Tam, 1999).

Given the reciprocal nature of the attachment relationship, it is likely that disabilities that hinder a child from reciprocating or communicating have a major impact on the development of insecure attachments (Alexander, Frederico, & Long, 2018; Howe, 2006; Warren & Brady, 2007). The following section details conditions and disabilities that affect the child's ability to communicate or challenge the caregiver's ability to respond with sensitive caregiving.

The extent to which the child can manifest attachment behaviours and therefore incite caregiving behaviours, may be impacted by their impairment. The first phase in developing attachment is dependent on the baby's preference, and subsequent familiarity for, the human smell, the sound of the human voice, and the outlines of the human face (Bowlby, 1982). Therefore, children with sensory impairments, such as hearing and vision impairment, are perhaps at a disadvantage in this initial phase of attachment formation. More so, caregiver sensitivity greatly impacts on attachment, and is dependent on the caregiver's ability to recognise and interpret their child's behaviour, cues, body language, facial expressions and speech (Howe, 2006). However, many children with disabilities are unable to clearly communicate their needs and wants, due to functional and sensory impairments (Howe, 2006).

Child characteristics that are associated with developmental disabilities and disorders may disrupt parents' ability to be responsive and sensitive to their child (Warren & Brady, 2007). These may include: low initiation rates, slow response times, gaze avoidance or atypical eye gaze, hypersensitivity to sensory input, social anxiety and shyness, perseveration and repetitiousness, unintelligible speech, poor short-term memory, mobility and physical limitations, and a wide range of challenging behaviour problems (Huebner & Thomas, 1995; Warren & Brady, 2007). Children with autism spectrum disorder, for example, may have trouble with behaviours that are key in attachment formation, such as 'joint attention', 'eye contact', 'referencing', and 'pointing' (Atkinson

et al., 1999; Carpenter, Pennington, & Rogers, 2002). Parents of children who are blind may become upset at the unresponsiveness of their baby, before they realise that their child has a visual impairment (Howe, 2006). Children who are blind or have visual impairment may also experience problems with attention and anxiety, which may result in difficulties in communicating with their caregiver, and therefore may impact on their attachment security (Alimovic, 2013).

Children with hearing impairment often have a communication barrier with their hearing parents that can result in developmental delays (Howe, 2006). This is significant since hearing may play an important part in the early attachment process. Fetal audition starts to mature quite early during gestation, and research has shown differential responding of the fetus to the mother's voice in comparison to unfamiliar voices (Moon, 2011). Typically-developing newborns show preference for their mother's voice within hours or days after birth, evidence of proximity-seeking behaviour (Bowlby, 1969; Moon, 2011). Clearly there is some link between the maternal voice – often that of the primary caregiver – and the infant's ability to recognise it, and their subsequent development of attachment. Furthermore, use of 'motherese', infant-directed speech that is higher in pitch with exaggerated contours than adult speech, has been shown to be important in language acquisition (Nelson, Hirsh-Pasek, Jusczyk, & Cassidy, 1989). Infants have been shown to be sensitive to the prosodic features of 'motherese', helping them to segment speech (Nelson et al., 1989). Therefore, infants with hearing loss may have difficulty learning to listen and subsequently have difficulty communicating, if they are not able to hear the prosodic differences in their caregiver's voice.

However, research has found that deafness does not have a direct impact on attachment development (Spencer & Koester, 2016). Rather, the role of experience during the sensitive periods of both language acquisition and attachment formation is more significant (Moon, 2011). Nonetheless, studies have found differences amongst children with hearing impairment and those without. In comparison to hearing parents of hearing children, one study found hearing parents of children with hearing impairment more rigid in their behaviours, and their children less active (Pipp-Siegel & Biringen, 1998). Lederberg and Mobley (1990) concluded that hearing impairment did have

an effect on the ability of the mother and child to communicate effectively, with this inability becoming more disruptive to the mother-child relationship as the child grows older, since age-appropriate activities become more reliant on language. Other researchers found that hearing impairment poses elevated risks for attachment problems, though only when other risk factors are present (Thomson, Kennedy, & Kuebli, 2011). Likewise, children who are deafblind are at greater risk for developing delays in their social and emotional development, including difficulty with attachment development (Hartshorne & Schmittl, 2016). More so, a child with a severe intellectual or physical disability, such as cerebral palsy, or a blind or deaf child, often experiences anxiety, due to their inability to communicate to their primary caregiver (Cass, Price, Reilly, Wisbeach, & McConachie, 1999; Huebner & Thomas, 1995; Laffan, 1997). This difficulty to communicate due to the child's disability, may have a profound impact on the child's ability to interact with their parent, and consequently the quality of the attachment that develops between child and caregiver.

### ***The Emotional and Psychological Experiences of Parents***

Perhaps an overlooked factor in the development of attachment in children with a disability, is the emotional and psychological impact on the parent. When faced with the news that their child has a disability, parents may experience several emotions and experiences, including: grief, trauma, depression, anxiety and high levels of stress. The following sections will discuss each of these in turn, describing how they may each affect the developing attachment relationship.

**Grief.** Grief is a common response to a diagnosis that your child has a disability or impairment, and often impacts on the emotional relationship that develops between parent and child (Huebner & Thomas, 1995; Kelso, French, & Fernandez, 2005; Pipp-Siegel, 1999; Yoshinaga-Itano, Zand, & Pierce, 2011). This grief is often a result of a sense of loss of the 'imagined healthy child' and hopes and dreams for that child (Fletcher, 2016; Godress, Ozgul, Owen, & Foley-Evans, 2005). Although similar to the grief experienced at the death of a child, this grief is usually a prolonged grief, and one

recurring at different points in the child and family's lives, at important developmental milestones (e.g. school entry), during holidays, or in comparison to other children (Fletcher, 2016; Foy, 1997; Kelso et al., 2005).

A part of the grieving process may be denial, with some parents in denial of their child who has more than one disability or impairment (Edwards, 2007). One response to grief is that some parents disengage from their infant, in anticipation and fear of the infant's death (Huebner & Thomas, 1995). Parents whose child has cancer may experience anticipatory grief, having doubts that their child will survive (Al-Gamal & Long, 2010; McCubbin, Balling, Possin, Friedrich, & Bryne, 2002). Other responses and emotions that follow or accompany this grief can include shock, denial, anger, anxiety, and depression (Huebner & Thomas, 1995; Kelso et al., 2005). Studies note that parents whose grief is unresolved may have difficulty responding sensitively to their child, not having accepted their child as having a disability, and often are at increased risk for insecure attachments (Fletcher, 2016; Howe, 2006; Thomson et al., 2011; Yoshinaga-Itano et al., 2011). The experience of grief can have a profound effect on the parent, and subsequently their attachment relationship with their child.

**Trauma.** Trauma is a construct that has been identified with parenting a child with a disability (Baker, Blacher, Crnic, & Edelbrock, 2002; Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Gerstein, Crnic, Blacher, & Baker, 2009; Green, 2007; Howe, 2006; Thomson et al., 2011). It has been defined as “a stressor that is generally outside the range of usual human experience and that would evoke significant symptoms of distress in most people” (Reyes, Elhai, & Ford, 2008, p. 905). In one study, interviewed mothers, described the birth and diagnosis of their child with a disability as a “traumatic event” (Green, 2007, p. 155). Similarly, parents who experienced premature births described it as traumatic and stressful (Baldoni, 2010). A preterm birth can result in illness or even death for the infant, and separation from the infant for long periods of time, both of which can cause anxiety and psychological stress in the parents (Baldoni, 2010). However, research on mothers and their premature infants who used skin-to-skin contact, showed improvement in maternal



physiological and psychological outcomes, and an increase in their sense of attachment to their infant, as well as lower stress and anxiety levels, in comparison to mothers whose infants were in an incubator and did not experience skin-to-skin contact (Campbell-Yeo, Disher, Benoit, & Johnston, 2015; Jones & Santamaria, 2018).

Pianta, Marvin, Britner and Borowitz (1996) proposed that the trauma of giving birth to a child with a disability, can disturb the parent's caregiving system, with the parent unable to protect their child. Moreover, parents who are unresolved with this experience of trauma, are at greater risk of being dysregulated and emotionally unavailable to their child (Fletcher, 2016; Howe, 2006). They may experience trauma-related symptoms, such as dissociation, and have difficulty with self-regulation, and reading the emotions of their infants (Hesse & Main, 2006; Main & Hesse, 1990; Moran, Bailey, Gleason, De Oliveira, & Pederson, 2008). Furthermore, for mothers experiencing trauma and these behaviours, engaging in intervention might be more difficult (Chin & Teti, 2013). Nonetheless, intervention supporting the needs of such mothers would undoubtedly be important in helping facilitate secure attachment relationships (Chin & Teti, 2013).

**Depression.** One of the most well-researched areas associated with parenting a child with disability and the parent's psychological attributes is maternal depression. Meta-analyses on depression have found that mothers of children with disabilities had an elevated risk for clinical depression than the general population (Bailey, Golden, Roberts, & Ford, 2007; Scherer, Verhey, & Kuper, 2019; Singer, 2006). Bailey and colleagues also confirmed that such mothers experience higher levels of distress, most especially if they parent a child with autism spectrum disorder (ASD) or serious behavioural problems (2007). Mothers with depression have been shown to be less sensitive towards their infant, often responding in a dismissive way that does not affirm the infant's experience (Carter, Garrity-Rokous, Chazan-Cohen, Little, & Briggs-Gowan, 2001; Gelfand & Teti, 1990; Jameson, Gelfand, Kulcsar, & Teti, 1997; Murray, Fiori-Cowley, Hooper, & Cooper, 1996; Toth, Rogosch, Manly, & Cicchetti, 2006). Furthermore, when interacting with their infants, these

mothers exhibited less positive affect and more negative affect (Campbell, Cohn, & Meyers, 1995; Cohn, Campbell, Matias, & Hopkins, 1990; Field, Healy, Goldstein, & Guthertz, 1990). Maternal depression also interrupts the formation of mother-infant synchrony and the infant's development of self-regulation (Feldman, 2007; Granat, Gadassi, Gilboa-Schechtman, & Feldman, 2017). Given the importance of sensitivity and emotional attunement to the quality of attachment, these behaviours are not conducive to forming secure attachments.

Regarding its effect on attachment security, one meta-analysis on maternal depression concluded that it was a significant factor (Atkinson, Paglia, Coolbear, Niccols, Parker, & Guger, 2000). In fact, clinical depression has been linked to insecure attachment (Coyle, Roggman, & Newland, 2002; Teti, Gelfand, Messinger & Isabella, 1995). Finally, mothers who experienced depression and stress at the same time increased the likelihood of their children having insecure attachments, in comparison to mothers who experienced depression or stress alone (Diener, Casady, & Wright, 2003). This supports the cumulative risk model proposed by Belsky (1984), indicating that an accumulation of contextual risk factors increases the possibility of insecure attachments (Diener et al., 2003).

Although maternal depression has been associated with increased likelihood of insecure attachment, it is not the presence of the depression that impacts on the attachment, rather how the depression affects how the mother interacts with her child (Toth et al., 2006). Toth and colleagues (2006) suggested that interventions targeting the mother's interaction with the child enhances secure attachment.

**Anxiety.** Unlike depression, literature on anxiety related to parenting a child with a disability has been less comprehensive (Atkinson et al., 2000; Belsky, 1984; Feldman, 2007). An Australian study reported that mothers of children with disability experienced higher levels of anxiety when compared to other Australian women (Bourke-Taylor, Howie, Law, & Pallant, 2012). Compared with the general population, parents of children with autism experience higher levels of anxiety (Gray,

1994, 2002; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, & Robbins, 1992; Montes & Halterman, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2007), with mothers of children with autism experiencing anxiety more so than fathers (Gray & Holden, 1992). Several studies have found that mothers of babies born prematurely or babies with very low birth weight, were at risk of high anxiety, which would likely influence the development of the infant (Baldoni, 2010; Feeley et al., 2012). Parents experiencing anxiety is often linked with controlling or intrusive behaviours towards the infant, such as directing the play or refusing gaze aversion (Biringen, 1990; Bretherton, 2000; Feldman, 2007; Weinberg & Tronick, 1998). Parents are less attuned to the infant, and less sensitive (Murray, Cooper, Creswell, Schofield, & Sack, 2007; McLeod, Wood, & Weisz, 2007; Shin, et al., 2008). Anxious mothers also have difficulty regulating their emotions (Etkin, Prater, Hoedt, Menon, & Schatzberg, 2010). In terms of vocalisations, mothers with anxiety maintain the use of ‘motherese’ (high-pitched, sing-song vocalisation) for much of the duration of the interaction, despite the infant’s level of responsiveness (Feldman, Granat, & Gilboa-Schechtman, 2005; Feldman, 2007; Murray, de Rosnay, Pearson, Bergeron, Schofield, Royal-Lawson, & Cooper, 2008). In other words, though the infant was showing signs of fatigue and gaze aversion, the mother would continue this vocalisation and interaction insensitive to the infant’s need to rest.

Additionally, two studies found that anxious mothers overcompensate, exhibiting high levels of touch and gaze synchrony with their infant; a result of their hyper-vigilance (Beebe et al., 2011; Granat et al., 2017). Furthermore, mothers with anxiety have reported more worries and fears regarding their infant’s health and development (Feldman, 2007). Significantly, depression and anxiety are often co-existing disorders, with child behaviour problems more likely occurring when the mother experiences both (Bagner, Petit, Lewinsohn, & Seeley, 2010).

Lastly, as with maternal depression, maternal anxiety has been associated with insecure attachment (Manassis, Bradley, Goldberg, Hood, & Swinson, 1994; Scher & Mayseless, 2000; Stevenson-Hinde, Shouldice, & Chicot, 2011; Stevenson-Hinde, Chicot, Shouldice, & Hinde, 2013).

Given the impact that maternal anxiety can have on the mother-infant relationship, more research needs to be done in this area.

**Parenting Stress.** Another risk factor that may prevent positive parenting practices is parenting stress, which has been linked to a decrease in caregiver sensitivity (Crnic & Low, 2002; Darke & Goldberg, 1994). Stress has been defined as “physiological, cognitive, or emotional strain or tension” (Pipp-Siegel, Sedey, & Yosinaga-Itano, 2002, p. 1). Parenting stress is one type of stress, and is the stress experienced in relation to one’s role as a parent (Pipp-Siegel et al., 2002). Many studies have investigated parenting stress in relation to parenting a child with a disability (see Neely-Barnes & Dia, 2008 for a review). Studies have shown that parents of children with an intellectual disability likely experience higher levels of parenting stress (Beckman, 1991; Roach, Orsmond & Barratt, 1999; Rodrigue, Morgan, & Geffken, 1990). Studies of parents and their children with autism have demonstrated that such parents also experience higher levels of stress compared to the general population (Dabrowska & Pisula, 2010; Hall & Graff, 2011; Kuhn & Carter, 2006). Indeed, mothers of children with autism experience higher levels of stress than fathers (Dabrowska & Pisula, 2010; Hastings & Brown, 2002). Parents of children with disruptive behaviours, such as ADHD, and parents of children with developmental disabilities reported higher stress levels than parents of children with chronic medical conditions such as HIV-infection and asthma, and typically-developing children (Gupta, 2007).

Studies of parents of children with intellectual and developmental disabilities attest to the challenges and stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Başgöl, Uneri, Cakin-Memik, 2011; Baxter, Cummins, & Yiolitis, 2000; Hassall, Rose, & McDonald, 2005). The parents of children with cerebral palsy have also reported higher stress levels than the general population (White & Boyce, 1993).

In contrast, parenting stress in parents of children with Down syndrome has decreased over the years, likely due to improvement in medical and social outcomes (Scott, Atkinson, Minton, &

Bowman, 1997). Parents of children with visual impairment experience less stress, due to improvements for their children who are able to attend regular schools and be more involved in community life (Alimovic, 2013). Studies of parents with children with hearing impairment have been inconsistent in their conclusions, with some reporting that parenting stress does not differ from that of parents with typically-developing children (Åsberg, Vogel, & Bowers, 2008; Lederberg & Golbach, 2002; Meadow-Orlans, 1994), while others reporting that parenting stress is higher (Quittner, Glueckauf, & Jackson, 1990). For parents not experiencing significant levels of parenting stress, factors such as social support appear to buffer the stress experienced (Åsberg et al., 2008; Thomson et al., 2011). Notably, one study reported slightly lower levels of parenting stress, which the authors contributed to the early intervention that the families were receiving during the study (Pipp-Siegel et al., 2002).

In contrast, parents of children who are deafblind experienced more stress than parents of children with hearing impairment, and parents with children without a disability (Beyzavi, 1993; Hartshorne & Schmittle, 2016). Likewise, parents of children with multiple disabilities and complex healthcare needs, such as CHARGE syndrome, experienced elevated stress levels (Kuster & Merkle, 2004; Reda & Hartshorne, 2008). Such children often have various health, behavioural, social and emotional needs that must be addressed, with parents often coordinating and taking them to multiple appointments, tests and early intervention sessions, contributing to their parenting stress (Carter, Cummings, & Cooper, 2007; Green, 2007; Hartshorne & Schmittle, 2016; Horn & Kang, 2012; Ziviani, Darlington, Feeney, Rodger, & Watter, 2014). Kyrkou (2018) pointed out that though all families experience challenges, such issues and challenges are further compounded when the child has multiple disabilities. Research has also suggested that the severity of the child's disability is linked to the parenting stress experienced (Macias, Roberts, Saylor, & Fussell, 2006; Richman, Belmont, Kim, Slavin, & Hayner, 2009). Evidently, the presence and severity of multiple disabilities or conditions in children with hearing impairment, is linked to higher levels of parenting stress, increasing the risk of poor parenting.

Finally, the type of stress (i.e., acute or chronic) has been given little attention in the stress literature (Quittner et al., 1990). Chronic stress is the type of stress experienced by parents of children with disability and has a greater impact on the parents and the family (Quittner et al., 1990). Identifying what type of stress parents are experiencing would be useful when providing support to such families, thus more research in this area would be beneficial.

Studies have also noted the impact of contributing factors to parenting stress, including the age of the child, the age of the child at the time of diagnosis, developmental milestones, behaviour problems and care needs, the caregiver's age and education, family functioning, as well as the family's cultural background and socioeconomic status (Åsberg et al., 2008; Marvin & Pianta, 1996; Neely-Barnes & Dia, 2008; Sloper, Jones, Triggs, Howarth, & Barton, 2003).

Other sources of stress include the navigation of service provisions and the financial costs associated with parenting a child with disability. Following the diagnosis of their child, caregivers often find navigating the maze of medical and early intervention services challenging, adding more to their stress (Bowman & Virtue, 1993; Douglas, Redley, & Ottmann, 2016; Farmer, Marien, Clark, Sherman, & Selva, 2004; Kelso et al., 2005; Meadow-Orlans & Sass-Lehrer, 1995; Moore, 2005; Neely-Barnes & Dia, 2008). Moreover, the financial burden on caregivers of children with disability was found to be yet another source of parenting stress (Jovanova & Radojichikj, 2013; Farmer et al., 2004; Fidler, Jacoby, & Gabis, 2016; Harper, Dyches, Harper, Rope, & South, 2013). In many families with a child with disability, one or both parents often have to change or forego work to care for their child, which can result in a lower quality of life due to financial constraints (Brown, Geider, Primrose, & Jokinen, 2011).

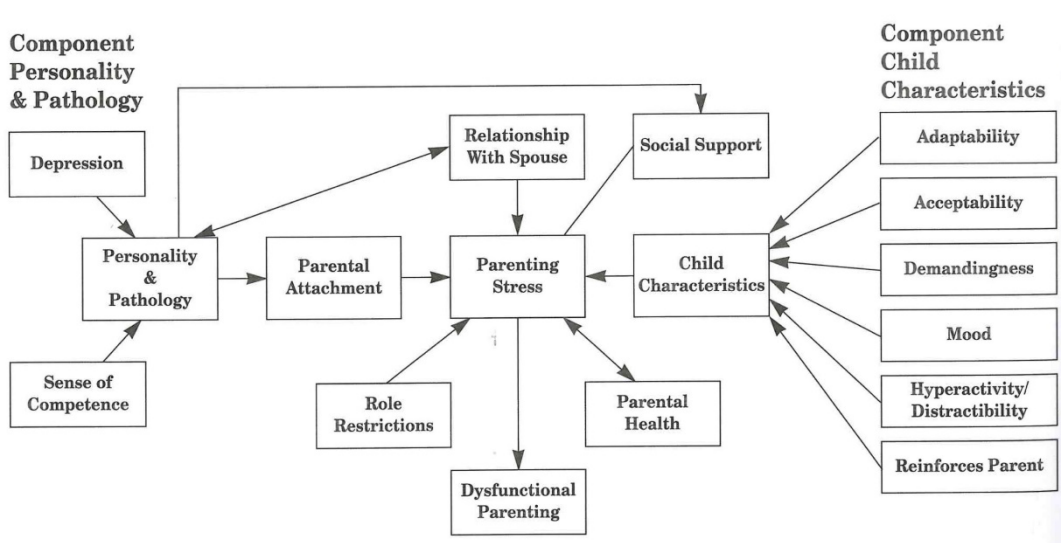
Research has also reported a strong correlation between high levels of parenting stress and depression and anxiety (Bailey et al., 2007; Lovejoy, Graczyk, O'Hare, & Neuman, 2000; Murray et al., 1996; Sharpley, Bitsika, & Efremidis, 1997). Regarding attachment security, parenting stress has been significantly linked with insecure attachments (Jarvis & Creasey, 1991; Teti, Nakagawa, Das, & Wirth, 1991; Tharner, Luijk, van Ijzendoorn, Bakermans-Kranenburg, Jaddoe, Hofman, Verhulst,

& Tiemeier, 2012). Indeed, in developing attachment, stress has been considered a psychological separation, with perhaps a greater impact on parenting than physical separation from the child (Jarvis & Creasey, 1991). This could be due to the negative relation of maternal stress to maternal sensitivity (Belsky & Fearon, 2002). Furthermore, lower parenting stress has been shown to contribute to positive attachment relationships, therefore alleviating parenting stress in parents with children with disability may benefit parents and children (Hadadian & Merbler, 1996).

Abidin's (1976) work in developing the *Parenting Stress Index* (PSI) has provided valuable knowledge about the impact of parenting stress and the factors contributing to it. Figure 2.2 displays the theoretical model of the PSI, including the various factors that intertwine to affect parenting stress (Abidin, 2012, p. 37).

Figure 2.2

*Theoretical Model of the Parenting Stress Index (PSI) (Abidin, 2012, p. 37).*



Most studies on parenting stress have used the *Parenting Stress Index* to measure parenting stress, likely due to its strong reliability and validity (Abidin, 2012). Such studies have also included studies on parents with children with disability, for example, hearing impairment (White & Boyce, 1993), visual impairment (White & Boyce, 1993), multihandicapped (White & Boyce, 1993), Down syndrome (White & Boyce, 1993), cerebral palsy (Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012; White & Boyce, 1993), developmental disabilities (Beckman, 1991), and autism (Hall et al.,

2012; Hoffman, Sweeny, Hodge, Lopez-Wagner, & Looney, 2009). However, an analysis of the PSI (short form) suggests using it with caution for children who have autism, since some of the items do not validly measure the severity of stress experienced (Zaidman-Zait, Mirenda, Zumbo, Wellington, Dua, & Kalynchuk, 2010). A limitation of these studies is their dependence on a self-report questionnaire. Such studies do not give an in-depth, personal understanding of the parents' experience of parenting stress, unlike studies that use interviews.

In regards to the present study, the PSI appears appropriate as it covers most of the parenting domains in Belsky's (1984) determinants of parenting model, as seen in Figure 2.2, including 'child characteristics', 'personality and pathology', 'relationship with spouse', and 'social support'. It also covers 'parental attachment', with Figure 2.3 showing how it is one factor impacting on parenting stress. Thus, the PSI was deemed a good tool to use in the present study which has sought to explore factors around the parent-child attachment relationship.

While it appears that a substantial portion of the literature on parenting a child with disability reports negative outcomes and experiences for the parents and family, there is a considerable body of literature that attests that there are positive outcomes (Hastings & Taunt, 2002). Much of this literature is linked with coping and sources of support.

### ***Coping and Support***

Having discussed the parenting stress and emotional experiences of parents with a child with a disability and its impact on attachment security, the following section will examine the methods of coping and sources of support used by these families.

**Coping.** A serious limitation of the literature on child disability is its focus on the negative experiences of parents and families. However, there is a growing body of research that looks at the positive aspects and experiences of parenting children with disability. Hastings and Taunt (2002) investigated whether parents held positive perceptions towards their role of parenting a child with



disability. They found 14 key themes, such as, the child as a source of joy, increase in personal strength, and strengthened family and marriage (Hastings & Taunt, 2002).

A recent U.K. study furthered these findings through conducting interviews with parents of a child with disability (Beighton & Wills, 2017). The study found similar themes as those of Hastings and Taunt (2002), as well as one unique theme, namely, the positive effect the child has on others (Beighton & Wills, 2017). Parents described how their child not only positively influenced their lives, but also influenced the lives of others who came in contact with them, such as friends and members of the community (Beighton & Wills, 2017). The other six key positive themes that Beighton and Wills (2017) found were: increased personal strength, changed priorities, greater appreciation of life, child's accomplishments, increased spirituality/faith, and more meaningful relationships. Similarly, Green (2007) interviewed mothers who had a child with disability, who emphasised the positivity experienced in their caregiving role. These mothers reported that as a result of caring for their child, they had become better and stronger people, had a greater appreciation of life, and experienced deeper and more meaningful relationships (Green, 2007). Such mothers also expressed the pride, joy and love they had for their child, and recognised the intrinsic worth of their child (Green, 2007). Green (2007) argued that there was a perceived stigma attached to parenting a child with disability, and that this can influence parents, decreasing their perceived positivity and benefits of caring for a child with disability. This issue is quite problematic as it reinforces the popular idea that parenting children with disability is a predominantly negative experience.

Studies on how parents with children with disability cope, have sought to investigate various factors that work as 'buffers' to parenting stress, and other negative experiences, such as anxiety, grief and depression. Coping has been defined as "the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person." (Lazarus & Folkman, 1984, p. 283). Studies on parents with children with autism have shown that parents do cope, and can cope well (Gray, 2006; Hall et al., 2012; Hayes & Watson, 2013; Pepperell, Paynter, & Gilmore, 2018). Mothers of children with an intellectual disability may face challenges in their parenting, but

have been shown to overcome their stress through a range of coping strategies, including the use of inner resources and problem-solving strategies (Beighton & Wills, 2017; Essex, Seltzer, & Krauss, 1999; Miller, Gordon, Daniele, & Diller, 1992). In a U.K. study, Glenn, Cunningham, Poole, Reeves, and Weindlings (2009) reported most mothers of children with cerebral palsy were able to cope, despite having higher than average parenting stress levels, as measured by the *Parenting Stress Index*. Such mothers reported that they found their child with cerebral palsy rewarding, had good emotional attachments with them, and were well supported by family and their spouses (Glenn et al., 2009). Mothers in the study who did not cope as well reported feeling isolated and poorly supported by their spouses (Glenn et al., 2009). This suggests that parents who appear to cope and adapt to the demands of parenting a child with a disability possess enhanced sensitive caregiving skills attuned to the specific needs of their child.

However, the types of coping mechanism employed are significant. Two major categories of coping strategies exist: palliative or emotion-based strategies, and cognitively-based strategies or problem-solving strategies (Lazarus & Folkman, 1984). The use of emotion-based coping strategies, such as avoidance, questioning “why”, denial, self-blame, rumination, and wishful thinking, have been associated with increased depression and poorer subjective wellbeing (Abery, 2006; Glidden, Billings, & Jobe, 2006; Nolen-Hoeksema, 2000). Parents of children with autism who used emotion-based coping strategies reported higher levels of stress (Dabrowska & Pisula, 2010; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Using minimising (i.e., downplaying one’s negative emotions and experiences) as a method of coping has also been found to be linked to psychological distress in mothers of children with developmental disabilities (Affleck & Tennen, 1991).

When parents used problem-solving strategies, such as seeking social support, seeking information, seeking spiritual support, seeking professional support, and reframing or positive reappraisal (Bingham, Correa and Huber, 2012; Glidden et al., 2006; Gray, 2006; Pepperell et al., 2018), they helped buffer certain stressors such as the initial diagnosis of their child’s disability,

undefined diagnosis and prognosis, and the possible unresponsiveness and insensitivity of medical professionals (Beighton & Wills, 2017). Mothers who used problem-based coping strategies experienced less stress and depression in comparison to those who used emotion-based strategies, with problem-based strategies acting as a protective factor (Essex, et al., 1999; Adams, Rose, Jackson, Karakatsani, & Oliver, 2018). A recent U.K. study of mothers of children with intellectual disability showed a link between mothers' use of problem-solving strategies and an increase in their positive affect (Adams et al., 2018). Using problem-solving strategies appeared to have empowered parents, reduced their feelings of isolation, and allowed them to move forward, adapt and meet their child's needs (Bingham et al., 2012).

Positive reappraisal has been shown to be an effective coping strategy across a number of studies (e.g., Beighton & Wills, 2017; Glidden et al., 2006; Hall et al., 2012; Hastings, Allen, McDermott, & Still, 2002). Thus, parents and families who held positive perceptions of their child's disability and had higher levels of self-efficacy, were more able to adjust to having a child with a disability and therefore demonstrated higher family functioning and coping (Beighton & Wills, 2017; Hastings & Brown, 2002; Lustig, 2002).

While older studies (e.g., Atkinson, Scott, Chisholm, Blackwell, Dickens, Tam, & Goldberg, 1995; Judge 1998; Sloper & Turner, 1993) detailed the negative impact of emotion-based strategies, more recent research has indicated that parents often use both types of coping strategies to deal with parenting a child with disability (e.g., Bingham et al., 2012; Lazarus, 2000). Bingham and colleagues (2012) have supported this by showing that parents often turned to emotion-based strategies first, which then led to the more useful and effective problem-solving coping strategies, over time. There appears to be evidence of a more complex relationship happening between palliative and problem-solving coping strategies, with both contributing to decreasing the effect of stressors (Bingham et al., 2012; Lazarus, 2000).

More recent evidence has begun to show the function of positive emotions in the stress and coping process, markedly different from the literature's focus on stress and coping as primarily a

negative experience. Drawing on Folkman's (1997; 2008) third mode of coping, meaning-based coping, the Danish study of Graungaard, Anderson and Skov (2011) proposed the theory of resource-creation as a way to understand why some parents with a child with a disability have stronger coping strategies, while others do to a lesser extent. Their research has suggested that parents' experience of coping is complex, with a mixture of negative and positive emotions, with positive emotions not being an indication of maladaptation or denial of reality (Graungaard et al., 2011). Parents use positive emotions and positive reappraisals to sustain their personal, inner resources, and give positive meaning to the situation, therefore allowing them to continue coping during stressful periods (Graungaard et al., 2011). These same parents acknowledged that a certain degree of positive illusions or avoidance of reality was needed to maintain their ability to cope (Graungaard et al., 2011).

Another study that looked at the coping strategies of parents of children with intellectual disability, also found meaning-based strategies helpful (Beighton & Wills, 2017). These parents also used other ways of coping, such as support seeking strategies, positive emotions and positive appraisals (Beighton & Wills, 2017). Thus, a review of the literature on coping suggests that parents of children with disability can use a range of coping strategies, with a mix of palliative, problem-solving and meaning-based strategies helping them to adapt with the intense, often chronic stress. Importantly, the body of literature that emphasised the positive aspects of parenting a child with disability shows how families can embrace disability as a part of their lives, rather than seeing it as a negative aspect.

**Support.** To help them cope, parents also have sources of support, including support from each other, family, friends, and professionals. Marital support and social support have also been identified as key domains of influence on parenting (Belsky, 1984). Both marital support and social support are associated with attachment security (Atkinson et al., 2000).

Social support is one type of coping strategy that has been shown to buffer against stress, especially during periods of high stress (Dunn et al., 2001). Social support is support stemming from

outside of the immediate family, and can be from the extended family, the local community, and professionals. This support can be practical, such as providing the parents information for the child's early intervention needs, or emotional, such as listening to the parent's daily experiences. Social support has also been reported as impactful and a frequently used coping strategy (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). In a North American study of parents of children who are deaf, parents who perceived that they received adequate support reported experiencing less stress than parents who perceived that they received less support (Åsberg et al., 2008). Notably, these families were receiving early intervention at the time of study, which the researchers commented may have impacted on results of lower parenting stress levels (Åsberg et al., 2008). Therefore, comparing these findings to a study on the same population that were not receiving intervention during the study might be worthwhile.

Other studies of children with chronic health conditions and disabilities also showed that parents' perception of higher levels of social support was linked to positive child outcomes, and a positive disposition among the parents (Farmer et al., 2004; Findler et al., 2016). One Canadian study found that families who received a high level of social support experienced average levels of family quality of life, despite the intensity of the child's disability or behavioural problems (McConnell, Savage, & Breitzkreuz, 2014). An Australian study by Pepperell and colleagues (2018) showed that mothers in particular reported a greater use of social support, including friends, family, and professionals, both for practical and emotional support. Mothers in this study reported seeking practical support, such as how to gain access to external agencies from their existing early intervention professionals, as well as emotional support, for example, joining groups of parents with children with ASD.

Provision of emotional support and respite from extended family (i.e., grandparents, uncles and aunts), was demonstrated as having a positive impact on parenting (Jovanova & Radojichikj, 2013; Hall & Graff, 2011). However, this impact was only secondary to the support that can be obtained from immediate family members. Family functioning has been identified as a key factor in parents'

ability to cope (Kandel & Merrick, 2007; Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu, & Wood, 2005; Taanila et al., 2002). Some studies showed parents who perceived having a child with a disability as beneficial to their children without disability and were also often able to draw support from the siblings (Jovanova & Radojichikj, 2013; Hall et al., 2012). Thus, social support can be an important protective factor against maternal depression and is indirectly linked to enhanced parenting and therefore increased likelihood of secure attachment (Sipal & Sayin, 2013).

Parents who are finding their marriage stressful often lack the energy to be emotionally present for their children (Belsky & Jaffee, 2006). A seminal study by Isabella and Belsky (1985) demonstrated that poor marital quality was linked to insecure mother-infant attachment. However, in successful marriages, the marriage acts as a source of support, and can even buffer any stress coming from the parent-child relationship (Belsky & Jaffee, 2006). This finding is significant and suggests that supporting the parents' relationship has a direct impact on the quality of the parent-child relationship.

Kersh and colleagues (2006) showed that in parents of children with developmental disabilities, mothers' parenting efficacy was related to their marital quality, although for fathers, non-spousal social support was a major predictor of their efficacy. The findings of this American study also suggest that marital quality can also be influenced by factors existing outside of the immediate family (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Furthermore, higher levels of marital quality were linked to lower levels of depression, parenting stress, and greater parenting efficacy (Kersh, et al., 2006). A recent study on parents with children with ASD, demonstrated that respite care was related to marital quality, with just one extra hour of respite care contributing to a significant increase in the parents' marital satisfaction (Harper et al., 2013). Providing respite care is one way to support marital quality, and can be implemented by extended family members and professionals alike. A meta-analysis by Risdal and Singer (2004) concluded that poor marital quality was not linked to presence of a disability, and suggested that parenting a child with a disability can bring the spouses closer

together and strengthen their marriage. Thus, supporting the marital quality of parents with children with disability may reduce the impact of risk factors that may surround these families.

The research has also highlighted the important role professionals have in supporting parents of children with disability. One study showed that professional support was linked to positive experiences of care, with parents expressing that they received respectful and supportive care, most of the time (Fordham, Gibson, & Bowes, 2012). Similarly, another study revealed that empathic support from professionals enhanced parents' inner resources, while lack of support from professionals was a source of distress (Graungard et al., 2011). For example, parents described having the support of special nurses as invaluable to them while their child was in hospital, commenting that without them they would not have survived (Graungard et al., 2011). Although, parents from the same study also described how communication with doctors and other health professionals was ineffective, causing them more unnecessary stress. Effective communication and collaboration with professionals were shown to be key to high-quality care (King & Chiarello, 2014). King and Chiarello (2014) stated that using communication to build rapport and create mutual understanding with parents increases parental involvement in early intervention.

The initial diagnosis of their child's disability is a major stressor for parents, and it has been shown that the attitude and behaviour of medical professionals and service providers towards parents at this time can act as a buffer against the difficulties parents may encounter (Bingham et al., 2012). In one study, results of interviews with mothers found that seeking professional support (e.g., persistently asking professionals to establish their child's diagnosis) was a key strategy used during the difficult time of the diagnosis (Bingham et al., 2012). However, a positive experience is not always the case. A Macedonian study comprising 31 parents and 31 children with developmental disabilities, demonstrated that medical professionals did not communicate or support parents during their child's diagnosis in an understanding and respectful way (Jovanova & Radojichikj, 2013). Although due to this study's limited number of participants, it is likely not an accurate representative of this population.

Another study revealed that parents found the time of diagnosis stressful as professionals lacked empathy and did not listen to their concerns (Kelso et al., 2005). Similarly, an Australian study found that parents thought professionals did not provide sufficient, useful information about their child's disability, upon diagnosis (Douglas et al., 2016). Carter and colleagues (2007) demonstrated how some parents felt that working with a range of professionals was difficult, likening it to a nightmare.

Fletcher (2016) outlined recommendations for best-practice when professionals tell parents of their child's diagnosis, including the need to provide clear information; to behave in a sensitive and empathic manner; to offer a follow-up appointment to discuss the diagnosis further; and, to provide information about counselling and parent support groups. Hastings and Beck (2004) attested to the helpfulness of parent support groups, with parents wanting professionals to promote these types of networks. Similarly, another study found that parents of a child with complex needs desired opportunities to connect with parents who were also experiencing parenting a child with complex needs, finding this type of support invaluable (Carter et al., 2007). Douglas and colleagues (2016) found that parents who connected to support groups early in their child's diagnosis found these groups helpful in navigating which services their child needed. Such parents were raising children with complex needs who needed care from a wide range of health, social, and educational professionals and service providers, and thus preferred it when providers from different agencies worked together to support them (Carter et al., 2007).

In sum, to buffer the risk factors parents of children with disability might face, professionals could strive to understand parents' perception of the social support they receive in relation to the stress they experience, as well as show an understanding of the coping strategies that may best support parents (Jovanova & Radojichikj, 2013; Douglas et al., 2016; Dunn et al. 2001; Hassall et al., 2005; Neely-Barnes & Dia, 2008). To provide support, professionals should learn to individualise the support they give to parents, matching the types of coping strategies that families use (Judge, 1998; Bingham et al., 2012). The following section describes family-centred and relationship-based



practices as two philosophies that have been shown to be helpful in supporting families with children with disabilities.

### ***Family-centred Practice and Relationship-based Practice***

Given the centrality of parent-child relationships and the impact of disability on the whole family, two early intervention practices are important to consider when supporting attachment relationships in parents and their children with disability. Such practices are family-centred practice and relationship-based practice, both of which have been shown to enhance the quality of early childhood intervention (Espe-Sherwindt, 2008). Family-centred practice focusses on the needs and goals of the whole family, and not just the child's (Dunst & Trivette, 2009). Professionals collaborate with parents, rather than lead early intervention efforts (Dunst & Trivette, 2009). In relationship-based practice, the interpersonal relationships between all participants is emphasised. Professionals work on building their relationship with the child, and with the family members. In both practices, collaboration, understanding, communication, and empathy are key.

Although family-centred care is one philosophy considered best-practice in early intervention, in reality, practice of family-centred care has not always met the ideal (Butler, Copnell, & Willets, 2014). Family-centred practice emphasises the centrality of the family and the needs of the family, when considering the child's needs, development and intervention (Dunst & Trivette, 2009; Rosenbaum, King, Law, King, & Evans, 1998; Espe-Sherwindt, 2008). Because of the importance of family functioning on parenting stress, early intervention and healthcare provision should focus on addressing the needs of the whole family, not solely the needs of the child (Hayes & Watson, 2013; Kandel & Merrick, 2007; Raina et al., 2005; Smith, Oliver, & Innocenti, 2001).

Equal partnerships are one aspect of family-centred practice that is lacking in practice. A review conducted on family-centred care in a paediatric intensive care unit in Victoria, Australia, concluded that parents were not given honest information about their child, which prevented them from building an equal partnership with healthcare providers (Butler et al., 2014). Other studies have also

highlighted that professionals have been lacking in providing families with information that they need, which is important in fostering families' sense of empowerment (Fordham et al., 2012; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007). While in hospital, nurses are the healthcare providers most in contact with parents, and therefore have the responsibility to provide family-centred care, which includes supporting and advocating for parental needs, providing important information, and supporting parents emotionally (Butler et al., 2014). Results of a study by Butler and colleagues (2014), found healthcare providers were not fulfilling these responsibilities. Parents in this study also felt that other responsibilities, such as social work and pastoral care, were not being met by the healthcare providers (Butler et al., 2014). Notably, parents were not given enough access to their children, with medical professionals taking over the caregiving role and parents having to ask permission to interact with their child (Butler et al., 2014).

In providing family-centred services to families with children with disabilities, service providers must acknowledge that the family is the constant in the child's life, and that the parents know their child best (Espe-Sherwindt, 2008). To improve family-centred practice, service providers could focus on the family's strengths, provide individualised intervention as all families are diverse, empower families, and collaborate with them, particularly in decision making and implementation of interventions (King & Chiarello, 2014). An important premise of family-centred practice is that "optimal child functioning occurs within a supportive family and community context: the child is affected by the stress and coping of other family members" (Rosenbaum et al., 1998, p. 6). It would therefore seem that family-centred practice promotes the child's relationships with other family members. On the whole, it seems that the family-centred approach is a way through which intervention focussed on promoting secure attachment can be practised (Moore, 2009). A focus on facilitating attachment relationships could be beneficial given the significance of attachment security to the child's social and emotional development. However, within the family-centred literature, there does not seem to be an explicit emphasis on building attachment relationships.

Another approach to early intervention is relationship-based practice, which emphasises the need to build relationships between service providers, parents and children. There are two aspects to relationship-based practice, or relationship-based preventive intervention. The first is a focus on the importance of the parent-child relationship, the second, the relationship between service providers and families, and how this influences parent-child interactions (Heffron, 2000; Howard, Williams, & Lepper, 2010). According to Moore (2013), “effective services are relationship-based, that is, based on a relationship between service providers and parents that is genuinely respectful, as well as a partnership between parents and service providers” (p. 4). Service providers, who are sensitive, empathic and responsive towards parents and families, are able to build trusting relationships, thereby also showing the parents an example of how their own relationship with their child can be (Kalmanson & Seligman, 1992). Further aims of the relationship-based approach include: increasing family coping skills; underscoring and supporting positive family relationships; and to building resilience in children (Heffron, 2000). It is therefore the early interventionist’s role to create multiple opportunities for the parent to develop their relationship with their child. Together, family-centred practice and relationship-based practice are modes through which early intervention services are delivered and can enhance the services being delivered (Moore, 2009). Their emphasis on building relationships between families and service providers, and the role of the service provider as one who is sensitive and responsive towards the family, reflect the crux of attachment security. Both modes of practice seem to support the formation of secure attachment relationships between parent and child, and may be an important factor in a study on attachment and infants with hearing loss and complex needs.

### **Attachment Theory and Infants with Hearing Loss and Complex Needs**

The previous sections have focussed on describing the experiences of parents with children who have disabilities, and how this may impact on the development of the parent-child attachment relationship. Since insecure-attachments are more likely to form in parent-child dyads who are surrounded by multiple risk factors (e.g., child’s disability, maternal depression), this section will

draw on the available literature to comment on attachment and such a population, that is, caregivers and their infants with hearing loss and complex needs.

### ***Defining the Population: Infants with Hearing Loss and Complex Needs***

A child with hearing loss and complex needs (HL-CN) can be described as a child who has a hearing loss, with one or more comorbid disabilities, impairments or conditions that require service provision and support from a wide range of health and social professionals (Carter et al., 2007; Hewitt-Taylor, 2010; McCracken & Pettitt, 2011; Rankin & Regan, 2004; Salisbury & Copeland, 2013). Notably, in North America, approximately 30-50% of children born with congenital deafness or hearing loss, will also present with one or more additional risk factors (e.g., malformations of the head or neck, hyperbilirubinemia, or Usher's syndrome in which vision impairment is possible) (Gallaudet Research Institute, 2011; North Dakota Chapter of American Academy of Pediatrics, 2008; Thomson et al., 2011). In the United Kingdom, a health report conducted on children with hearing loss and additional complex needs reported that one in 1000 children there are born deaf or hard of hearing, and about 40% of that population are also born with "additional health, social or educational needs ranging from asthma or dyslexia, to more severe disabilities like cerebral palsy, autism or Down syndrome" (McCracken & Pettitt, 2011, p. 64). In Australia, data on this population are quite limited, with a fairly recent study on children undergoing cochlear implantation reported that out of 88 children, 33% were also diagnosed with additional needs (Birman, Elliott, & Gibson, 2012). These data appear to follow the trend from data in other countries, with children with hearing loss and additional needs consisting of 30-40% of the deaf or hard of hearing population (Birman et al., 2012; Gallaudet Research Institute, 2011; McCracken Pettitt, 2011; North Dakota Chapter of American Academy of Pediatrics, 2008; Thomson et al., 2011). The composition of families with children with HL-CN may also include culturally and linguistically diverse groups, single parents, low-income or families experiencing chronic poverty, rural families, or parents with mental health issues (McCracken & Pettitt, 2011; Warren & Brady, 2007; Ziviani et al., 2014). Though research

shows that the presence of a disability does not lead to insecure attachment, in the case of infants with HL-CN, the presence of multiple disabilities, impairments or conditions may increase the risk of attachment insecurity (Hartshorne & Schmittel, 2016; Reda & Hartshorne, 2008). Indeed, there is evidence to suggest that due to the presence of other risk factors, infants with hearing loss *and* complex needs are at elevated risk for challenges to their attachment security, and thus may develop insecure attachment relationships with their primary caregivers (Spencer & Koester, 2016; Thomson et al., 2011).

### ***Factors Surrounding Infants with Hearing Loss and Complex Needs***

Belsky's (1984) cumulative risk model on parenting is one way to understand the presence of several risk factors surrounding infants with HL-CN and their parents. According to this model, the three major determinants of parenting are: the parent's personality and psychological well-being, the characteristics of the child, and the contextual sources of stress and support (i.e., social support, occupation, marital quality). Among these three, the determinant that possesses the least risk to optimal parenting is the characteristics of the child, while the determinant that possesses the most risk is the parent's personality and psychological well-being (Belsky, 1984). Thus, within a parent-infant dyad, if the infant has a disability and the parent's psychological well-being is sound, the parent is more likely able to cope with this risk. However, if the infant has a disability and the parent has mental health issues (e.g., depression), there may be a greater chance that optimal parenting will be threatened. Moreover, this model proposes that an accumulation of risk factors only increases the threat to the parent-infant dyad, with the worst-case scenario having all three major determinants as sources of stress (Belsky, 1984). Therefore, in families with infants with HL-CN, the quality of parenting, and subsequently the attachment security, is more dependent on the parent's psychological well-being, than on the presence of hearing loss and additional disabilities. Thus, professionals providing early intervention to families with infants with HL-CN may need to focus on improving or supporting the parent's psychological well-being.

As it stands, there is little research specifically on attachment and children with hearing loss and complex needs. This is likely due to the diversity of this group of children (i.e., children with hearing loss and additional disabilities include a range of conditions such as autism, Down syndrome, cerebral palsy, CHARGE syndrome), as well as being a small subset of the disability population. CHARGE syndrome is a particularly complex though recognisable genetic syndrome, “involving extensive medical and physical difficulties that differ from child to child” (CHARGE Syndrome Foundation, 2020). The letters in CHARGE stand for features common to those with the syndrome: Coloboma of the eye, Heart defects, Atresia of the choanae, Retardation of growth and development, and Ear abnormalities and deafness, however not all these features are used to diagnose the syndrome (CHARGE Syndrome Foundation, 2020). A review of the literature around this specific area shows scattered focus. For example, intervention that has targeted children with disability and their attachment relationships with their primary caregivers have tended to focus only on improving caregiver sensitivity in the parent (Atkinson et al., 1999; Capps, Sigman, & Mundy, 1994; Clements & Barnett, 2002; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2012; Siller, Swanson, Gerber, Hutman, & Sigman, 2014). Such studies are significant in that they have contributed to the evidence that caregiver sensitivity is a significant causal factor in attachment security, much more so than the child’s characteristics, in this case, disability (Bakermans-Kranenburg et al., 2003).

Other studies have focussed on the parent’s psychological well-being, and its impact on attachment security (e.g. Teague, Newman, Tonge, & Gray, 2018). Yet another study states that with children who have complex needs, responsiveness to their signals is crucial (Chen, Klein, & Haney, 2007). In children with CHARGE syndrome, Reda and Hartshorne (2008) reported that it takes children with CHARGE syndrome and their parents a longer time to bond. Significantly, a meta-analysis conducted on positive parenting and children with developmental disabilities found a moderate association between the two (Dyches, Smith, Korth, Roper, & Mandleco, 2012). Dyches and colleagues (2012) attested that this finding suggests that positive parenting does have an impact on children with disabilities, and therefore warrants further investigation. Thus, a review of the

research shows that there is no existing study that synthesises all these aspects of attachment formation together, in the specific population of infants with hearing loss and complex needs.

Other studies have focussed on incorporating attachment principles into their practice. One study emphasised service providers building “a therapeutic relationship based on attachment principles” with children with intellectual and visual disabilities (Sterkenburg, Janssen, & Schuengel, 2008, p. 133). This approach appeared to lessen the occurrence of challenging behaviours amongst the children who participated in the intervention (Sterkenburg et al., 2008). Similarly, a recent Australian study explored the perspectives of early childhood interventionists towards attachment and its place in early intervention practice (Alexander et al., 2018). This study concluded that most ECI professionals understood the importance of attachment to child development, and acknowledged that in children with disability, attachment development may be more difficult (Alexander et al., 2018). These ECI professionals also perceived that an understanding of attachment was important in their work. Findings also revealed that less than half of the study participants learnt about attachment in their undergraduate studies, with most having learnt about attachment ‘on the job’ (Alexander et al., 2018). The study authors further stated that there is still a lack of knowledge amongst service providers around how to practise attachment in ECI, and that more research is necessary to improve attachment-focussed ECI (Alexander et al., 2018). Hence, it appears that for parents and their children with multiple disabilities or complex needs, intervention best suited to this population involves knowledge of the importance of attachment, increasing caregiver sensitivity, and improving parents’ ability to understand their child’s cues.

### **Methodological Considerations**

In relation to the present study, several methodological considerations should be discussed. Such issues include a critique of previous research designs, and the need for mixed-method approaches to studying the unique and specific population that is infants with HL-CN, due to the limited available research on this topic.

As stated, the researcher was unable to locate any existing studies specifically addressing attachment and infants with HL-CN. To combat this challenge, this literature review has focussed on studies on attachment and children with disability, as well as studies on children with multiple disabilities. A review of the methodologies used in such studies on attachment and children with disability show quantitative approaches used most frequently, while qualitative or mixed-method approaches used in fewer studies. One critique of recent studies on attachment and children with disabilities is their reliance on self-report questionnaires to derive data. One Israeli study utilised self-report questionnaires to obtain data on mothers' experience of stress, attachment, guilt and social support in parenting children with disability (Findler et al., 2016). One hundred and ninety-one mothers of children with developmental disabilities answered questionnaires, with results indicating that attachment avoidance was directly and negatively linked to a mother's happiness (Findler et al., 2016). However, the findings can only be generalised to mothers of children aged 3-7 years with autism, cerebral palsy, hearing impairments, or intellectual disability, and not with dual diagnosis. Furthermore, the authors themselves recognised that the data were derived solely from the mothers, and that obtaining data from other family members or professionals would have enhanced the study (Findler et al., 2016).

A USA study also utilised self-report questionnaires to collect data on attachment perceptions and parents of children with autism (Goodman & Glenwick, 2012). In this study, six self-report questionnaires were given to 76 mothers and 30 fathers of children with autism, aged 2-10 years (Goodman & Glenwick, 2012). One of the questionnaires used was the *Parenting Stress Index* (PSI) (Abidin, 2012), which due to its established reliability and validity, has also been used in the current study. Similarly, an Australian study on parents and children with autism also used a number of self-report questionnaires to gather data (Teague et al., 2018). Twenty-nine parents of children with ASD and 20 parents of children with developmental disability completed four questionnaires, with results showing that parents of children with autism reported higher levels of stress and anxiety, and attachment insecurity in children, when compared with children with other developmental disabilities



(Teague et al., 2018). As with Goodman and Glenwick's (2012) study, Teague and colleagues' reliance on questionnaires gave breadth to their study, though not depth.

Finally, an Australian study utilised surveys to measure early interventionists and their knowledge and views on attachment (Alexander et al., 2018). The authors noted that since no previous studies on this topic could be found, the questions were drafted specifically for the survey, based on a review of the literature. The survey used was created with a mixture of closed and open questions, with open questions seeking a broader picture of the respondents' experience. Unlike the studies previously that utilised closed questionnaires only, Alexander and colleagues (2018) sought to gain more in-depth responses from their participants, through the use of open-ended questions.

A mixed-methods approach combines qualitative and quantitative research methods, with the underlying assumption that this will yield a greater understanding of the phenomenon being studied (Creswell, 2013; Creswell & Plano Clark, 2007; Tashakkori & Teddlie, 2010). However, there have been few recent studies on attachment and disability that have utilised qualitative methods, less still, a mixed-methods approach. A couple of exceptions include a U.K. study on attachment and children with cancer (Bishop et al., 2015); and a Belgian study on parents' perspective of their attachment with their child with intellectual disability (Vandesande, Bosmans, & Maes, 2019). In the aforementioned studies, only Vandesande and colleagues' (2019) study made use of a mixed-methods approach. Their study utilised both qualitative interviews and quantitative questionnaires to explore parents' views on their attachment with their children with severe, intellectual disabilities (Vandesande et al., 2019). Interestingly, in a dated study on attachment and the perceptions of mothers whose children had autism or Down syndrome, the researchers noted that it was only through the "more intimate and intensive experience of the interviews" that the difference between the parenting experiences of mothers with children who had autism and mothers with children who had Down syndrome surfaced (Hoppes & Harris, 1990, p. 368). Therefore, incorporating qualitative interviews in the present study on developing attachment relationships and infants with HL-CN, may assist to establish a more intimate understanding of relationships.

Notably, several studies of attachment and disability have utilised videotaped observations (e.g., James, Wadnerkar-Kamble, & Lam-Cassettari, 2013; John, Morris, & Halliburton, 2012; Oppenheim et al., 2012; Overbeek, Sterkenburg, Kef, & Schuenge, 2015; Poslawsky et al., 2014; Rozga, Hesse, Main, Duschinsky, Beckwith, & Sigman; 2018; Siller et al., 2014). These studies varied in their use of videotaped observations, ranging from video-feedback, where the interventionists videotaped parent-child interaction and viewed this videotape with the parent to help them reflect on their behaviours, to videotaped parent-child interactions that were coded using a video-coding system (e.g., the *Emotional Availability* coding system). These studies often focussed on enhancing parental sensitivity, through parental reflection of their behaviours during the videotaped play interaction, or through the parents gaining a better understanding of their children's behaviours. All studies utilising videotaped observations showed some improvement in the parents' caregiver sensitivity, with some studies also showing an association to the children's attachment security. These studies support the evidence-base on the use of videotaped observations to explore parents' caregiver sensitivity towards their children with disability.

Since the present study aims to understand the factors around attachment and young children with HL-CN, a mixed-methods approach that incorporates quantitative (e.g. self-report questionnaires), and qualitative (e.g. interviews and videotaped observations) methods was chosen as the most appropriate approach to use.

## **Conclusion**

A review of the literature on attachment and parenting a child with disability has revealed a paucity of studies specifically on the factors around the attachment relationships of young children with HL-CN. Nonetheless, the existing evidence suggests that if there is an accumulation of risk factors surrounding the parent-child dyad, problems with the developing attachment relationship are more likely to occur (Belsky, 1984; Spencer & Koester, 2016; Thomson et al., 2011). Based on studies identifying the risk factors surrounding parents and their children with disabilities, it would be logical

to suggest that the interventions for parents and young children with HL-CN should emphasise improving caregiver sensitivity, and include attachment-based principles. Furthermore, service providers should support the psychological well-being of primary caregivers, based on the strong influence of this domain on parenting quality (Belsky, 1984; Belsky & Jaffee, 2006). In light of these key points important questions that arise are, what do we know about attachment and infants with HL-CN? Moreover, what do service providers know about attachment relationships? Supporting the caregiver's psychological wellbeing is important, but what other forms of support would help facilitate attachment relationships between caregivers and infants with HL-CN? Do service providers have a role in supporting their attachment relationships? With these key points and questions in mind, the current study proposed the following research questions:

- 1) What is the nature of the attachment process for infants with hearing loss and complex needs (HL-CN)?
  - a. What do caregivers and service providers understand about the attachment process for infants with HL-CN?
  - b. What factors may affect attachment formation in infants with HL-CN?
  
- 2) What is the role of service providers in helping facilitate developing attachment relationships between infants with HL-CN, and their primary caregivers?

The following chapter will present the methodology used for the pilot study by discussing its research design, mixed-methods research, case-study research, and detailing its data collection and analysis procedures.

## Chapter 3 Methodology

This exploration of how an infant with hearing loss and complex needs (HL-CN) develops an attachment relationship with their primary caregiver, was guided by a theoretical framework based on attachment relationships, as understood within the bioecological systems model (Bronfenbrenner, 1977, 1979, 1986, 2001), and Belsky's (1984) determinants of parenting model (see Chapter 1). This chapter discusses the study's methodology by first explaining the research design, secondly, by describing mixed-methods and case study research, thirdly by assessing the quality of the research design, and finally, by elaborating on the data collection and analysis methods used in Case Study 1 (CS1), the pilot case study.

### Research Design

A research design can be defined as a logical plan that guides the researcher in his or her decisions regarding the collection, analysis and interpretation of data, inevitably linking the data to the study's research questions and theoretical propositions (Creswell & Plano Clark, 2007; Yin, 2018). This study's research design followed an exploratory sequential mixed-methods strategy, towards a descriptive multiple-case embedded design (Creswell, 2018; Creswell & Plano Clark, 2007; Yin, 2018). An exploratory sequential strategy is a type of mixed-methods approach where the main qualitative component is supplemented with a subsequent quantitative component (Creswell, 2013). A descriptive multiple-case embedded design is a type of case study design comprising two or more individual case studies, each embedded with two or more units of analysis, and aimed at gaining an in-depth and rich understanding of the phenomenon (Yin, 2018). This research design was chosen since in such a design, subsequent databases build upon initial databases, providing a richness to the data collected (Creswell, 2018; Creswell & Plano Clark, 2007; Yin, 2018).

### ***Mixed-Methods Research***

Mixed-methods research “is an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks” (Creswell, 2013, p. 4). Researchers often choose a mixed-methods approach because of the underlying assumption that combining both forms of approach will give a greater understanding of the research problem than either approach on its own (Creswell, 2013; Creswell & Plano Clark, 2007; Tashakkori & Teddlie, 2010). Mixed-methods research is often guided by the philosophy of pragmatism which by its nature, “focusses on the problem to be researched and the consequences of the research” (Feilzer, 2010, p. 7). This pragmatic approach involves combining different research methods, and thus an array of evidence, to allow the researcher to answer research questions in the best possible way (Johnson & Onwuegbuzie, 2004; Wheeldon & Åhlberg, 2012; Yin, 2018). Similar to qualitative research, this use of pragmatism sees the researcher’s role as invaluable in providing expertise, experience, and intuition (Creswell, 2018; Johnson & Onwuegbuzie, 2004; Wheeldon & Åhlberg, 2012; Yin, 2018). The role of the researcher in this study will be discussed in more detail in a later section (see p. 90, ‘Researcher as Instrument’).

Mixed-methods research makes use of the strengths of quantitative and qualitative research, and in doing so also partially offsets their respective weaknesses (Creswell & Plano Clark, 2007; Tashakkori & Teddlie, 2010). In quantitative research these weaknesses are a reliance on statistics and large sample sizes, as well as a focus on cause and effect (Creswell, 2018; Stake, 2010; Tashakkori & Teddlie, 2010). In qualitative research, weaknesses may include time-consuming data collection and data analysis; and, the presence of the researcher potentially biasing data collection (e.g., during interviews and participant observations) (Creswell, 2018; Yin, 2018). A major strength of qualitative research is depth, that is, the ability to uncover and explore the complexities and richness of an area of inquiry (Creswell, 2018). In quantitative research, a major strength is breadth, that is, the ability to reach a great quantity of participants that are of statistical significance (Creswell,

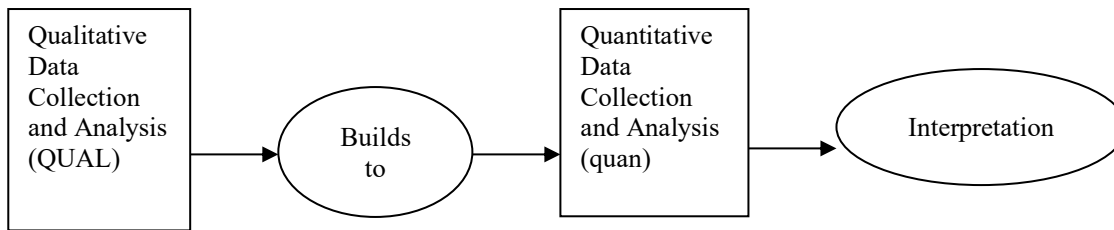
2018). Thus, in the present study, these two strengths together provided a greater understanding of the phenomenon under investigation.

A major analysis technique in mixed-methods and case study research is triangulation (Creswell, 2018; Creswell & Plano Clark, 2007; Stake, 2010; Yin, 2018). Triangulation involves converging quantitative and qualitative methods to compare or contrast quantitative results and qualitative findings (Creswell, 2014; Creswell & Plano Clark, 2007; Yin, 2009; 2018). In mixed-methods research, triangulation can be used in order to build and justify themes, where evidence from multiple and varied sources of data are examined and corroborated (Creswell, 2018; Creswell & Plano Clark, 2007; Stake, 2010). Triangulation also adds to the validity of the evidence collected in a study (Creswell, 2018; Stake, 2010). The present study used both qualitative and quantitative data during triangulation, however it emphasised qualitative methods and data (QUAL), supplemented with quantitative methods and data (quan). Since qualitative data were the main source of data, they are referred to in upper case letters (QUAL), while quantitative data are referred to in lower case letters (quan; Creswell, 2018).

Specifically, in a mixed-methods exploratory sequential design, data collection, analysis and interpretation are sequential, with a second database building onto the findings from the first database (Creswell, 2018). In the current research, the study started with an exploration through qualitative data collection and analysis, wherein the findings were then used in a second quantitative data collection and analysis stage, as depicted in Figure 3.1 (Creswell, 2014, p. 228).

Figure 3.1

*The Stages of an Exploratory Sequential Mixed-Methods Design (Creswell, 2014, p. 228).*



*Note: Capitalisation denotes emphasis or priority on the quantitative or qualitative data, analysis, and interpretation in the study (QUAL, QUAN) while lowercase letters indicate less emphasis or priority (quan, qual). An arrow indicates a sequential form of data collection; one form builds or connects with the other (Creswell, 2014, pp. 228-229).*

In the present study, the first qualitative exploration stage was followed by a quantitative data collection and analysis stage. This second stage was followed by a third qualitative stage, and another quantitative stage. This fourth quantitative stage was in turn followed by five stages of qualitative data collection, the sixth stage being a mix of qualitative and quantitative methods. In the present study nine stages of data collection were undertaken with each subsequent database building on to the initial databases (see Table 3.2).

In this mixed-methods approach, quantitative and qualitative data collection and analysis methods were integrated to conduct case studies. The following section outlines the rationale for using qualitative case studies in the current research.

### ***Case Study Research***

The current study was predominantly driven by a qualitative approach, specifically, case study research. The case study research method's most appealing advantage is its capacity to "investigate a contemporary phenomenon (the "case") in depth within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident" (Yin, 2009, p. 18). In-depth investigation is advantageous because it can utilise a number of data collection procedures and analysis strategies over a sustained period of time (Creswell, 2013; Yin, 2018). The case study has

access to an array of data collection and analysis methods, and is also able “to deal with a full variety of evidence - documents, artifacts, interviews, and observations”, more so than other research methods (Yin, 2009, p. 11). In particular, “embedded case studies may ... call upon surveys or other quantitative techniques to collect data about the embedded unit(s) of analysis” (Yin, 2009, p. 63). This extends the ‘variety of evidence’ that the researcher can access, to quantitative data that supplements the qualitative data (Yin, 2009). Using multiple sources of evidence is a key principle in case study data collection, since “no single source has a complete advantage over all the others ... and the various sources are highly complementary” when used together (Yin, 2009, p. 101). According to Yin (2018) the embedded case study represents a form of mixed-methods research. Another strength is that case studies can focus in on real-life events and test the researcher’s chosen theories and beliefs directly with the events, as they occur (Flyvbjerg, 2006).

However, case study can be a challenging research method because of the onus on the researcher to systematically collect and analyse often a large quantity of data (Stake, 2010; Yin, 2018). An added limitation is the potential to be buried in data that is not relevant to the study’s research questions. However, if designed well, these weaknesses can become strengths. The challenges and limitations of doing case study research therefore require a rigorous approach in handling data, that is, conducting validity and reliability checks throughout the study, in order to develop justifiable interpretations from the data that emerge (Creswell, 2018; Flyvbjerg, 2006; Stake, 2010; Yin, 2018). To draw conclusions from the data, case study research uses analytical generalisations, “in which a previously developed theory is used as a template with which to compare the empirical results of the case study” (Yin, 2009, p. 38). This is opposed to what quantitative research studies use - statistical generalisations (Yin, 2018).

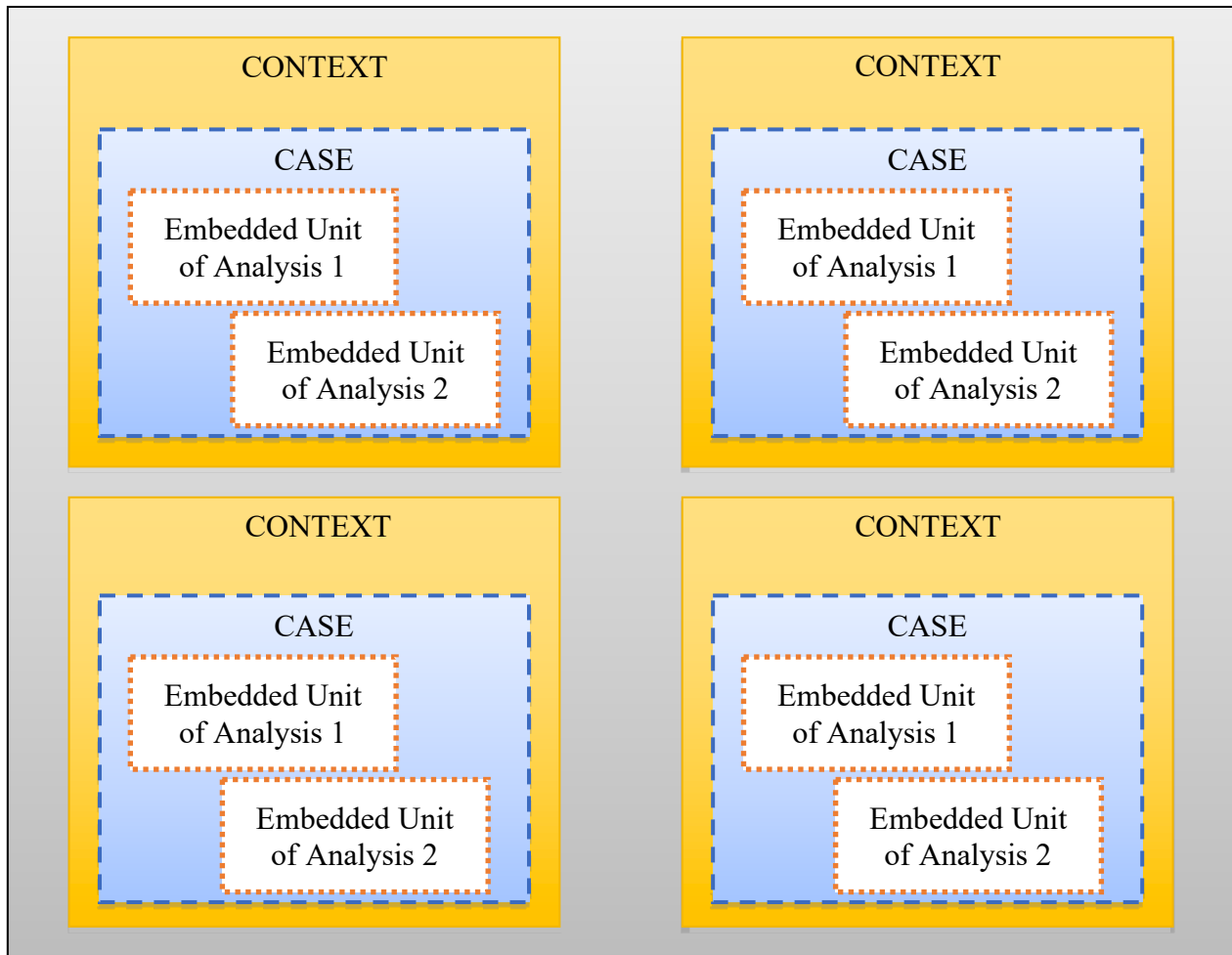
The multiple-case embedded design is arguably the design that allows for a more robust and multi-level case study, and therefore stronger analytical generalisations (Yin, 2018). This design is displayed in Figure 3.2 (adapted from Yin, 2009, p. 46). The multiple-case embedded design comprises two or more case studies, each having a case with embedded units of analysis, enclosed by



the context particular to that case. The dotted line around the case signifies that the boundaries between case and context are not always clear-cut (Yin, 2009). The design is embedded in the sense that there are two or more units of analysis measured in the one case. A unit of analysis is defined as the subject of the case study, that is, the phenomenon being investigated, and is distinguished from the context, in other words, the data collected that lie outside of the case (Yin, 2009). In the present study, the child's attachment relationships with different caregivers were considered separate units of analysis, or subunits, and were explored to contribute to an overall understanding of the child's developing attachment relationships, that is, the case. The context consisted of the possible variables within the child's bioecological systems. Such variables included: the child's temperament, the child's degree of impairment/s, the caregiver's spousal, social, and community support, early childhood intervention systems and structures, educational systems and structures, government systems and policies towards disability and families, and societal and cultural attitudes and beliefs towards disability. Importantly, the definition of the unit of analysis could be modified as a result of the findings during data collection (Yin, 2009).

Figure 3.2

*The Type 4 Multiple-Case Embedded Design (Yin, 2009, p. 46).*

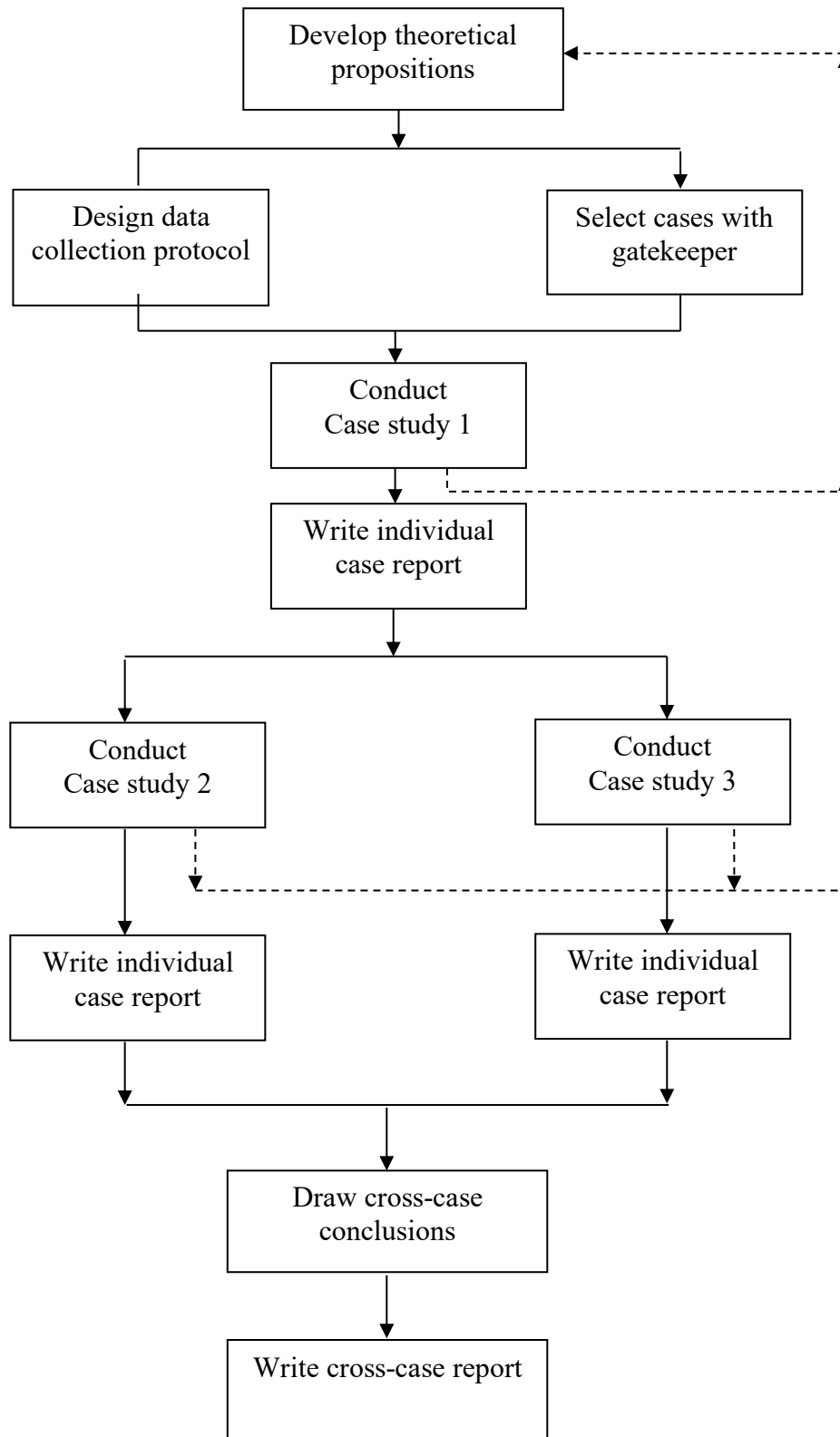


In a multiple-case design, replication logic is important as it aims to generalise the results of the first case study, through replication of the same data collection and analysis methods in one or more studies (Yin, 2018). Thus, a multiple-case design is considered more robust than a design with only one case study because it is able to use replication logic, where the analytical conclusions derived from two or more cases are stronger and more convincing than if derived from one case (Yin, 2018). In a multiple-case design, each case is chosen carefully so that it either: “(a) predicts similar results (a literal replication) or (b) predicts contrasting results but for anticipatable reasons (a theoretical replication)” (Yin, 2009, p. 54). To conduct a literal replication, at least two cases are needed. For a theoretical replication, four or more cases are needed with the aim of testing variations in the theoretical assumptions of the research study (Yin, 2018).

In the current research study, the initial research design consisted of Case Study 1 (CS1) (a pilot) followed by Case Study 2 (CS2) and Case Study 3 (CS3). Using the same data collection and analysis methods, case studies two and three were designed to be replications of the first case study. Figure 3.3, adapted from Yin's figure (2009, p. 57), showcases the study's multiple-case study procedure, with CS1 followed by CS2 and CS3. An important aspect of the diagram is the dashed-line feedback loop that indicates that an important discovery may have occurred in one of the case studies (Yin, 2009). This may lead the researcher to test the study's initial theoretical assumptions, through adapting the research design by adding alternative cases, or making changes to the case study protocol of subsequent cases (Yin, 2018).

Figure 3.3

*The Multiple-Case Study Procedure: Case Study 1 as Pilot Study followed by Case Studies 2 and 3 (Yin, 2009, p. 57).*



### ***Research Design Quality***

To guard against anticipated threats to the quality of the research design, certain criteria were addressed. These were: maintaining the theoretical foundation of the study; fidelity to the proposed research design; maintaining the rigour of both the qualitative and quantitative components of the mixed-methods study; and, analytic and interpretive rigour. Criteria considered were drawn from O’Cathain and colleagues’ (2010) comprehensive framework on assessing mixed-methods research, as well as the work of Stake (2010) and Yin (2018) on qualitative research. O’Cathain’s (2010) framework consists of eight domains of quality, informed by the research of six major mixed-methods researchers (Caracelli & Riggin; 1994; Creswell & Plano Clark, 2007; Dellinger & Leech, 2007; O’Cathain, Murphy, & Nicholl, 2008; Onwuegbuzie & Johnson, 2006; Tashakkori & Teddlie; 2010). A discussion of each of the four quality criteria addressed in the study now follows.

**Theoretical Foundation.** Ensuring a quality design involves a review of the literature to provide the study with its theoretical foundation and background, and to guide the study’s research questions and methods (Dellinger & Leech, 2007; Stake, 2010). This review includes the concept of ‘rationale transparency’, which involves providing a sound justification for the use of mixed-methods (Caracelli & Riggin, 1994; Creswell, 2018). Also, ‘planning transparency’, which guarantees the researcher has detailed the paradigm used in the study, and research design, data collection, analysis and reporting strategies (Creswell, 2018). These items were addressed in the current study, as evidenced by the theoretical framework (see Chapter 1), literature review (see Chapter 2), and methodology chapter.

**Design Fidelity.** While a pragmatic approach to research required fluidity, the criterion ‘design fidelity’ ensured that the quantitative and qualitative methods chosen were employed in a manner that did not deviate from the research design (Creswell & Plano Clark, 2007; Caracelli & Riggin, 1994; Teddlie & Tashakkori, 2009). The sequence of the data collection stages and phases was carefully

observed to maintain the exploratory, sequential aspect of the mixed-methods design (Morse, 2010). Similarly, Yin's (2018) suggestion of using a case study protocol (the steps followed in the collection and analysis of data), and developing case study databases of each type of data collection instrument, helped in maintaining design fidelity and reliability.

**Maintaining Rigour.** An appraisal of the strengths and weaknesses of both quantitative and qualitative approaches was required to reduce the possibility of shared bias and to increase the breadth (quantitative) and depth (qualitative) of this study (Caracelli & Riggin, 1994; Onwuegbuzie & Johnson, 2006). Regardless of which methodology is dominant, the principles of each should be upheld (Morse, 2010).

In this study, the principles of the supplementary quantitative components were maintained despite being embedded within the main qualitative multiple-case design. 'Sampling adequacy' guaranteed that the sampling technique and sample size for each method used was adequate according to the context of the research design (Creswell & Plano Clark, 2007; Onwuegbuzie & Johnson, 2006).

In mixed-methods research, this sampling principle should also be followed. Importantly, the sample size used for the quantitative instrument should be different to the qualitative sample size (Morse, 2010). An exception to the rule is if the quantitative instrument being used has external norms. The researcher may therefore administer the quantitative instrument to the qualitative sample, referencing the normative data when interpreting the participant's scores (Morse, 2010). This was the case for the current study, where two quantitative self-report questionnaires were given to the small qualitative sample. Utilising the normative data available ensured breadth in the results of the quantitative instruments.

Rigour of the qualitative aspects of the study was maintained through the use of multiple sources of evidence. These included: interviews, observations, documentation, and self-report questionnaires (Yin, 2018). Other ways that helped to maintain the rigour of the study were having a key informant or gatekeeper – a person that allows access to the setting of the case, review panels,

and member checking (e.g. providing participants with a copy of interview transcripts to check for errors or misrepresentations) (Stake, 2010; Yin, 2018).

**Analytic and Interpretive Rigour.** Analytic rigour guaranteed that the data analysis strategies were suited to the research questions and were conducted accordingly (Teddlie & Tashakkori, 2009). More so, the study should have interpretive rigour, that is, inferences that are reflective of the findings, and the methods used to collect and analyse these findings, as well as on the theory and knowledge surrounding the research (Dellinger & Leech, 2007; O’Cathain et al., 2008; Onwuegbuzie & Johnson, 2006; Teddlie & Tashakkori, 2009). In both mixed-methods and qualitative case study research, the notion of converging sources of evidence through the process of triangulation is advantageous in validating research findings (Stake, 2010; Yin, 2018). In an exploratory, sequential design, each subsequent database can build upon the initial databases, thereby strengthening the final interpretations (Creswell, 2013). Morse (2010) asserted that in mixed-methods designs, there is no need to limit the number of supplemental components, since the design “can be as complex as the phenomenon demand[s]” (p. 350). In addition, a major strength of the multiple-case study design is the use of replication logic through having multiple case studies, amassing to a stronger analytical conclusion (Yin, 2018). Cross-case analysis can also strengthen the validity of the conclusions (Yin, 2018). The current study used the strengths of a sequential, multiple-case research design and incorporated triangulation and cross-case analysis of the cases to analyse and interpret the evidence (see Figure 3.3).

In sum, the study applied an exploratory, sequential strategy to a descriptive multiple-case study embedded design. Each individual case of the multiple-case design consisted of embedded units of analysis, with each unit of analysis being an important aspect in the child’s attachment relationships. The context included the variables surrounding the case. The quality of the research design was considered by testing it against design criteria. The following section will elaborate on the case

studies; their setting, participants, case study protocol, instruments, data collection procedures, and data analysis strategies.

### **Case Study 1**

As previously stated, CS1 was conducted as a pilot study in order to test the feasibility of using an exploratory, sequential multiple-case embedded design, to explore how an infant with hearing loss and complex needs traverses through the stages of attachment formation within their bioecological systems framework. Primarily, CS1 aimed to: test and trial the data collection and analysis methods; allow for familiarity with administering the instruments; test the adequacy and rigour of the instruments within this particular population; and, assess the proposed data analysis techniques through reliability and validity checks (Bryman, 2016; Creswell, 2013; Stake, 2010; van Teijlingen & Hundley, 2002; Yin, 2018).

Secondly, it was anticipated that analysis of the various databases within CS1 would inform the case study protocol and data collection and analysis methods to be applied to the subsequent case studies. This follows the study's multiple-case study procedure as detailed in a previous section (see Figure 3.3). Conducting a pilot study does not guarantee success of the major study answering the research questions; rather, it increases the likelihood (van Teijlingen & Hundley, 2002).

The following section elaborates on the sampling strategy, setting, participants, and data collection and analysis procedures of the case studies. Any changes to this case study protocol that occurred as a result of CS1 will be discussed in detail at the end of the following chapter (see 'Impact on Methodology', p. 207).



### ***Purposive Sampling***

Purposive or purposeful sampling is a sampling procedure that intentionally selects participants and sites that have experience in the key concept being investigated, and can maximise the possibility of gathering data that will help answer the research questions (Creswell, 2013; Creswell & Plano Clark, 2007; Miles & Huberman, 1994; Palys, 2008). In case studies, participants' feelings, attitudes and the reasons behind these are particularly important (Palys, 2008). The focus is therefore on the individual and the individual's position within a group (Palys, 2008). Moreover, not all participants have equal status in the research.

For this study, the importance of purposive sampling is that it enabled the researcher to access a small, specific group of people that fit the parameters of the study. Infants with HL-CN and their families are a focussed and small part of the overall population. The targeted participants fulfilled certain criteria, and were sourced from a specific early childhood intervention setting, with the participants including an infant with HL-CN, their primary caregiver, secondary caregiver, and their service provider from the early childhood intervention centre (ECIC).

### ***Setting***

The case studies took place within the context of an ECIC that provides services for families and their infants who have hearing loss and those who have HL-CN. Children accepted into the ECIC are between 6 weeks and 5 or 6 years of age. Though located in metropolitan Sydney, the ECIC has a broad catchment area, with some families travelling over 2 hours to attend therapy sessions. The ECIC has been in its current location since 2011, however was first established in 2001 at a previous location.

This ECIC was both family- and child-centred, that is, practice was centred on the goals and needs of the child and family, rather than on the goals of the service providers (Dunst, 2002; Dunst, Trivette, & Deal, 1994). The ECIC provided individual and group sessions, as well as home visits when agreed upon as necessary by the family and ECIC team (e.g., when the children and families

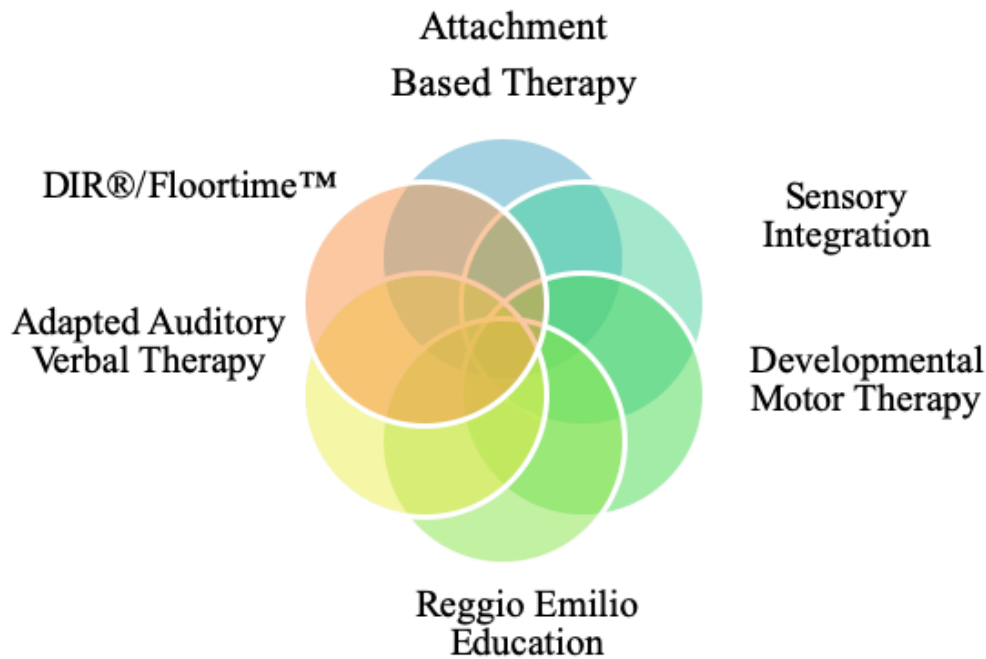
first begin). The ECIC had a naturalistic environment similar to a home setting – with couches or arm chairs in each therapy room, and a welcoming kitchenette and tearoom where the service providers encouraged the families to socialise.

The ECIC utilised an interdisciplinary approach wherein specialists from various disciplines assess the child and family, and then meet to discuss their assessment and together develop an intervention plan (Jessup, 2007). Members of the ECIC interdisciplinary team included: an occupational therapist (present 2 days a week), a physiotherapist (present 2 days a week), special educators, educators of the deaf, speech pathologists, audiologists, and a music therapist (present 1 day a week). External physiotherapists, occupational therapists for vision, social workers and psychologists also provided specialist support when needed.

In terms of the early intervention models and therapies used by the ECIC, the service providers have created and prescribed to a methodology, named, the *COMBINES Methodology* (see Figure 3.4). This methodology integrates a variety of philosophies and therapies, with the aim of providing personalised support for each individual child and family, and teaching parents the tools and knowledge to continue with the support and therapy of their child. The COMBINES Methodology has attachment theory at its foundation, acknowledging that a child must first learn to connect and have a relationship with another in order to want to listen, play, and learn (Landy, 2009). The COMBINES Methodology also incorporates elements of: Reggio Emilia Education that promotes child-centred practice (Malaguzzi & Cagliari, 2016); adapted auditory-verbal therapy (AVT) (Estabrooks, MacIver-Lux, & Rhoades, 2016; Ling, 2002) to teach the child how to listen; Sensory Integration Therapy and DIR®/Floortime™ (Ayres, 1970; Greenspan & Wieder, 1998; Wieder & Greenspan, 2003) that promotes ‘following the child’s lead’ during play and addresses sensory issues; occupational therapy, physiotherapy, and developmental motor therapy for fine and gross motor development (Gronski, 2013); and feeding therapy for those children who have feeding and anxiety issues (Addison et al., 2012).

Figure 3.4

*Philosophies, Models and Therapies of the COMBINES Methodology.*



A family is assigned one main service provider to conduct therapy sessions, for example, a speech and language pathologist. During sessions the interdisciplinary team may work together to provide the support that the child needs, by drawing on their various therapies and philosophies. At times the main service provider, a speech and language pathologist, for example, will conduct a session in collaboration with the occupational therapist, based on the family's goals, and the child's development.

Moreover, because of its family-centred approach, the ECIC focussed on parent education and encouraged the child's parent or caregiver to be present during all individual sessions. In this way, the service providers and parents worked together to meet the family's ECI goals. During therapy sessions, service providers discussed the aims of the session and worked with the parent to support the child. The service provider also modelled and coached the parent on early intervention strategies, and encouraged them to continue these strategies at home. The ECIC also provided information pamphlets, and guidance about procedures, audiological operations, such as cochlear implantation,

and other therapy services available outside of the centre. The ECIC did not provide formal respite, however, helped parents liaise with community workers and other agencies to obtain required respite. Child minding for siblings was available on certain days by volunteers and students, particularly during group therapy sessions to give the parents an opportunity to relax and chat with each other in the tearoom.

The ECIC also accepted funding, including *Better Start for Children with Disability* (Better Start) and *Helping Children with Autism* (HCWA), and during the case study data collection period, had begun the shift towards the *National Disability Insurance Scheme* (NDIS). The *Better Start for Children with Disability Initiative* commenced in 2011, and provided funding for early intervention services. Children eligible for Better Start were diagnosed with one of the following disabilities: Cerebral palsy, Deafblindness, Down syndrome, including mosaic Down syndrome, Fragile X syndrome with full mutation, Hearing impairment, Sight impairment, Prader-Willi syndrome, Williams syndrome, Angelman syndrome, Kabuki syndrome, Smith-Magenis syndrome, CHARGE syndrome, Cornelia de Lange syndrome, Rett's Disorder, Cri du Chat syndrome; or Microcephaly (Australian Government, Department of Social Services, 2020). Children registered with Better Start were able to access up to \$12,000 (maximum \$6,000 per year) to pay for early intervention services including: audiology, occupational therapy, orthoptics, physiotherapy, psychology and speech pathology. Children had to be registered before they turned six, and had access to funding until they turned seven.

The HCWA program began in 2008 for the early diagnosis and treatment of children with autism or any other pervasive developmental disorder (PDD) (Australian Government, Department of Health, 2020). Children diagnosed with autism or any other PDD by a paediatrician or psychiatrist were eligible to access HCWA funding, but only if they had not already accessed Better Start funding. Early intervention services that such children could access included: psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists or physiotherapists.

Rollout of the NDIS across Australia commenced in 2013, and under the *National Disability Insurance Agency* (NDIA) has stated that it “can provide all people with disability with information and connections to services in their communities such as doctors, sporting clubs, support groups, libraries and schools, as well as information about what support is provided by each state and territory government” (National Disability Insurance Agency, 2020). For children aged 0-6 years who have a developmental delay or disability, the NDIS created the *Early Childhood Intervention* approach to support such children and their families. Under this program, parents or carers are advised to contact an Early Childhood Partner if concerns about their child’s development have been identified. An Early Childhood Partner is a service provider providing early childhood intervention services to the family, for example, a physiotherapist, or speech and language pathologist. The Early Childhood Partner works with families to develop an NDIS plan and access NDIS funding. The NDIA proposed a five-year plan for the rollout of the NDIS, with Better Start and HCWA funding being replaced with the NDIS by the year 2020.

Overall, the ECIC at the centre of this study presented a warm and welcoming atmosphere with service providers focussed on the family and child’s needs, meeting them at their level. The various service providers of the interdisciplinary team worked together to look at the ‘whole child’, in order to best provide the services needed. As part of the child’s microsystem, the service providers influenced the child’s development and thus the development of their attachment relationships (Bronfenbrenner, 1977).

Having conducted a previous research study at the ECIC, the researcher gained access to a gatekeeper, a person supportive of the research and who gave permission for data collection (Creswell & Plano Clark, 2007). The impact of this previous study will be discussed in detail in a later section (see ‘Researcher as Instrument’, p. 90). The researcher approached the gatekeeper in person and presented a verbal proposal of the current research study. With the invaluable help and support of the gatekeeper, Louise, who was also the ECIC’s Coordinator, the researcher was able to gain access to the setting and its resources, and therefore conduct the research study at this centre. Participant

Information Sheets (see Appendices A and B) outlining the main objectives and research procedures of the study were submitted to Louise for review before the study commenced (Creswell, 2013).

For CS1, data collection took place at this ECIC, as well as the participants' home. The participants lived in an apartment that was situated 10 minutes from the ECIC. In the fourth phase of data collection, the participants had moved to a different apartment about 45 minutes from the ECIC.

### ***Participants***

Each case study consisted of four participants: the infant with HL-CN, his or her primary caregiver (mother), his or her secondary caregiver (father), and the family's main service provider at the ECIC.

**Infant.** Since the focus of this study is understanding the attachment process of infants with HL-CN, certain criteria needed to be met for an infant's participation in the study. In order to observe how infants with HL-CN form attachment relationships, child participants were chosen based on an observation of their attachment phase, rather than their age. In typically-developing children, attachment behaviours follow a pattern that can be seen across four sequential phases (Bowlby, 1969).

They are:

- Phase I: Orientation and Signals with Limited Discrimination of Figure  
(shortly after birth to first few months of life)
- Phase II: Orientation and Signals Directed towards One (or More) Discriminated Figure(s) (6 to 12 months of age)
- Phase III: Maintenance of Proximity to a Discriminated Figure by means of Locomotion as well as Signals (begins between 6 and 7 months through to 3 years of age)
- Phase IV: Formation of a Goal-corrected Partnership (3 years onwards)

The first two phases are of particular interest in the present study, as they are the phases before a clear-cut attachment to a primary caregiver has been established.

As such, a child may have been over 12 months old, but may have been within the first phase of attachment development, that is, orientation and signals with limited discrimination of figure (Bowlby, 1969).

Thus, the inclusion criteria for child participants consisted of: a mild to profound hearing loss, with a comorbidity of disabilities, illnesses or impairments, therefore requiring varied support services, and at an early attachment phase (phase 1 or 2) (Hewitt-Taylor, 2010; Landy, 2009; Landy & Menna, 2006; Rankin & Regan, 2004; Zaidman-Zait, Curle, Jamieson, Chia, & Kozak, 2015).

**Caregivers.** In attachment theory, the child's primary caregiver is the carer who has cared for the child most since birth. In most cases this will be the child's biological mother (Bowlby, 1969). Secondary caregivers may include the biological father of the child, as well as other close family members involved with the child, for example, grandparents or siblings.

**Service provider.** The general term 'service provider' was used to label all agency providers at the ECIC, as well as those accessed by the family elsewhere. Given the particular needs of the child, such providers included: occupational therapists, physiotherapists, special educators, speech and language pathologists, medical personnel, psychologists, social workers, audiologists, orthoptists, orientation and mobility instructors and technology teachers (Cumming & Wong, 2012; Guralnick & International Society on Early Intervention, 2000; Landy & Menna, 2006).

For the current study, the ECIC had an interdisciplinary team of the Coordinator Louise, who holds a Masters in Deaf/Blind Education; Sarah, a Speech and Language Pathologist; Gemma, a Speech and Language Pathologist and Audiologist; Jasmine a Special Educator; Joe an Occupational Therapist; Karina a Physiotherapist; Cynthia an Audiologist; and, Amanda, a Music Therapist. Also on that team was Jessie, the Administrator Officer, as well as a couple of regular volunteers. The members of this team varied in the degree of their experience and fields of expertise and knowledge, yet all collaborated and worked together to provide for the needs of the families and children. To

protect the privacy and confidentiality of the participants, all names used to report this study are pseudonyms.

**Case Study 1 Participants.** For CS1, the nominated family included an infant- Rosa, and her primary caregiver- Ali (mother), her secondary caregiver- Ben (father), as well as service provider- Sarah, who had been working with the family since Rosa was 3 months old. At the start of the study, Rosa was 11 months old, had a profound bilateral sensorineural hearing loss and had been diagnosed with CHARGE syndrome. Prior to commencing therapy at the ECIC, she had undergone two heart operations (one at birth, and one at 6 months). Rosa had been diagnosed with heart defects, antenatally - ventricular septal defect (VSD) and coarctation of the aorta. She was also tube-fed until 7 months old, had attended two feeding clinics, and had seen a number of feeding and ENT specialists (see Appendix C for a summary of the child's medical and health issues). At 9 months of age, Rosa had a successful cochlear implant surgery for her left ear, despite scans indicating that she had an abnormal auditory nerve. Rosa also wore a hearing aid on her right ear. Rosa's parents described Rosa as having a carefree and joyful personality, mild-tempered, though stubborn at times. They also described her love of music and songs, her favourite toys being musical instruments and ducks.

For the duration of CS1, the mother Ali was identified as Rosa's primary caregiver, and regularly attended her child's ECI therapy sessions. Rosa's father, Ben, was identified as her secondary caregiver, and attended one therapy session during the course of CS1. At the time of the study, Ali was completing her degree in Primary Education, and had previously worked as a Preschool Teacher. Ben was part of a small business that distributed plumbing components.

In CS1, the service provider working with the family was Sarah, a qualified Speech and Language Pathologist. At the time of the study, Sarah had been a speech pathologist for 28 years, had been working in hearing impairment for 16 years, and had been working with her current colleagues in this field of children with hearing loss and additional needs for 13 years.



### ***Case Study Protocol***

According to Yin (2018), the case study protocol guides the researcher in conducting the data collection, and thereby increasing the reliability of the case study. It may have the following sections:

1. Introduction to the case study and purpose of protocol
2. Data collection procedures
3. Outline of the case study report
4. Case study questions
5. Evaluation

Table 3.1 shows the original case study protocol for CS1.

### ***Researcher as Instrument***

The researcher is considered a main instrument in qualitative and mixed-methods research, where the researcher's interpretations, values, and beliefs are of significance to the study (Creswell, 2018; Johnson & Onwuegbuzie, 2004; Wheeldon & Åhlberg, 2012; Stake, 2010; Yin, 2018). As Maxwell (2013) highlighted, when discussing the role of the researcher, “*you* are the research instrument in a qualitative study, and your eyes and ears are the tools you use to gather information and to make sense of what is going on” (p. 88). In the same vein, the relationships that the researcher makes during the study process has a large impact on how the study progresses (Maxwell, 2013). The notion of ‘reflexivity’, that is, that the “researchers' backgrounds, interests, skills, and biases necessarily play unique roles in the framing of studies and in the collection, analysis, and interpretation of data” further supports this (Miller, 2008, p. 754). Indeed, Miller asserted that in some qualitative studies, “researchers are seen as visible, biased integral players in the process” (2008, p. 754).

Table 3.1

Case Study Protocol (Yin, 2018)

<p>1. <u>Introduction to the case study and purpose of protocol</u></p> <p><b>Objectives:</b></p> <ul style="list-style-type: none"> <li>• To gain an in-depth understanding of the formation of attachment relationships between an infant with hearing loss and complex needs and their caregivers</li> <li>• To test the validity and reliability of the case study data collection and analysis strategies</li> </ul> <p><b>Theoretical framework: (seminal works)</b></p> <ul style="list-style-type: none"> <li>• Attachment theory (Bowlby, 1969, 1973, 1980; Ainsworth, Bell, &amp; Stayton, 1974)</li> <li>• Belsky's determinants of parenting model (1984)</li> <li>• Bronfenbrenner's Bioecological systems model of human development (1977, 1979, 2001)</li> </ul>
<p>2. <u>Data collection procedures</u></p> <p><b>Data collection plan:</b></p> <ul style="list-style-type: none"> <li>• Gain ethics approval</li> <li>• Keep a logbook</li> <li>• Approach gatekeeper/key informant</li> <li>• Site observation</li> <li>• Identify potential participants</li> <li>• Live observation</li> <li>• Self-report questionnaire – <i>Parenting Stress Index</i></li> <li>• Interviews – mother, service provider</li> <li>• Self-report questionnaire – <i>Experiences in Close Relationships Scale</i></li> <li>• Videorecorded observations</li> <li>• Gather documentation</li> </ul> <p><b>Validity and reliability checks:</b></p> <ul style="list-style-type: none"> <li>• Member checking</li> <li>• Report findings to research supervisors and discuss</li> <li>• Discussions with key informant</li> <li>• External coding</li> <li>• Establish inter-rater agreement with interview and video data</li> </ul>
<p>3. <u>Outline of case study report</u></p> <ul style="list-style-type: none"> <li>• Description of live observation</li> <li>• Line graph to display <i>Parenting Stress Index</i> results</li> <li>• Table of key constructs from interviews</li> <li>• Quadrant graph to display <i>Experiences in Close Relationships Scale</i> results</li> <li>• Column graphs to display videorecorded observations after video analysis</li> <li>• Table summary of key information derived from documents</li> <li>• Description of the whole-case analysis and any conclusion</li> </ul>

Table 3.1 [cont.]

*Case Study Protocol (Yin, 2018)*

<p>4. <u>Case study questions</u></p> <ul style="list-style-type: none"> <li>• What do we understand about the process of attachment in relation to infants with hearing loss and complex needs (HL-CN)?</li> <li>• What are the key earlier stages in the development of attachment?</li> <li>• How do caregivers develop attachment with a young child with HL-CN?</li> <li>• Can service providers facilitate attachment relationships between young children with HL-CN, and their primary caregivers?</li> <li>• If so, what does this look like in practice?</li> </ul>
<p>5. <u>Evaluation</u></p> <ul style="list-style-type: none"> <li>• Were there any problems/limitations in conducting the case study?</li> <li>• Were there any instruments that did not work well?</li> <li>• Were there any changes to the data collection procedures?</li> <li>• Are there improvements that could be made to the protocol?</li> <li>• What needs to be changed in the case study protocol for subsequent cases?</li> <li>• Were the research questions answered?</li> <li>• What conclusions can be made?</li> </ul>

In this light, it must be noted that prior to conducting the present study, the researcher was familiar with the setting, having completed a previous study there, and had worked as a volunteer at the ECIC for 4 years. These dynamics resulted in both advantages and drawbacks to data collection. The researcher was aware that this familiarity with the setting and to those within, had the potential to impact on the data collection and analysis procedures. Thus, the researcher undertook several measures to maintain the integrity of the data collection and analysis. Such measures included member checking, regular reporting of findings to the research supervisors, discussions with the key informant Louise, the use of an external coder blind to the specific objectives of the study, as well as ensuring inter-rater agreement during coding (Stake, 2010; Yin, 2018). Here inter-rater agreement “requires that the raters make exactly the same decisions about the same phenomenon” (Multon & Coleman, 2018, p. 863). These measures will be discussed in more detail in later sections of the thesis.

Due to the time already spent at the ECIC, the researcher had developed a professional and congenial relationship with the service providers, having gained their trust and confidence. Therefore, the ECIC team were supportive of the research study, were willing to participate in it, and were able

to see the value of the research in terms of their own professional development, the ECIC's development, and also saw the research as beneficial to the families and children they worked with. In particular, Louise, the ECIC's Coordinator, supported the researcher by providing her expertise and other resources, acting as both gatekeeper and informant (Stake, 2010; Yin, 2018).

The sense of trust that the researcher shared with the service providers allowed her to become a part of the ECIC environment (Bronfenbrenner, 1977), wherein she was able to view this setting both from the inside and from the outside. The service providers trusted the researcher, they were open with the data collection process, and seemed to transfer that sense of trust to the families they were working with. In other words, because Louise and her team trusted the researcher, the parent participant in this case study appeared trusting of the researcher and were cooperative during data collection.

One drawback to the researcher's familiarity with the service was the providers' vested interest in the success of the research study, which, by further propagating confidence in its success and in the researcher, at times functioned as a double-edged sword. While the researcher held that rapport, trust and confidence from the team, and many of the families that attended the ECIC, the researcher at times worked purposefully to maintain an objective lens. The researcher was an advocate of this ECIC and its work and philosophies, which posed a threat to her judgment as an investigator. However, as mentioned, regular reporting to her research supervisors, as well as discussions with the key informant tempered any bias to maintain the transparency of the data collected. Moreover, in qualitative research, this drawback can become a strength, since the researcher can utilise this experiential understanding of context and situation in making interpretations (Maxwell, 2013; Stake, 2010).

It can be argued that being inside the environment of the case study allowed the researcher to better understand the complexities of this specific bioecological microsystem (Bronfenbrenner, 2001), gain empathy (Stake, 2010) and therefore be able to provide a clearer and more in-depth understanding of the case study. In a sense, the researcher took part in 'action research', wherein

participants of a setting take on the role of co-researchers to enact changes in the practice of a setting (Somekh, 2008). In particular, the researcher worked with the key informant Louise, to investigate how attachment was being practised in the ECIC. This is a key part of action research where “through adopting the role of researchers, practitioners are able to reflect on and make explicit the tacit knowledge that guides their practice” (Somekh, 2008, p. 6). In sum, the researcher was cognisant of her impact as a researcher within a familiar setting, and took specific measures to counteract any possible partiality whilst conducting the current study.

### ***Instruments***

In total, there were eight different instruments used across the four phases of the case study. The following discussion will present the four phases and the instruments used in each, with a rationale for each instrument chosen. In each phase, not all data were analysed immediately after it was collected. Some of the data analysis occurred after all the data had been collected for a particular phase, and for other data, analysis occurred at the end of data collection for the entire case study. The quantitative and qualitative data collection instruments and analysis methods used in each phase are displayed with their corresponding research questions in Table 3.2.

Table 3.2

*Relationship Between the Case Study, Data Collection Instruments and the Research Questions.*

	<b>Logbook QUAL</b>	<b>First meeting and observation QUAL</b>	<b>PSI quan</b>	<b>Interviews (3) QUAL</b>	<b>ECR quan</b>	<b>Initial video- recorded observations (2) QUAL</b>	<b>Main video- recorded observations (4) QUAL</b>	<b>Follow up Interviews (2) QUAL</b>	<b>Interview QUAL</b>	<b>Documents (ECIC, medical, audiological) QUAL</b>
<b>RQ 1a)</b>	<b>X</b>			<b>X</b>		<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	
<b>RQ 1b)</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
<b>RQ2</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>

*Note: Uppercase letters denote emphasis or priority of weight (QUAL, QUAN) while lowercase letters indicate less emphasis or priority (quan, qual) (Creswell & Plano Clark, 2007, pp. 64-65).*

An important part of qualitative research is keeping records (Stake, 2010), therefore the researcher kept a hand-written logbook of field notes throughout the study. This logbook included notes on data collection and analysis procedures, the research design, case study protocol, informal conversations with participants, observations, the researcher's memos of therapy sessions, and personal thoughts, concerns and ideas (Stake, 2010). These data were analysed and used to corroborate findings from the other sources of evidence.

### ***Phase 1***

The purpose of this phase was to gain background information of the participants, using both quantitative and qualitative methods. To that end, Phase 1 utilised four instruments: initial meeting and observation of the participants; the *Parenting Stress Index Fourth Edition* (PSI); interviews with the mother and service provider, and, the *Experiences in Close Relationships-Revised Scale* (ECR).

**1a First Meeting and Live Observation.** Before collecting data, it was vital that the researcher established a level of rapport with the participants to increase their comfort and the ease of the data collection procedures. This was achieved by meeting the mother and child during their ECI therapy session with the service provider. The service provider, who had spoken to the mother about the research study, introduced the researcher to the mother. Following approval to participate in the study from the mother, the researcher sat in during the therapy session to observe how the session was conducted. Therapy sessions were approximately 1 hour in duration.

**1b Parenting Stress Index Fourth Edition (PSI).** As discussed in the literature review, in early attachment relationships the primary caregiver's levels of sensitivity and attunement to their child are major predictors of attachment security. High amounts of stress and emotional distress may hinder sensitivity and attunement; therefore, it was anticipated that ascertaining the parental stress levels of each caregiver in the study would give an indication of the extent and variation to which this

factor may have impacted on the developing attachment. The *Parenting Stress Index Fourth Edition* (PSI) was used; a self-report questionnaire with 101 items plus a Life Stress scale “designed to evaluate the magnitude of stress in the parent-child system” (Abidin, 2012, p. 2).

The PSI is divided into two domains, Child and Parent, combining to form the Total Stress scale, from which participants rate each of the 101 items using a 5-point Likert scale. In the Child domain, six subscales evaluate sources of stress, obtained from the parent’s own report of their child’s characteristics. These subscales include: Distractibility/Hyperactivity (DI); Adaptability (AD); Reinforces Parent (RE); Demandingness (DE); Mood (MO); and, Acceptability (AC). There are seven subscales in the Parent domain, including: Competence (CO); Isolation (IS); Attachment (AT); Health (HE); Role Restriction (RO); Depression (DP), and, Spouse/Parenting Partner Relationship (SP). These subscales evaluate sources of stress that are related to the parent’s characteristics. Finally, the Life Stress scale comprised 19 items that cover “family contextual issues such as parental separation, loss of income, and problems at work” (Abidin, 2012, p. 2).

The main goal of revising the PSI from the third edition (published in 1995) was “to address weak items and out-dated language without disrupting the empirically validated and clinically relevant structure of the PSI” (Abidin, 2012, pp. 3-4). Since the publication of the third edition of the PSI, the research base surrounding the psychometric measure has increased dramatically, further solidifying its validity. This has also resulted in a broader, worldwide use of the PSI, and subsequently, empirical findings from a number of fields such as: attachment (Rholes et al., 2006), anxiety and parenting (Murphy, Marelich, Armistead, Herbeck, & Payne, 2010), at-risk children (Nelson, Stage, Duppong-Hurley, Synhorst, & Epstein, 2007; Newman, Stevenson, Bergman, & Boyce, 2007), and parental depression (Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2009; Silver, Henegham, Bauman, & Stein, 2006). The PSI has withstood translations into many different languages for use across different cultures, whilst maintaining its factor structure, validity, and reliability (Johnson, 2015). Based on a review of the studies that have used the PSI, Abidin (2012) has drawn two significant conclusions: “first, that parenting stress is a universal construct; and



second, that as a universal construct, parenting stress is a measure that is useful across diverse populations” (p. 50). In terms of reliability, the third edition of the PSI reliability coefficients for the two domains and the Total Stress Scale were .96 or greater, indicating a high degree of internal consistency (Abidin, 2012, p. 49). Furthermore, on most scales, the PSI’s fourth edition demonstrated improved internal consistency (Abidin, 2012). Considering these factors, the researcher judged the PSI to be a solid psychometric instrument, and it has provided a useful quantitative database to supplement the case studies’ main qualitative databases. Specifically, results from the PSI were used to guide the questions used in the qualitative interviews.

**1c Interviews.** As the current study was focussed on understanding attachment and attachment relationships, interviewing was used to learn about the experiences and perspectives of the key people involved with the child with HL-CN. The use of face-to-face, semi-structured interviews conducted in a conversational way provided insight into the understanding of attachment of those key stakeholders (Maxwell, 2013; Seidman, 2006; Stake, 2010; Yin, 2018).

The interview questions were guided by key topics (Appendix D) informed by the literature and the results from the PSI. These topics divided the interview schedule into two parts, the first part focussed on the primary caregiver’s sociocultural context and demographical information, such as the primary caregiver’s age, occupation, educational background, socioeconomic background, including where she grew up and where she currently resides. The second part of the interview focussed on the primary caregiver’s experience of parenting a child with HL-CN. In this section, the researcher hoped to address factors including the caregiver’s understanding of attachment, early intervention, experience of social support, as well as the caregiver’s appraisal of their child’s temperament and other developmental attributes. It was anticipated that personal interviews would help establish rapport with the participants, thus the researcher was able to explore variables and ideas in greater depth (Yin, 2018). Following the ‘flow’ of the conversation, and actively listening to the

interviewee 'tell their story' allowed the researcher to ask spontaneous questions to derive better and richer responses (Seidman, 2006; Stake, 2010; Yin, 2018).

The interview topics with the service provider focussed on their experiences working in the field of ECI, both generally and specifically to the ECIC. Questions of the service provider's understanding of attachment theory and attachment relationships were also addressed, both in general and specific to the family they were working with.

Interviews with participants were conducted either on site at the ECIC, or at the participating family's home. The researcher proposed to conduct one interview with the service provider, and one interview with the mother. Durations of interviews varied between 30 minutes to 1 hour. Interviews were audio-recorded using an iPhone 6, since audiotapes provide a precise rendition of an interview and the interviewer need not rely on his or her own recollection, though Yin (2018) cautions that using a recording device is not a substitute for listening closely during an interview.

**1d The Experiences in Close Relationships-Revised Scale (ECR).** Drawing from attachment theory, Rholes and colleagues proposed that a person's adult romantic attachment style has a bearing on the quality of caregiving that that person is able to provide to his or her own child (Rholes et al., 2006). Moreover, a recent review of studies on self-reported adult attachment styles and parenting has found compelling evidence for the link between the two (Jones, Cassidy, & Shaver, 2015). Other empirical studies (e.g., Cohen, Zerach, & Solomon, 2011; Millings, Walsh, Hepper, & O'Brien, 2013; Zayas et al., 2011) also found that the quality of caregiving that a person experiences as a young child, is linked to a person's romantic/peer adult attachment styles, thereby supporting the "intergenerational transmission" hypothesis (Rholes & Simpson, 2004).

Fraley, Waller and Brennan's (2000) self-report questionnaire was used in this study to assess the quality of the primary caregiver's relationship with his or her significant romantic partner. The instrument's psychometric properties have been assessed, found valid and reliable according to the key propositions of attachment theory (Sibley & Liu, 2004; Sibley, Fischer, & Liu, 2005). The ECR

was devised to obtain a person's romantic attachment style, based on the continuous attachment dimensions of 'anxiety' and 'avoidance', theorised to be the two crucial underlying constructs of a person's adult attachment style (Fraley et al., 2000). Therefore, it was surmised that by administering such an instrument with the primary caregiver, the researcher would gain some indication of the quality of the mother's relationship with her husband, and therefore an indication of her adult attachment style. Consequently, based on the aforementioned theoretical and empirical evidence, this would give some indication of the mother's caregiving style towards her child, thus providing further evidence of the mother and child's developing attachment relationship.

## ***Phase 2***

Phase 2 consisted of videotaping a therapy session to observe how a typical therapy session was conducted. Data collected from this phase would build on the data collected from Phase 1, as well as inform data collection in Phase 3.

**Videotaped Observations (Initial).** Videotaped observations provide an opportunity to review the data collected, whereas in a live observation, the researcher relies on his or her memory (Morse & Pooler, 2002). Videotaped data can be "played and replayed; sped up, slowed or paused; discussed, analysed, and reanalysed, thus providing insights that otherwise would be unobtainable" (Morse & Pooler, 2002, p. 63). For this initial videotaped observation, the researcher sought to capture the participants' behaviours during a typical therapy session. The researcher endeavoured to be a 'fly on the wall' and asked the participants to conduct a therapy session as they regularly would. Two to three cameras were used to record different angles: an iPhone 6, a Canon SLR and a Samsung SLR. Sessions were approximately 1 hour in length. Two video recordings were taken as part of Phase 2.

These initial videotaped observations were used to test the feasibility of both the researcher's original quantitative video-coding scheme and the qualitative descriptions, during the analysis stage. To ensure the reliability of the video analysis, the researcher undertook a collaborative process with

the key informant, Louise (Miles & Huberman, 1994). This process involved viewing the Phase 2 videotaped observations, and conducting discussions where key constructs and codes were identified. The researcher and key informant viewed the videos a number of times until all significant constructs and codes were identified and their descriptions or definitions agreed upon. As a result of this process, inter-rater agreement in both the qualitative and quantitative analysis methods was reached (Multon & Coleman, 2018).

Having completed the qualitative and quantitative analysis of the two video recordings, the researcher presented the findings to the informant and together they re-evaluated the qualitative analysis method and revised the quantitative video-coding scheme. Through this evaluation, the construct validity of the researcher's original video-coding scheme was ensured (Yin, 2018). In other words, the researcher was able to identify "the correct operational measures for the concepts being studied" (Yin, 2009, p. 40).

### ***Phase 3***

This phase consisted of videotaping therapy sessions. The Phase 3 videos differed from the Phase 2 videos in that they were analysed after the feasibility of analysis strategy of the initial videotaped observations in Phase 2 was confirmed. Data collection was planned for several weeks in order to track trends across the videotaped sessions. Data from this phase were also matched with the results from the previous phases and subsequent phases.

**Videotaped Observations (Main).** Videotaped observations of sessions enabled the researcher to make observations of interactional behaviour and thus provided a more in-depth picture of how attachment was both understood and enacted in practice by the participants. The videotaped sessions were recorded over a period of time in an attempt to reveal and track caregiver sensitivity, and therefore attachment development over time, similar to other longitudinal studies on mother-child interaction (e.g., NICHD Early Child Care Research Network, 2006; Biringen, Matheny, Bretherton,

Renouf, & Sherman, 2000; Dallaire & Weinraub, 2005). The researcher was present during the therapy sessions to adjust cameras when required. The first videotaped session focussed on the play interaction, and attunement and sensitivity between mother and child only, and was analysed using a quantitative video analysis method, the *Child and Adult Relationship Experimental Index* (CARE-Index) (Crittenden, 2008). According to the CARE-Index Manual, protocols for videotaping involve: taping the mother-infant play for 3 to 5 minutes, at the participants' home, in a laboratory or in a clinical setting (Crittenden, 2010). A small box of toys suitable for a wide range of development should be placed on the floor. The adult is to be asked to "play with your baby as you usually would. You can use the toys, or not, as you choose. Sit so you are comfortable and don't worry about the camera" (Crittenden, 2010, p. 59).

An external, independent CARE-Index coder was chosen to code this first videotaped session. The coder was an expert in using the CARE-Index, having reached forensic level reliability. The coder was also a CARE-Index trainer, and was the researcher's trainer during a CARE-Index training program. The coder has used the CARE-Index to assess relational risk in infants for several years, working as a consultant, and has presented at conferences in America, Europe, and Australia.

Subsequent sessions focussed on the ECIC therapy session, techniques used, and interactions between mother, child and service provider. These video recorded sessions were analysed qualitatively and quantitatively by the researcher for key constructs and any trends that emerged over the period of data collection. This resulted in a qualitative description of each videotaped therapy session, and quantitative graphs of each of the significant constructs found. Video sessions were approximately 50 to 60 minutes in duration.

The meta-analysis of Bakermans-Kranenburg and colleagues (2003) on interventions measuring improvement in caregiver sensitivity, suggested that the most effective interventions employed a modest number of sessions (i.e., less than 16 sessions, with sessions focussing specifically on sensitivity). Taking this into account, the researcher surmised that videotaping a total of four to five sessions over time would likely reveal changes in caregiver sensitivity. The number of sessions

and duration was also based on the researcher's previous study, where a total of seven sessions were videotaped over a 5-month period, from the commencement of the family attending early intervention (Bernardo, 2011). This study aligned with the meta-analytic results indicating that a moderate number of sessions are linked with the effectiveness of interventions focussed on caregiver sensitivity (Bakermans-Kranenburg et al., 2003).

Video recording of mother-child interaction is a prominent methodological aspect of attachment theory. A number of studies have made use of videotaped observations to explore aspects of attachment relationships and patterns (e.g. NICHD Early Child Care Research Network, 2006; Biringen et al., 2000; Campbell & Sawyer, 2009; Dallaire & Weinraub, 2005; Fiamenghi et al., 2010; Meadow-Orlans et al., 1995; Meadow-Orlans & Steinberg, 1993; Seskin, Feliciano, Tippy, Yedloutschnig, Sossin, & Yasik, 2010). As previously mentioned, the synchronous, asymmetrical interaction patterns between caregiver and child may be so discrete as not to warrant notice (see Chapter 2 Literature Review). The current study proposed that microanalysis of videotaped mother-child interaction was a justifiable instrument of measure, particularly when observing the hypothesised atypical attachment behaviours of young children with HL-CN and their caregivers (Beebe, 2003; Fiamenghi et al., 2010; Howe, 2006; Warren & Brady, 2007). The chosen procedure was influenced by the studies of Fiamenghi et al. (2010) and Meadow-Orlans et al. (1995), where videotaped observations of mother-child interactions were collected, and used to support other data, such as interviews and surveys. This aligns with Yin's (2018) principle of triangulating evidence from multiple sources of data.

#### ***Phase 4***

The fourth and final phase consisted of follow-up interviews with the service provider and mother, initial interviews with secondary carers, and collection and analysis of documentation, including the researcher's logbook. Data were used to supplement data collected in the previous

phases, as well as record any changes to the child's developing attachment relationships, as perceived by the service providers and primary caregivers.

**Follow-up Interviews.** Follow-up interviews with the service provider and mother were planned to take place following the completion of Phase 3 videotaped observational data. Interview topics focussed on clarifying information from the first round of interviews, key constructs that emerged during Phase 3 data collection, and feedback for the researcher in terms of how the case study was conducted. All but one of the follow-up interviews were conducted at the ECIC, with the interview with the CS1 mother, held at her home. These interviews ranged from approximately 30 minutes to 1 hour in duration. Interviews were audio recorded using an iPhone 6.

**Interview with Secondary Caregiver.** Upon consideration of the significance of the secondary caregiver, an interview with the child's secondary caregiver was also conducted. Research points towards the importance of the child's attachment relationships with their secondary caregivers, most often the child's father (Fearon & Belsky, 2016; Belsky & Jaffee, 2006). Information obtained from these interviews with the father supplemented data collected from interviews with the mother, service provider and the videotaped observations, and strengthened any conclusions made. The topics used in the Phase 1 interviews were also used for interviews with the father. In each case study, interview duration ranged from 30 minutes to 1 hour. The interview with CS1 father was conducted through Skype. Interviews were audio recorded using an iPhone 6.

**Documentation.** In case studies, gathering and analysing documents are considered very beneficial to the overall research design and resulting findings (Yin, 2018). In all case studies, certain documents provided additional data that helped to 'fill in the gaps' of the whole picture. Such data came from the child's medical documents, which the ECIC had access to and kept records of, the child's audiogram and audiological information, the ECIC's child evaluation reports, and the ECIC's

own internal and external documents regarding their early intervention philosophy and methodology, accessed either directly from the Coordinator, through professional development workshops or online through the ECIC's webpage. The information gathered from these various documents were corroborated with the data from the previous phases, and often supported the information obtained from interviews and the videotaped therapy sessions.

### ***Ethics***

Key to ethical research is the informed consent of the participants, upholding the ethical view that all individuals have a right to autonomy (Coady, 2010). In early childhood research, children cannot legally give informed consent, thus a parent or guardian must give consent on their behalf (Cody, 2010). Other ethical principles focus on how researchers ought to treat participants during their study, so as to minimise the risk of harm, and maintain participants' privacy, confidentiality, and anonymity (Coady, 2010; Hammersley & Traianou, 2012; Yin, 2018). Specific procedures and protocols are put into place to uphold these principles; however, the researcher should also build ethical relationships as they conduct their research (Coady, 2010; Hammersley & Traianou, 2012).

The present study undertook the ethics approval process of the University of Sydney Human Research Ethics Committee (HREC). The research protocols, designs, Participant information statements and participant consent forms for parents/carers and service provider were all reviewed by the HREC. The *Understanding Attachment: Young Children with Additional Needs Interview Schedule* (see Appendix D) and the proposed video coding scheme (see Appendix E) were also reviewed by HREC. Following approval from HREC (see Appendix F), and report of this approval to the ECIC, data collection began.

All case study participants were given participant information sheets prior to data collection, which explained the ethical responsibilities toward participants (for *Participant Information Sheet – Service Provider* see Appendix A, and for *Participant Information Sheet – Parent/Caregiver* see Appendix B). These participant information sheets detailed that the study was voluntary; required



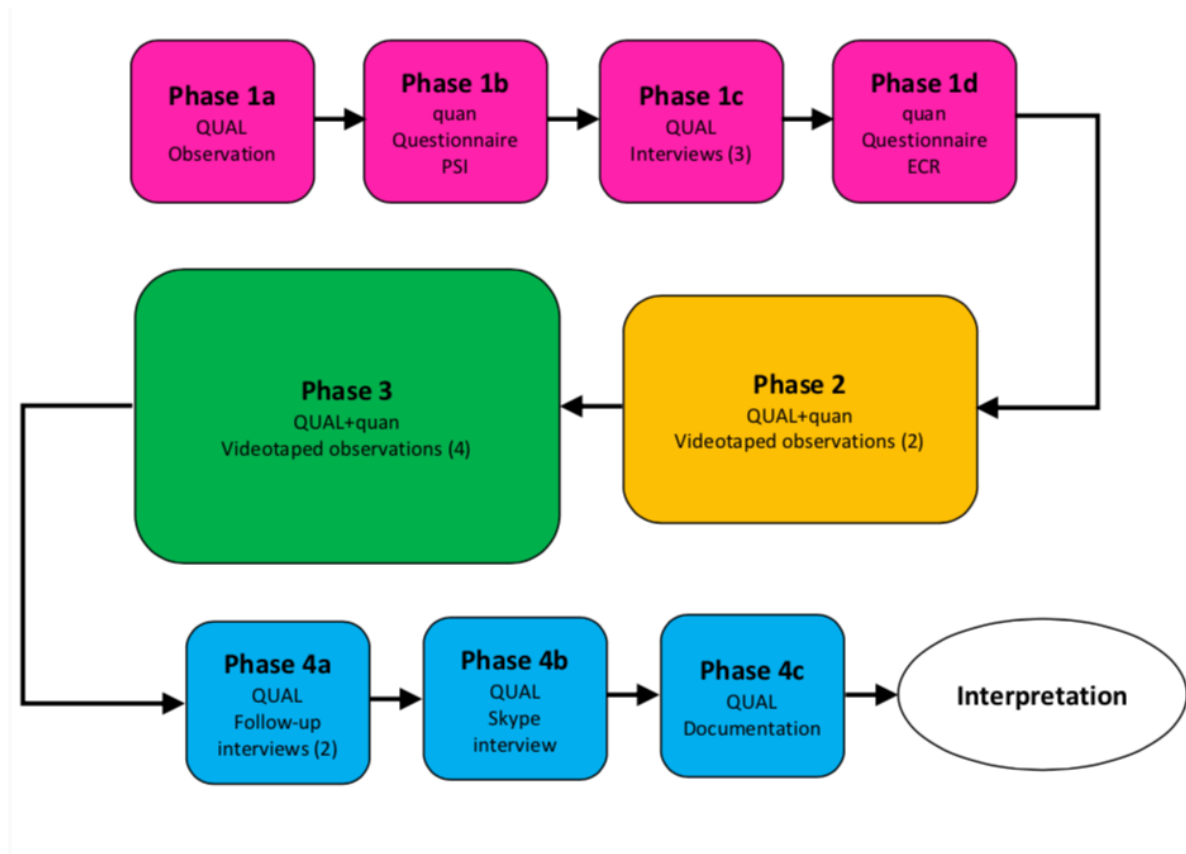
informed consent; would pose no risk of harm to themselves or to their child; was confidential; anonymous; private; and, that they had the right to withdraw from the study at any time without any penalty. All participants also received a verbal explanation of the research study. Signed consent forms were obtained from all participants, with parents (the primary caregiver) also giving consent for their children (see Appendix G). Consent was asked for: audio-recording (interviews), video-recording, photographs, collecting and reviewing documentation, reviewing interview transcripts, and completing two psychometric questionnaires (see Appendix H). Signed consent forms from the secondary caregivers were obtained before the researcher conducted their interview (see Appendix I).

### ***Pilot Study (Case Study 1) Procedure***

The procedure for data collection was divided into four phases, as indicated by the differentiation of colours in Figure 3.5. Data collection for each phase was intended to be fluid, working around the schedule of the family and service provider. Data collection was predicted for a period of 20 weeks.

Figure 3.5

*Procedural Phases of Data Collection and Analysis in Case Study 1 (Pilot Study).*



**Phase 1a Live Observation.** The researcher met and observed the participants during the infant’s therapy session at the family’s home. No cameras were used as this was a live observation.

**Phase 1b Parenting Stress Index Fourth Edition (PSI).** The PSI was administered to the primary caregiver of the pilot case study after the live observation. The researcher explained what the PSI was and that it would take approximately 20 minutes to complete. The researcher was available for any questions that the primary caregiver had while completing the PSI.

**Phase 1c Interviews.** Interviews with the primary caregiver were conducted at the caregiver’s home at a time convenient for the caregiver. The interview with the service provider was conducted during work hours at the ECIC, during the service provider’s free time. All interviews were

audiotaped using an iPhone 6 and transcribed verbatim. A copy of the transcripts was given to the participants for member checking.

**Phase 1d Experiences in Close Relationships-Revised Scale (ECR).** For the pilot case study, the ECR was administered to the primary caregiver after her initial interview. The researcher gave the questionnaire to the primary caregiver to take home and complete in her own time, with the instruction to return it to the researcher at the next scheduled meeting for data collection.

**Phase 2 Videotaped Observations (Initial).** This first phase of videotaped observations was conducted to test the feasibility and reliability of the data collection and analysis techniques, in particular, the researcher's own video coding scheme. Videotaped observations were conducted in the participants' home during their therapy sessions on a Friday morning. Two cameras were used: the iPhone 6 and a Canon SLR. The researcher held the iPhone 6 and used it to capture a close-up or medium shot of the participants. The Canon camera was on a tripod and positioned in the back right-hand corner of the room, and captured a wide-angle shot of the participants and their environment. The participants included Rosa, her mother Ali, and the service provider Sarah. Two videos were taken of two sessions, with each session lasting approximately 1 hour. One week separated the second video from the first video.

**Phase 3 Videotaped Observations (Main).** Videos were taken during the weekly scheduled therapy session of the infant at the ECIC. Four videos were taken over 4 months, with approximately 1 month separating each video. Three cameras were used: the iPhone 6, a Canon SLR, and a Samsung SLR. The iPhone 6 was stationary on a GripTight GorillaPod Stand, and connected to a microphone system with a lapel microphone worn by either the service provider or mother. The iPhone was placed in the middle of the room on the couch, facing the participants to capture a wide-angle shot. Both the Canon camera and Samsung camera were on tripods. All three cameras were used to video the 10-

minute play interaction, and remained stationary. The first video taken was a 10-minute play interaction between the mother and the infant, which took place before the therapy session. Only the mother and her infant were present during this video. All subsequent videos recorded the therapy session in its entirety lasting approximately 50 minutes. The service provider, mother and infant were present during recording. The researcher was also present to adjust the cameras.

**Phase 4a Follow-up Interviews.** A follow-up interview with the primary caregiver, the infant's mother, was conducted at their home, during a time convenient to them. The follow-up interview with the service provider was conducted at the ECIC, during the service provider's break time. Interviews lasted from 30 minutes to 1 hour. As with the interviews in Phase 1, both interviews were audiotaped using an iPhone 6 and transcribed verbatim.

**Phase 4b Interview with Secondary Caregiver.** An interview with the secondary caregiver, the infant's father, was conducted via Skype at a time convenient for him. The interview was audiotaped, then transcribed verbatim by the researcher for analysis.

**Phase 4c Documentation.** Documents from the ECIC were obtained. The infant's medical and audiological records were also obtained and examined, ready for analysis.

### ***Summary***

This chapter has presented the study's research design, provided a rationale for a mixed-methods approach and multiple-case study embedded design, detailed the data collection and analysis methods, discussed ethics approval, and introduced the pilot case study's procedure. The following chapter will present the results of CS1. It will also highlight the implications for subsequent case studies following the analysis of the results, as well as any changes made to the case study protocol and research design in light of the pilot case study.

## Chapter 4 Case Study 1 (Pilot Study)

As stated previously in Chapter 3, the aim of Case Study 1 (CS1) was to assess the feasibility of using an exploratory, sequential multiple-case embedded design, as a means of exploring the developing attachment relationships of an infant with hearing loss and complex needs (HL-CN). Firstly, CS1 intended to test the data collection instruments and analysis methods; test the adequacy and rigour of the instruments within this population; and, assess the proposed data analysis techniques through reliability and validity checks (Bryman, 2016; Creswell, 2013, 2018; Stake, 2010; van Teijlingen & Hundley, 2002; Yin, 2018). Secondly, it was expected that the analysis of data from CS1, would inform any changes to the case study protocol of the case studies that followed.

This chapter will address the aims stated above by detailing the data collection and analysis procedures and presenting any limitations encountered. It will then provide a discussion of the impact of this analysis and the results for the subsequent case studies.

### Data Collection and Analysis Procedure

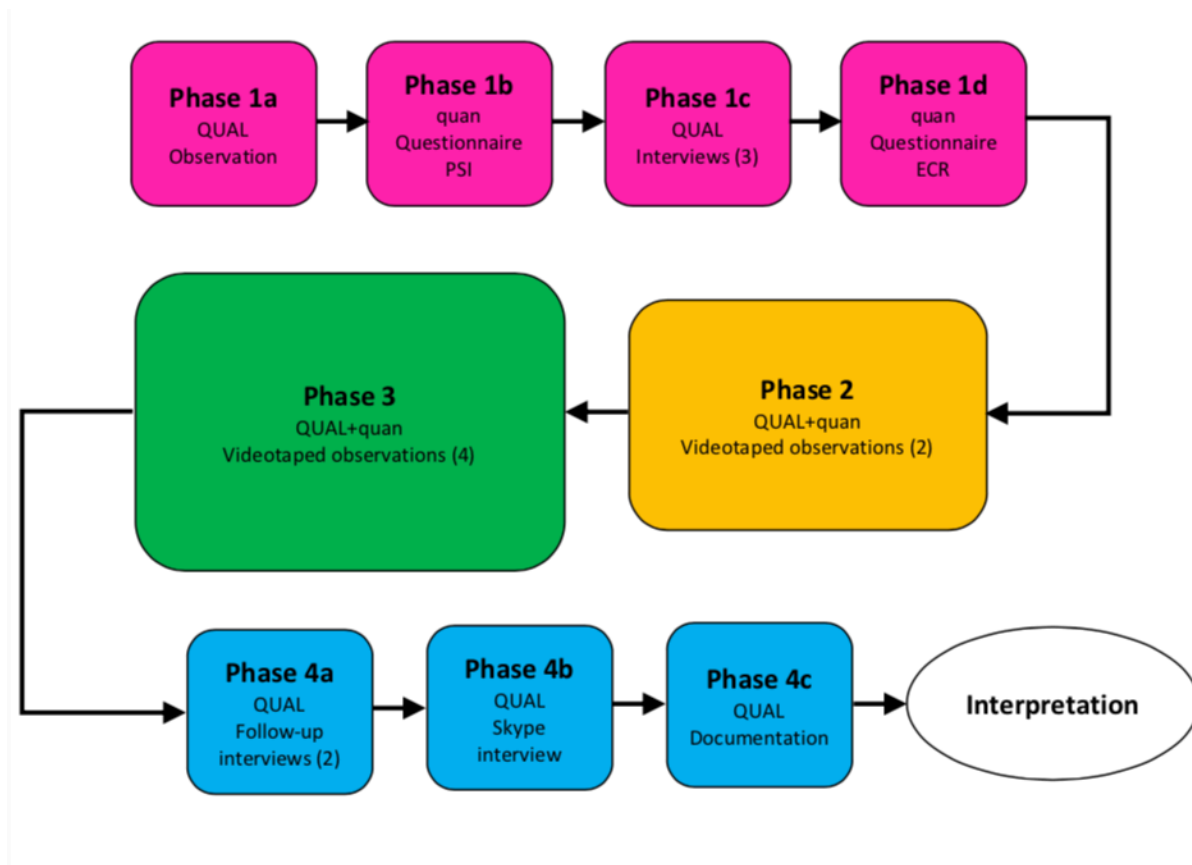
As outlined in Chapter 3, the data collection and analysis methods used in CS1 were divided into four phases (see Figure 4.1). The projected period for data collection was 20 weeks. However, due to a number of unanticipated factors that included a 9-week break due to summer holidays; a second interview with the mother (Ali) in Phase 1; and scheduling the video-recording sessions and interviews around the family's schedule (family holidays, doctors' appointments, sick days, father's (Ben) work hours), data collection took place over 28 weeks.

The next section explains how data collection and analysis occurred in each of the four phases, following the mixed-methods exploratory, sequential research design, described in the previous chapter. Data from each instrument used in each of the four phases were organised and reported under five headings: collection, analysis, results, and, if any, limitations and implications. How said

limitations were addressed, and a discussion of the implications for subsequent phases and case studies will conclude this chapter.

Figure 4.1

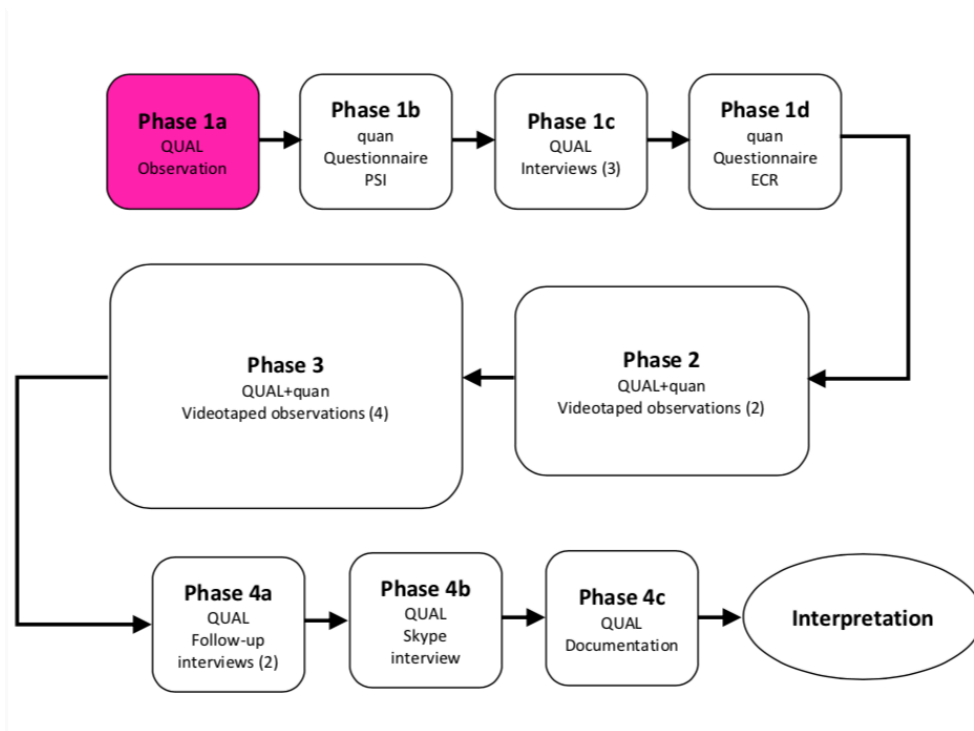
*Phases of Case Study 1 Data Collection and Analysis.*



### ***Phase 1***

Phase 1 obtained background information of the participants using a variety of qualitative and quantitative instruments which included: a live observation of the participants during an early childhood intervention (ECI) therapy session, the *Parenting Stress Index, Fourth Edition* (PSI) (Abidin, 2012), interviews with the service provider and mother, and the *Experiences in Close Relationships Revised-Scale* (ECR) (Fraley, Waller & Brennan, 2000).

### 1a – Live Observation.



**Collection.** A live observation of the participants was used as a reliability check for participants meeting the inclusion criteria. That is, infants in phase 1 or 2 of attachment development, with a mild to profound hearing loss, a comorbidity of disabilities, illnesses or impairments requiring varied support services. Moreover, it was vital for the researcher to assess the setting to be used for the videotaped observations planned for Phase 2; for camera positioning and camera angles. Prior to meeting the researcher, Ali had been informed by the service provider (Sarah) about the research study, had agreed to participate in the study, and had signed consent forms. Sarah and the researcher then met with Ali and her daughter, Rosa, before observing an ECI therapy session which was held on the floor in the family’s living room.

**Analysis.** After observing the therapy session, the researcher made notes in her logbook about this first meeting and observation. These notes included observations on what occurred before, during and after the therapy session, as well as notes on where best to situate the cameras for the Phase 2 video-recorded observations. These hand-written notes were used as background information to guide the researcher during Phases 1 and 2 of data collection. For example, during the interview, these notes

helped the researcher highlight what questions to ask regarding Rosa's characteristics and health conditions. A more detailed analysis of the logbook will be presented in a later section (see 'Documentation', p. 194).

**Results.** As noted in the researcher's logbook, before the session began, Sarah had spoken to the researcher about Rosa. Sarah described Rosa's health conditions, hospitalisations, a near death experience as a newborn, and two successful heart operations. Sarah stated she first started therapy with the family when Rosa was about 3 months old. Sarah described Rosa's cochlear implantation and switch on at 9 months of age. Sarah described Rosa as a lively infant who especially enjoyed music and playing with musical instruments.

During the therapy session, Rosa was observed to be very aware of sound seen through her engaging in lots of turn-taking and joint attention with Sarah and her mother. However, Rosa was observed to engage in more turn-taking with Sarah than with her mother. Ali appeared attentive to Rosa and encouraging. She listened and followed Sarah's cues and coaching during the session. At times, Ali appeared a little anxious and hesitant as she would sometimes fidget with her hands and bite her nails. She would also sometimes look away from Rosa with a concerned expression. Though for the most part, Ali had positive affect, smiled and engaged with the therapy activities, and was playful and mostly attuned to Rosa. Sarah appeared confident, and balanced her interactions with Rosa and her coaching of Ali. She spent most of the therapy session interacting with Rosa.

Before the therapy session started, Ali also spoke to Sarah and the researcher in length about an upcoming appointment from which they would receive genetics and blood test results. The researcher observed that Sarah gave Ali time to tell her about Rosa and the events of their week, before beginning the therapy session. Sarah showed understanding towards Ali and actively listened. Their relationship appeared to go beyond simply a professional therapist-client relationship, to an open and trusting friendship.

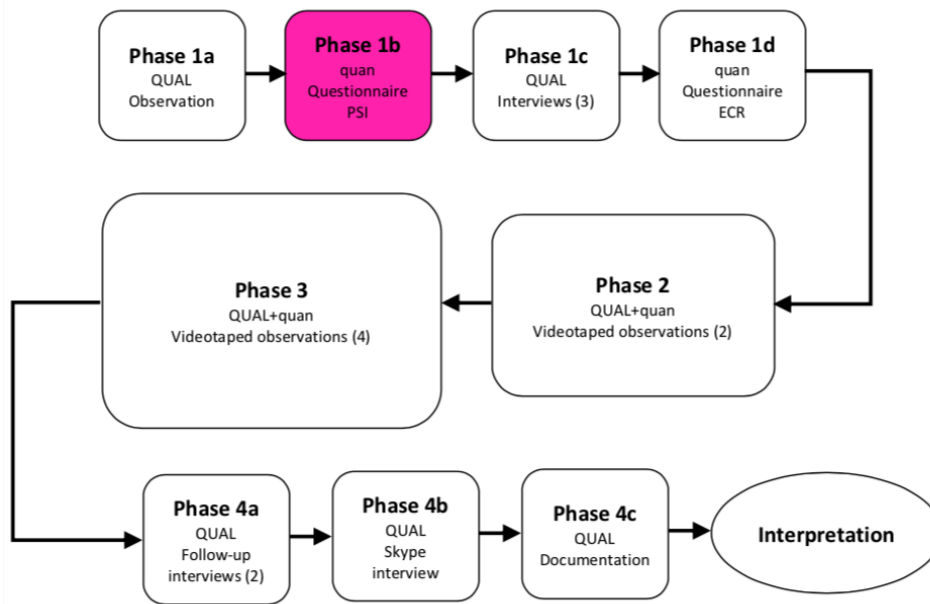


In regards to her attachment development, Rosa was observed to be in phase 2, that is, Orientation and Signals Directed towards One (or More) Discriminated Figure(s) (6 to 12 months of age) (Bowlby, 1969).

**Limitations.** Because this observation aimed to be as non-intrusive as possible, the researcher did not want to take notes during the session. Thus, the researcher relied only on her memory when writing out observational notes of the therapy session, unlike the subsequent video-recorded therapy sessions, which the researcher could re-play and watch over and over again.

**Implications.** As the researcher relied on her memory to make a record of the live observation, the record may not have been an accurate portrayal of the observation, warranting caution. Although, observing this therapy session live, without a camera proved useful. The researcher was able to judge where best to place the video cameras as well as what camera angles and what tripod height to use. This information was helpful when considering the set-up of cameras during the Phase 2 video-recorded observations of therapy sessions. Importantly, the researcher was able to complete the reliability check of the participants as meeting the inclusion criteria.

### 1b – Parenting Stress Index.



**Collection.** Following the study’s exploratory sequential mixed-methods design, the quantitative questionnaire aimed to build on the qualitative background information gathered from the meeting and observation of the participants. The PSI is a reliable and well-validated psychometric measure that provides a report of a person’s self-perceived stress in relation to their role as parent or caregiver (Abidin, 2012; Johnson, 2015) (see discussion p. 98, Chapter 3).

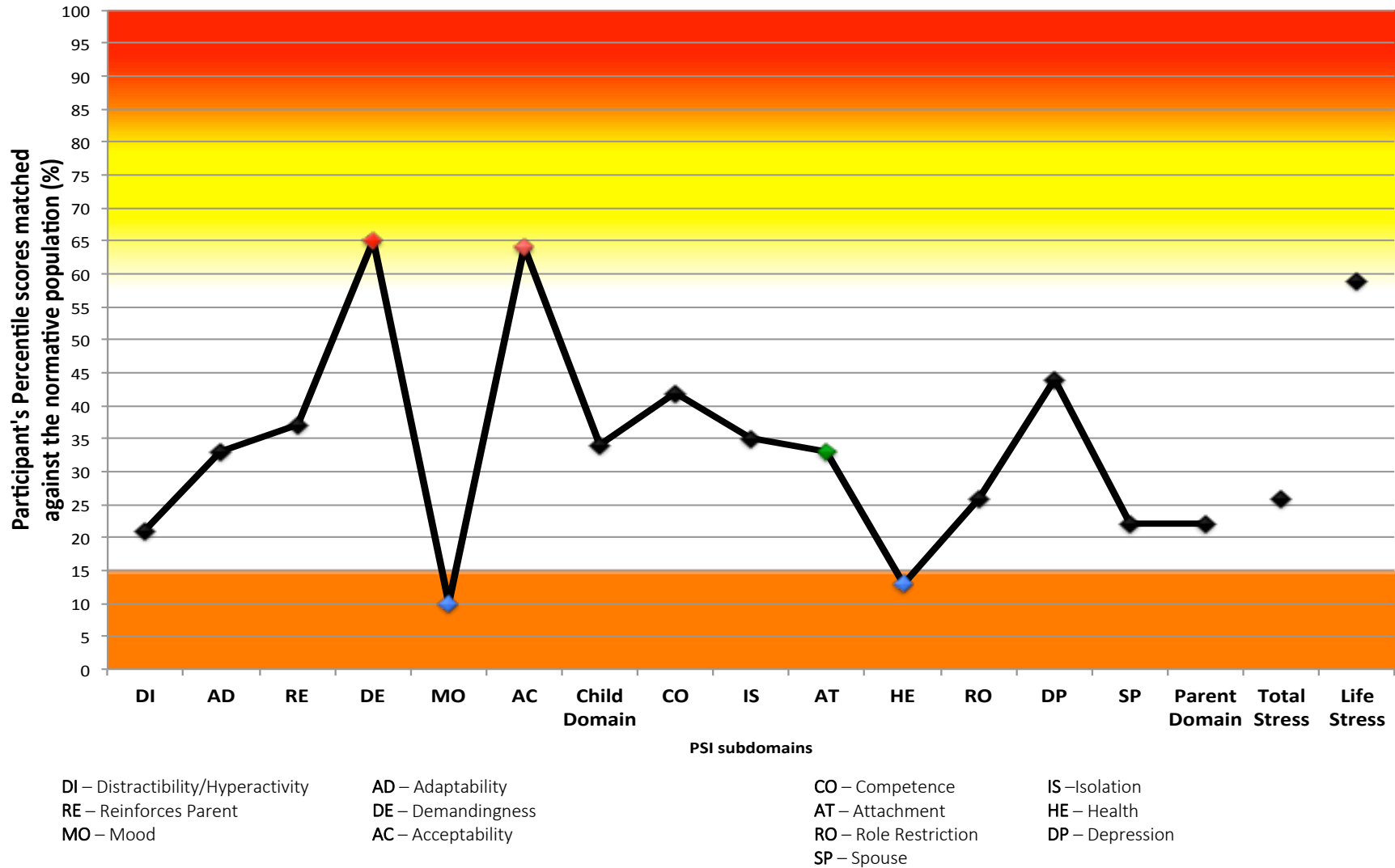
The PSI was given to Ali to complete at her home, after the end of the live observation of Rosa’s therapy session. The researcher explained to Ali what the PSI was, how to complete it, and that it would take approximately 20 minutes. Ali was assured that she could ask the researcher any questions if any of the questionnaire items were unclear. Ali asked the researcher to mind Rosa while she completed the PSI.

**Analysis.** Ali’s responses to each item of the PSI were collated and matched against the normative population provided by the PSI manual (Abidin, 2012). Using the steps described in the PSI manual and the analysis sheets provided, Ali’s raw scores were translated into percentile values and *T* scores, according to the age group that matched Rosa’s age (Abidin, 2012). A table similar to the hardcopy (see Appendix J) was made to show Ali’s results, including her raw scores, *T* scores,

percentile values, and defensive responding score (Abidin, 2012). From this table, a graph was created that plotted Ali's percentile values, in comparison to the normative population (see Figure 4.2).

Figure 4.2

Case Study 1 Mother's Parenting Stress Index Profile.



Ali's PSI profile was also compared to the mean profiles of parents with children with hearing impairment, vision impairment, developmental delay, and multiple disabilities, as provided by the PSI manual (Abidin, 2012; see Table 4.1).

The researcher chose to administer this instrument before conducting interviews, to first examine Ali's PSI results, and use these findings by asking interview questions specific to the results. For example, if Ali's results indicated high levels of stress deriving from the subdomain 'Spouse', the researcher would alter the interview schedule by noting that a focus on the parent's spouse was needed. This PSI database was also compared to the results from the first observation, the *Experiences in Close Relationships-Revised Scale* (ECR), and the video-recorded observations of therapy sessions from Phases 2 and 3, in order to triangulate any common findings. This is one example of several within this study, of converging evidence across databases (Stake, 2010; Yin, 2018).

**Results.** The findings illustrate Ali's perceptions of parenting stress at the beginning of the study. Figure 4.2 shows Ali's scores from all Child and Parent subdomains, her total Child Stress score, her total Parent Stress score, her Total Stress score, and her Life Stress score. The white and yellow segments on Figure 4.2 mark the normative range (16<sup>th</sup>-84<sup>th</sup> percentile) with yellow representing the upper normal range (60<sup>th</sup>-85<sup>th</sup> percentile). The orange segments mark the ranges just outside of the normal range (<15<sup>th</sup> percentile and 85<sup>th</sup>-90<sup>th</sup> percentile). The red segment represents the range critically outside the normative range (>90<sup>th</sup> percentile). Scores from Ali that fall outside of the normative range are marked blue, and scores that are in the upper normative range are marked red. The 'Attachment' Parent subdomain, of particular significance to this study, is marked green.

Regarding Total Stress, Ali reported a raw score of 175 (26<sup>th</sup> percentile), which was within the normal range (16<sup>th</sup>-84<sup>th</sup> percentile) (Abidin, 2012). At face value, Figure 4.2 suggests Ali's PSI results were within the normative population. Ali received a Defensive Responding score of 25, which fell outside the recommended cut-off score of 24 (Abidin, 2012). Given that the PSI manual details there is "some evidence from research... [that] associate[s] high defensiveness scores with parental

minimizing problems” (Dombrowski, Timmer, Blacker, & Urquiza, 2005, as cited in Abidin, 2012, p. 15), Ali’s Defensive Responding score warranted caution in the interpretation of her scores. According to the PSI manual, a type of false negative identified in the parent is the defensive individual, and “often, these parents’ reaction is, ‘If I admit I have these problems, I will fall apart and be overwhelmed’” (Abidin, 2012, p. 15). The manual proceeds, “however, when the same parents are faced with a nurturing, supportive individual in a counselling relationship, they readily admit to a wide array of concerns and problems that they did not reveal on the PSI-4” (Abidin, 2012, p. 15). This point suggests that such a parent may disclose more information to a trusted individual. Alternatively, Ali may simply have been a parent that was experiencing low stress, being a very competent parent, with a good support system in place and economically was not at a disadvantage (Abidin, 2012). Therefore, by collecting more data (interviews with Ali and Sarah) the hypothesis that Ali was responding defensively could be confirmed or disproved. The remaining PSI results for Ali are summarised below.

### ***Child Domain***

Overall, Ali’s results reported a Child Domain score of 83 (34<sup>th</sup> percentile), which sat within the normal range (16<sup>th</sup> to 84<sup>th</sup> percentile). Within this domain, the Demandingness and Acceptability subscale scores were in the upper portion of the normal range (marked red in Figure 4.2). Though these scores were not clinically significant, they license consideration. According to the PSI manual, Demandingness as a type of stress “is magnified when the parent is overly committed to being a model parent [and] young parents tend to earn elevated scores” (Abidin, 2012, p. 17). This matched with the background information of Ali (see section on CS1 Participants, Chapter 3), who had worked within the early childhood profession, was in the process of studying primary education, and was a young, first time mother at the time the PSI was administered.

According to the Parenting Stress Index manual, a high Acceptability score suggested, “the child possesses physical, intellectual, and emotional characteristics that do not match parental

expectations” (Abidin, 2012, p. 18). While Ali produced an Acceptability score falling within the 65<sup>th</sup> percentile, it was considered a score in the upper normal range, and therefore somewhat reflected Ali’s perception of her Child’s characteristics, as suggested by the PSI Manual. Interestingly, the Mood subscale score fell below the normal range, 10<sup>th</sup> percentile, which suggested that Ali perceived her daughter as crying or fussing very little, not moody and therefore possessed a happy, relaxed temperament (Abidin, 2012).

### ***Parent Domain***

Within the Parent Domain, a total score of 92 (22<sup>nd</sup> percentile) fell in the lower end of the normal range (16<sup>th</sup>-84<sup>th</sup> percentile). This finding suggests that very little of Ali’s stress derived from the Parent Domain subscales (Abidin, 2012). Notably, this score was also lower than the overall Child Domain score of 83 (34<sup>th</sup> percentile), which indicated Ali perceived that her stress levels were more associated with Rosa than with herself. As stated in the manual, perhaps she remained “candid while responding to stressors associated with [her] child’s characteristics, but [was] much less candid when responding to [her] own characteristics or situational stressors” (Castaldi, 1988, as cited in Abidin, 2012, p. 15).

Competence and Depression subscale scores, though falling within the normal range, were more elevated in comparison to the other Parent domain subscale scores. This suggested that Ali may not have found the role of parent as reinforcing as she had expected, and was perhaps overwhelmed by the feeling that “this child is more than I bargained for”, having answered *Agree* to item 29 in the Parenting Stress Item Booklet – “Being a parent is harder than I thought it would be” (Abidin, 2012, p. 19).

Within the Depression subscale, Ali answered *Agree* to item 82 “I wind up feeling guilty when I get angry at my child, and this bothers me”, which did not necessarily reflect that she was depressed, but rather that she may have been dissatisfied with herself in her parenting role and with her life circumstances (Abidin, 2012, p. 20). This is linked to item 29 “Being a parent is harder than I thought

it would be”; understandable as Ali was parenting a child with multiple disabilities, and according to the mean profile of parents with children with multiple disabilities, such parents tended to score high in both Child and Parent subdomains (Abidin, 2012; see Table 4.1). The Health subscale score of six (13<sup>th</sup> percentile) falls below the normal range, and suggested that Ali believed she was in good health.

Ali’s PSI profile was compared to the mean profiles from clinical groups that can be associated with Ali and Rosa. Table 4.1 displays the raw scores from Ali and of the associated parents with children with disabilities. Based on the total stress scores, Ali’s PSI profile fell within two standard deviations from these mean profiles, with a standard deviation of 31.15 and a mean score of 228.6. All other PSI profiles fell within one standard deviation. Evidently, Ali’s PSI profile is an outlier when compared with the mean profiles of the four other types of parents. This could suggest that Ali was not experiencing high stress levels as is the case with the mean profiles. However, to reiterate, the researcher posited that due to Ali scoring very close to the cut-off score for defensive responding, she might have been responding defensively. Therefore, Ali’s PSI scores should be interpreted with caution. Regarding interviews, these PSI results informed which questions needed to be revised in order to address the results.

Table 4.1

*Case Study 1 Mother’s PSI Profile Compared to the Mean Profiles of Other Clinical Groups (Abidin, 2012).*

	Ali and Rosa	Parents with children with hearing impairment	Parents with children with visual impairment	Parents with children with multi-handicaps*	Parents with children with developmental delay
Child domain score	83	113	109	120	121
Parent domain score	92	128	121	123	133
Attachment subdomain score	8	13	12	12	14
Total stress score	175	241	230	243	254

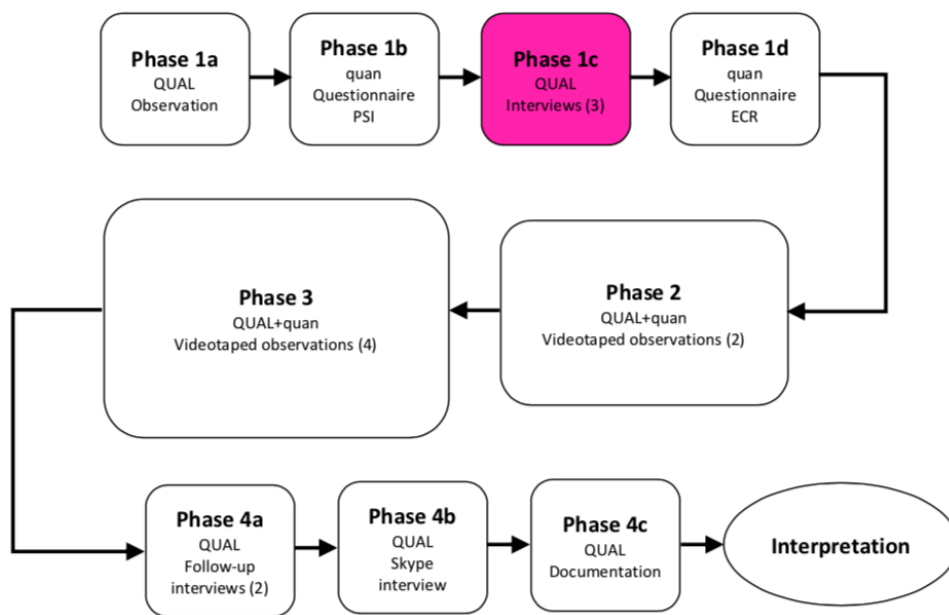
*\*Note: Language usage is reflective of the language used in the PSI manual (Abidin, 2012, p. 147).*



**Limitations.** One limitation was that the norms of the PSI were based on a North American sample that included 1,056 adults, 534 mothers and 522 fathers, deriving from 17 states from south, west, north-east and mid-west parts of the USA (Abidin, 2012). Since the current study is an Australian one, this is an important limitation to consider as American demographics differ from Australian demographics, with notably higher Hispanic and African-American populations. Another limitation was that the mean profiles provided by existing research using PSI did not match entirely the profile of the case study participants, specifically, parents of children with HL-CN.

**Implications.** Based on the results of the PSI, namely the scores that fell outside of the normative range and the scores that were in the upper normative range, the researcher revised the interview schedule by focussing on key topic areas. These included: Ali's belief in her competence as a parent; her social and spousal support; their socioeconomic situation; the nature of the demandingness of her daughter; physical, intellectual and emotional characteristics of her daughter that did not match Ali's expectations; the daughter's lack of moodiness and reasons for this; and, further exploration of feelings of guilt Ali may have possessed. Furthermore, an emphasis was placed on questions that related to the hospitalisations and operations that her daughter and the family experienced; her daughter's disability; the support and empathy received from health professionals; and, her health as a young mother (see Appendix D). The rationale behind this revision was to gather further evidence that would either support or debunk the hypothesis that Ali had been responding defensively while completing the PSI.

### 1c – Interviews.



**Collection.** The researcher used a voice recording application on an iPhone 6 to audio record the interviews. The case study protocol planned for two interviews in this phase, one with the mother and one with the service provider. However, after conducting the initial interview with the mother, the researcher found that they had ran out of time, and that a second interview was necessary to obtain answers to all the questions in the interview schedule. During the initial interview, Ali gave extensive, detailed responses to the researcher’s questions. The researcher was hesitant to break the flow of Ali’s narrative and decided not to ask all the questions. Thus, two interviews were conducted with Ali, and one interview was conducted with Sarah, the service provider. The first interview with Ali lasted approximately 45 minutes, with the second interview lasting approximately 1 hour. There was 1 week separating the first and second interviews.

Both interviews were conducted at the participants’ home to accommodate the family’s schedule, in particular Rosa’s feeding and nap times. The first interview was conducted during Rosa’s nap time, however on that particular day, Ali had not been able to put her to sleep, thus at the time of the interview, the researcher and Ali were in Rosa’s room, as Ali continued to put Rosa down for a nap. This also had an impact on the amount of time scheduled for the interview, with Ali taking up some of that time to put Rosa to sleep. The second interview was conducted in the family’s living

room, as Rosa was already napping in her room. Both interviews were semi-structured and conducted in a conversational way, with the researcher asking a few leading questions guided by the interview protocol.

The interview with Sarah was conducted in one of the therapy rooms at the early childhood intervention centre (ECIC). It lasted approximately 40 minutes. This interview remained semi-structured and addressed all seven topics in the original interview schedule for service providers (see Appendix D).

*Analysis.* The audio-recordings of the three interviews were transferred to a computer, and transcribed verbatim on to a Word document by the researcher. Participants were given a transcript of their interview for member checking (Stake, 2010). Member checking was a part of maintaining the rigour of the study and ensuring the quality of the research design. The participants reported that their interview transcripts did not contain any errors, confirming the accuracy of the data collected.

Interview data are commonly analysed through ‘coding’, a process of “deriving and developing concepts from data” (Corbin & Strauss, 2008, p. 65). Nvivo 10, a computer-assisted analysis software was used to code the interview data (Bazeley & Jackson, 2013; Edhlund & McDougall, 2012). Though a qualitative analysis software, Nvivo 10 is also used for mixed-methods research (Bazeley & Jackson, 2013; Edhlund & McDougall, 2012). Bazeley (2010) noted how some software have “developed specific capacities for integrative mixed method analyses” (p. 45) including Nvivo, to allow for combination or conversion of qualitative and quantitative data. As such, Nvivo 10 can be used for “a variety of data, such as documents, images, audio, video, questionnaires and web or social media content”, and thus was chosen as an efficient tool for organising and analysing the researcher’s mixed-methods data (Edhlund & McDougall, 2012, p. 12).

In Nvivo, ‘nodes’ or ‘codes’ represent key concepts or themes found significant to the research project (Edhlund & McDougall, 2012). There are different ways of coding data, often determined by the methodological approach (Gibbs, 2007). For this research study, an abductive approach to

analytical, thematic coding was used (Tavory & Timmermans, 2014). This process was iterative and involved two ways of coding: a predefined coding scheme based on the literature (deductive), and free ‘bottom-up’ coding (inductive) (Tavory & Timmermans, 2014; Urquhart, 2013). The researcher began analytically coding the interview transcripts through a predefined coding scheme. This scheme was created based on the study’s theoretical and conceptual frameworks (see Chapter 1), review of the relevant literature (see Chapter 2), the key themes from the first manual coding of the transcripts, and on the data gathered from the previous instruments (first live observation, PSI). This coding scheme included codes such as ‘parenting stress’, ‘hearing loss’, as well as key people, such as ‘Rosa’, ‘Ali’ and ‘doctors’. Free ‘bottom-up’ coding was then used to record the emergence of key themes that were not part of the predefined coding scheme (Urquhart, 2013). The research continued to use bottom-up coding until the point of saturation, that is, where no new codes could be identified from the interview data (Corbin & Strauss, 2008). Following this, codes that emerged from bottom-up coding were consolidated with the codes from the pre-defined coding scheme. Any duplicated or similar codes were merged together, and any insignificant codes deleted. Table 4.2 displays the final set of codes used in CS1, a combination of the pre-defined codes and codes that emerged through the coding process.

The sections that follow describe in detail the Nvivo coding methods and functions used to complete the iterative, analytical approach to coding.

One method of coding the pre-defined codes was through Nvivo’s ‘queries’ function. This function “can recognise which parts of the project’s sources contain the desired information” (Edhlund & McDougall, 2012, p. 13). For example, a word query of ‘Rosa’ was run, resulting in a list of the frequency and location of the word ‘Rosa’ within the interview transcripts. The researcher was then able to code all items on this list under the code ‘Rosa’, which significantly cut down the time spent individually coding ‘Rosa’ through the transcripts. For additional categories not in the predefined coding scheme, the function of ‘in vivo’ coding was used, that is, the codes were made

from the exact words and phrases of the participants, as the researcher analysed the interview transcript (Edhlund & McDougall, 2012).

Table 4.2

*Case Study 1 Interview Codes.*

Code
1. Understanding of attachment – <ul style="list-style-type: none"> <li>• Process of attachment development</li> <li>• Mother’s understanding</li> <li>• Father’s understanding</li> <li>• Service provider’s understanding</li> <li>• Coordinator’s understanding</li> </ul>
2. Factors around attachment – <ul style="list-style-type: none"> <li>• Child’s temperament and characteristics</li> <li>• Child’s disabilities</li> <li>• Quality of maternal care</li> <li>• Mother’s personality</li> <li>• Mother’s psychological attributes</li> <li>• Mother’s background</li> <li>• Social support</li> <li>• Marital quality and spousal support</li> <li>• Occupational stressors (work and family)</li> <li>• Socioeconomic status</li> <li>• External stressors</li> </ul>
3. Attachment relationships
4. Caregivers’ attitude towards pregnancy
5. Caregivers’ experience of child’s diagnosis
6. Caregivers’ hopes and concerns for their child
7. Early Childhood Intervention <ul style="list-style-type: none"> <li>• Attitudes towards ECI</li> <li>• ECI strategies, therapies and models</li> <li>• Interdisciplinary approach</li> <li>• Relationship of service provider with mother and child</li> <li>• Relationship of mother and service provider</li> <li>• Centres and hospitals</li> </ul>

'In vivo' coding was chosen as it was able to reflect and explore the interviewees' own words (Bazeley & Jackson, 2013; Corbin & Strauss, 2008). Initially, interviews were coded using a unit of analysis (UoA) of individual words. However, as the researcher coded through the interview, and a total of 250 'in vivo' codes emerged, it became evident that a more efficient method of analysis was to code by a UoA of phrases and sentences. Using phrases and sentences (e.g. 'breathing issues') as opposed to individual words (e.g. 'breathing') more clearly described the themes that emerged. The researcher therefore coded the transcript twice, the second time focussing on coding key themes rather than key words.

During the second transcript coding, words that were already coded were organised into 'thematic' codes. To do this, the researcher used the Nvivo function of 'spread coding', which changed individual key words into phrases or paragraphs to reflect the key theme being coded (Bazeley & Jackson, 2013; Edhlund & McDougall, 2012). Any duplicated codes were merged, and any codes that were similar were also merged. Codes that were redundant (e.g. 'emotion regulation' and 'self-regulation') or considered insignificant or outside the parameters of the study (e.g. 'abortion') were deleted. Due to the volume of codes, codes were then organised hierarchically into themes. More specific themes were classified into their broader categories using nodes: 'parent node' → 'child node' (Edhlund & McDougall, 2012). In Nvivo, a node is a compilation of references about a specific theme, place, or person. Nodes can be organised in hierarchies, moving from general topics at the top (the parent node) to more specific topics (child nodes) (Edhlund & McDougall, 2012). For example, 'Factors around attachment' → 'Child's temperament' → 'determined'.

This abductive process of analytical, thematic coding was also used for Sarah's interview transcript, as well as all other interview and follow-up interview transcripts in the subsequent phases.

**Results.** After using Nvivo to analyse the mother and service provider's interview transcripts, several themes emerged. These were then revised, simplified and collapsed into key themes. These seven key themes included: *Understanding attachment*, *Factors around attachment*, *Attachment*

*relationships, Early Childhood Intervention, Caregivers' attitude towards pregnancy, Caregivers' experience of child's diagnosis, and Caregivers' hopes and concerns for their child.* Each of these seven main themes was a parent node, with 230 subthemes organised hierarchically into child nodes (see Appendix K). Thus codes were categorised into each of these themes. The key findings from each theme will be discussed, looking at Ali's responses first, and Sarah's second.

***Understanding attachment.*** Ali described attachment as a reciprocal relationship between the child and caregiver, placing emphasis on the safety and security felt by the child. Sarah had a more technical understanding of attachment by noting first the caregiver's attunement with the child, who then reciprocates. When asked what she knew about attachment and attachment theory, Ali remarked,

I don't really know that much about attachment theory, I've done the theory on everything else! Look basically the only thing I know is that if you want a child to be able to learn they need to be comfortable in their surroundings and in a trusting you know honest, kind of reciprocal love relationships, you know you can't expect a child to thrive in an environment where they don't feel safe and secure in.

Sarah described her understanding by stating:

I suppose pointing out the difference between attachment and the bond is a good start. So the bond is just the love that a... mother has for her child, which is a given. ... but the attachment is when the mother, or the parent, or the caregiver, ... is in tune with their child and is absolutely at their level and so the child then gives back and responds and you get this two-way... rhythm or dance ... which is very different to just a one-way bond.

She explained that often the child's impairments hindered the attachment from developing. In Rosa's case, Sarah noted that she had no visual acuity and had sensory issues, therefore Sarah tackled those first before she could begin to engage Rosa and build on their relationship.

When asked if parents at the ECIC understood what attachment was, Sarah admitted that they probably did not at first, and needed to be taught how attachment worked. Interestingly, Sarah articulated that through her reflection of her practice of attachment and through the researcher's earlier study at the ECIC, parents she had worked with were able to gain a clearer understanding of attachment and the mechanisms behind it, and it helped them to develop that attachment relationship with their child:

I've changed the way I work... To actually identify and ... follow it through and look at how it changed, and everything, I think that was incredibly invaluable for her [mother of a previous child], so now, I'm very open about it. All new families... we talk about the attachment, and we talk about the two-way, and I comment and parents really understand what we're, looking for and doing, and it's much easier for them.

***Factors around attachment.*** This theme was categorised into several factors directly or indirectly affecting the child and caregiver relationship (see Appendix K for all the child nodes within this parent node). Some key findings that emerged include: 'Child's disabilities', 'Child's temperament and characteristics', 'caregiver sensitivity', 'attunement', 'guilt', 'anxiety/worry', 'feeling pressure', 'perfectionist', 'results-driven', 'sees information as important', and 'coping mechanisms'. Importantly, both Ali's and Sarah's interviews revealed that a major factor in the child's developing attachment relationship is the caregiver and his or her characteristics. Within this, are the caregiver's ability to be sensitive and attuned to the child, and their ability to cope with stressors. Specifically, Ali's perfectionism, results-driven attitude and tendency to apply pressure on



herself and therefore feel guilt, seemed to hinder her ability to be more sensitive and attuned to the emotional needs of Rosa. Ali noted:

I'm grateful I'm a preschool teacher and that I understand it, but then I also feel the extra pressure applied upon me, not from anyone else, but by myself. I'm a really high achiever and I really like to do the best that I can, and because I am that preschool teacher and I do have that knowledge, I battle on a daily basis if I'm doing enough.

In her interview, Sarah commented that Ali was:

not valuing, just going for a walk with her [Rosa] in the pram, and talking to her about the birds in the trees ... doing ... the regular stuff ... that mums do with their babies. She doesn't value that, because it's not accelerating her progress enough, which suggests Ali's focus on Rosa's results and progress.

Interestingly, under 'Child's temperament and characteristics', Ali described Rosa as: "...always happy, always smiling, she never cries always chilled out". This supported Ali's PSI result where she scored Rosa as low on the 'Demandingness' Child subdomain.

Though not asked directly if she was stressed, the content of Ali's interview suggested that during the traumatic and difficult experiences of parenting Rosa, Ali was under high amounts of stress. Importantly, Ali's coping mechanisms led her to possess a strong sense of empowerment, determination, and proactivity, despite all the difficulties they had faced: "Yes, being proactive and knowing that I was always pushing forward, definitely helped like I think that's my personality as well, I strive to complete things and always to the best of my ability". In terms of Ali's ability to cope with stress, Sarah noted that Ali was stressed perhaps due to the pressure she placed on herself to uphold perfection.

When asked about families and their coping mechanisms in general, Sarah replied: “I just don’t know what coping well looks like... when you look at what they’ve got to deal with”, which alluded to the hardships families experienced in parenting a child with complex needs. Moreover, the consequences of a child’s disability, such as hospitalisations, operations, appointments, and social support or lack of support from the caregiver’s spouse, family, friends, the community, and healthcare professionals, are important factors influencing the developing attachment.

In regards to support from her spouse, Ali admitted that Ben could support her more by learning and doing early intervention therapy strategies with Rosa. She also expressed concern that Ben did not take enough time off work to support Ali during important medical appointments and procedures. This corroborates with Sarah’s comment:

...And this constant pressure that she puts on herself, which her husband, doesn’t have, obviously he doesn’t put that pressure on himself so... I can see that they’re at very different, phases with it all, and whilst he’s very supportive, he doesn’t get where she’s coming from and she doesn’t get where he’s coming from, and I can see ... there’s going to be a bit of work further down the track,

showing the incongruence between Ali and Ben.

Furthermore, after considering Sarah’s remarks above on the constant pressure Ali placed upon herself, the researcher concluded that Ali was stressed, however she minimised this stress in order to cope with daily life. This supports the PSI results and the researcher’s hypothesis that Ali had been denying or minimising the stress she experienced.

Another key code which came under the child node ‘social support’, was the importance Ali placed on collaborating and receiving empathy and support from doctors, other healthcare professionals, and service providers. Ali described at length how her experiences with Rosa’s feeding

tube were very traumatic: "...endocrine just taking her blood and making her go on that diet and that was the most difficult for me and again as I said the tube was the most traumatic part". Ali described the difficulty she had working with a feeding clinic team that did not have the same goal as she did of removing Rosa's feeding tube. In the end she found a new feeding team that helped her support Rosa's oral feeding. Eventually this resulted in Rosa's feeding tube being removed at 7 months, from which Rosa was successfully able to feed orally.

Ali also spoke of Rosa's two heart operations and an incident where she had stopped breathing and almost died; further experiences that were very difficult for her. In particular she described those doctors and professionals that she felt supported her and did their best to support Rosa, for example the ENT specialist and heart specialist. When asked what she thought about everything that had happened to them, Ali replied: "Didn't expect it would be like that at all ... I think there were so many problems that we had to deal with and... not knowing how bad everything was going to be...". Clearly, there were many factors surrounding Rosa's complex needs that made the experience of parenting difficult for Ali, and likely impacting on the development of their attachment relationship.

*Attachment relationships.* When asked about her relationship with Rosa, Ali responded: "I think it's getting stronger every day, I mean it definitely was difficult, I'm not going to lie". Ali went on to describe that when Rosa was very little she liked it best when Rosa was asleep because it was only then that Ali knew Rosa would be safe. This shows the anxiety and worry Ali experienced during this trying time.

When asked about how she perceived Ali and Rosa's relationship, Sarah admitted that Ali should be more attuned to Rosa's emotional needs, rather than focussed on Rosa's progress and therapy strategies:

It's only a couple of weeks ago that Ali and I had this real honesty chat where ... you're [Ali] putting too much emphasis on doing therapy with her [Rosa] every second of the day and

putting so much pressure on yourself that it's actually going to be negative for yours and her relationship.

***Early Childhood Intervention.*** When asked about effective ECI strategies, Ali highlighted the importance of play-based learning in doing therapy. She also described how Sarah focussed on building a relationship with Rosa, rather than on explicitly working on therapy:

...From the beginning you could see that she was basically just laying down the groundwork and was building this rapport up with Rosa and when she walks into the room, Rosa gets so excited now, so for me it's simply a matter of just having an established relationship and a trusting relationship, and from that I believe Rosa will learn anything.

Sarah displayed a comprehensive understanding of ECI practices. She emphasised how at their ECIC, attachment was the central puzzle in their COMBINES Methodology (see Figure 3.4 in Chapter 3). Another key aspect of this methodology was the relationship that service providers formed with the parent and child. When asked how her relationship with Ali and Rosa had progressed, Sarah admitted that at the start it was mostly her interacting with Rosa, as she had to gain Ali's trust and show Ali what Rosa was capable of. Sarah compared this to how they worked together now:

but now... I'd come in and say ok so you know what, what have you been doing this week, and she'll happily show me the things she's been doing and we often work from there, or, you know I'll model and then I'll hand them over to Ali and she'll carry on and she's much more comfortable with me.

This quote demonstrates the family-centred and relationship-based approach of the ECIC, where service provider and parent work together in supporting the child, moving towards the goals

and needs of the family. Sarah also noted that a common experience at their ECIC was parents gaining a sense of empowerment: "... the 3-4- year old parents, are much more, proactive, much more kind of, in control of their own, ideas and ... investigations ... I think they become much more empowered as time goes on".

Overall, Ali's attitude towards the ECIC was positive:

The love that Sarah and Louise gave, ...I didn't even know these people, ... when I went in to meet them, everyone stole Rosa off me and everyone wanted a cuddle, whereas at the [other] centre everyone was kind of like, "oh yes just to this room" and you know didn't even look at Rosa and didn't even talk to Rosa and for me that was like this fits with my philosophy on how a child should be dealt with especially ... if we're gonna be doing some kind of therapy, so, that's how, they were amazing.

However, Ali admitted that perhaps the ECIC needed to provide more information and structure, suggesting that providing more information sheets might be helpful to other parents. Further, Ali alluded to the need to improve the level of organisation at the ECIC, in regards to the information about ECI that was given to the parents, and the lax structure of the therapy sessions.

***Caregivers' attitude towards pregnancy.*** During Ali's pregnancy, tests showed that their baby had a high risk of having Down syndrome. Ali and Ben were not in agreement when they heard this news; Ben wanted to terminate the pregnancy, while Ali was adamant that she would keep her baby regardless. Further tests revealed that their baby had a heart condition, and not a syndrome. Ali was unconvinced that the only problem that her baby had was a heart condition. Speaking to her General Practitioner, Ali was told that it was likely that her baby did have a syndrome that is Di George's syndrome. Ali described how Ben's main concern was that their baby would have cognitive delays

and not be able to go to mainstream schooling. She spoke about how she watched Ben cry for the first time in her life.

***Caregiver's experience of child's diagnosis.*** Ali and Ben had a very difficult experience with Rosa's diagnosis. Before Rosa was born, she was characterised as having Di George's syndrome, and so when she was born she was treated as a baby with that syndrome. This was a misdiagnosis and doctors could not ascertain Rosa's condition. When Ali and Ben were told that Rosa had CHARGE syndrome, Ali perceived that the doctors were quite proud and unsympathetic:

"I couldn't go to sleep that night, last night saying to you that there was nothing that I could see that was wrong with your daughter and then at 4 o'clock in the morning I woke and I went, "She's a CHARGE baby!". She [the doctor] was so excited that she had picked what was wrong with her it was like you know a notch on her belt like "I had deserved some kind of pat on the back", and they handed me this information sheet and said "Your baby could be deaf and blind".

Ali noted how she found it intimidating sitting in a room of six doctors while they told her and her husband about their child's diagnosis, and felt that she was expected to keep it all together.

***Caregivers' hopes and concerns for their child.*** Ali's main hope for Rosa was that she would be able to talk. However, Ali, on reflection, changed her answer to wanting happiness and confidence for Rosa. On the other hand, Ali believed that her husband Ben would want Rosa to be able to have lasting friendships and confidence. Major concerns that Ali had centred on Rosa not being able to crawl, to walk or to fit in at school.

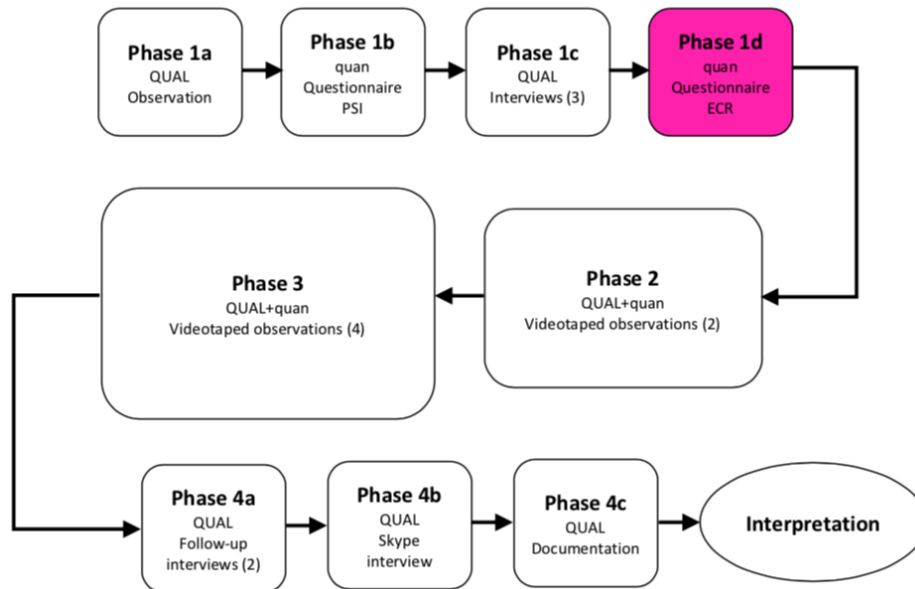
**Limitations.** The interview schedules for both the caregiver and service provider were designed as semi-structured interviews, with seven topics and examples of possible questions, under each topic (see Appendix D). However, when conducting Ali's interview, it became less structured, as the researcher chose to ask only a few open-ended questions in order to follow Ali's narrative of her experience of parenting. As a result, the first interview covered only a few of the topics from the original interview schedule in detail. Thus, the researcher concluded that a second interview was necessary to obtain more detail on these topics, as well as further information on key themes that emerged, both from the first interview and from Ali's PSI results. A possible limitation from the interview with the service provider was that the researcher had undertaken an interview with the same service provider for a previous study, which may have biased the researcher during the interview process.

**Implications.** The decision to conduct a second interview with the CS1 mother, Ali, changed the case study protocol to include the option of conducting more than one interview with the primary caregivers in the subsequent case studies, to ensure that all topics in the interview schedule were covered. Also, for interviews with the primary caregiver, the original semi-structured interview schedule was replaced in favour of an unstructured, open-ended interview schedule. This was to give the primary caregiver the opportunity to freely narrate his or her experiences. The researcher still used the interview schedule as a guide, asking only a few of the original questions and prompts to ensure that key topics were being addressed.

From the analysis of the transcripts conducted through Nvivo, some of the key themes were transformed into constructs that could be observable in the video-recorded data collection phases (Phases 2 and 3). For example, the caregiver's ability to be sensitive to their child was transformed into the construct 'sensitivity' for the research investigator's coding scheme. This construct is also a part of the CARE-Index, a video analysis system that measures the quality of mother-child sensitivity during a 3-minute video-recorded play interaction (Crittenden, 2010). Creating constructs that were

observed in the video data provided another method of triangulating data across the study's different databases.

### 1d - Experiences in Close Relationships Scale.



**Collection.** As outlined in Chapter 3, Methodology, the *Experiences in Close Relationships-Revised Scale* (ECR; Fraley, Waller & Brennan, 2000) is a self-report questionnaire that measures an adult's attachment-related anxiety and avoidance. Attachment-related anxiety is the degree to which an individual is concerned about the availability and responsiveness of romantic partners, and attachment-related avoidance is the degree to which an individual is comfortable with intimacy and healthy dependence on another (Fraley, 2012). The assessment of a person's attachment-related anxiety and avoidance determines their adult romantic attachment style (Fraley, 2012). The ECR was given to Ali after her second interview was conducted, so as not to bias her responses to the interview questions around her relationship with her husband. The researcher described the ECR to Ali, asked her to complete it in her own time, and to submit it to the researcher upon completion.

**Analysis.** The ECR contained 36 items that assessed Ali's romantic relationships in general, and assessed her relationship with her current romantic partner (see Appendix H). Eighteen items



measured attachment-related anxiety, and 18 items measured attachment-related avoidance. A 7-point scale was used with responses ranging from *Strongly Disagree* to *Strongly Agree*. The average score of all 18 items that measured anxiety gives the respondent's attachment-related anxiety score. Similarly, the average score of all 18 items that measured avoidance gives their attachment-related avoidance score. Typically, if respondents select *Strongly Disagree* or *Disagree* for most items, their average anxiety and avoidance scores would be low, scoring only a one or two out of seven. Some items were 'reverse keyed' to obtain the proper scores, as noted on the online guide (Fraley et al., 2000).

To obtain Ali's average attachment-related anxiety and avoidance scores, her responses to each of the 36 items, were put into a Microsoft Excel spreadsheet of a scoring template obtained from Fraley's ECR webpage (2012). This scoring template automatically calculated Ali's average scores, including the items that needed to be 'reverse keyed'. A chart was generated to depict Ali's average scores within Bartholomew and Horowitz's framework of the four categories of individual differences in adult attachment styles: Dismissing, Fearful, Preoccupied, and Secure (Bartholomew & Horowitz, 1991; see Figure 4.3). Based on the ECR's 7-point rating scale, Ali's average anxiety score was plotted on the vertical axis with values that ranged from 1 to 7. Scores falling near 1 were considered 'low anxiety', while scores near 7 were considered 'high anxiety'. Similarly, Ali's average avoidance score was plotted on the horizontal axis with values that ranged from 1 to 7. Scores that fell near the 1 value were 'low avoidance' and scores that fell near the value 7 were 'high avoidance'.

Subsequently, Ali's ECR scores were compared to the ECR norms given on Fraley's webpage (2012). To triangulate data, Ali's ECR results were also compared to her scores on the PSI subdomain 'Spousal/Parenting Partner Relationship' as well as to Sarah's and Ali's interview responses to questions regarding Ali's spouse and marital quality, and any relevant comments Ben made in his interview. Once again, following the exploratory sequential design of the study, findings from this instrument built upon the findings from the previous instruments.

**Results.** Ali scored 1.67 on the attachment-related anxiety dimension and 1.39 on the attachment-related avoidance dimension. That is, Ali scored low on both dimensions, which indicated her adult romantic attachment style to be secure (the secure quadrant is marked green in Figure 4.3). In other words, Ali was confident and secure in her romantic relationships in general, and in her relationship with her husband (Fraley, 2012). Typical of a secure individual, this meant that Ali held a positive image of herself “as worthy and lovable”, and a positive image of others, “viewing them as responsive and attentive” to her (Fraley & Shaver, 2000, p. 142). Furthermore, her secure adult romantic attachment style points to a relationship where both adults can use each other as a ‘secure base’ and as a ‘safe haven’ during times of distress (Fraley & Shaver, 2000).

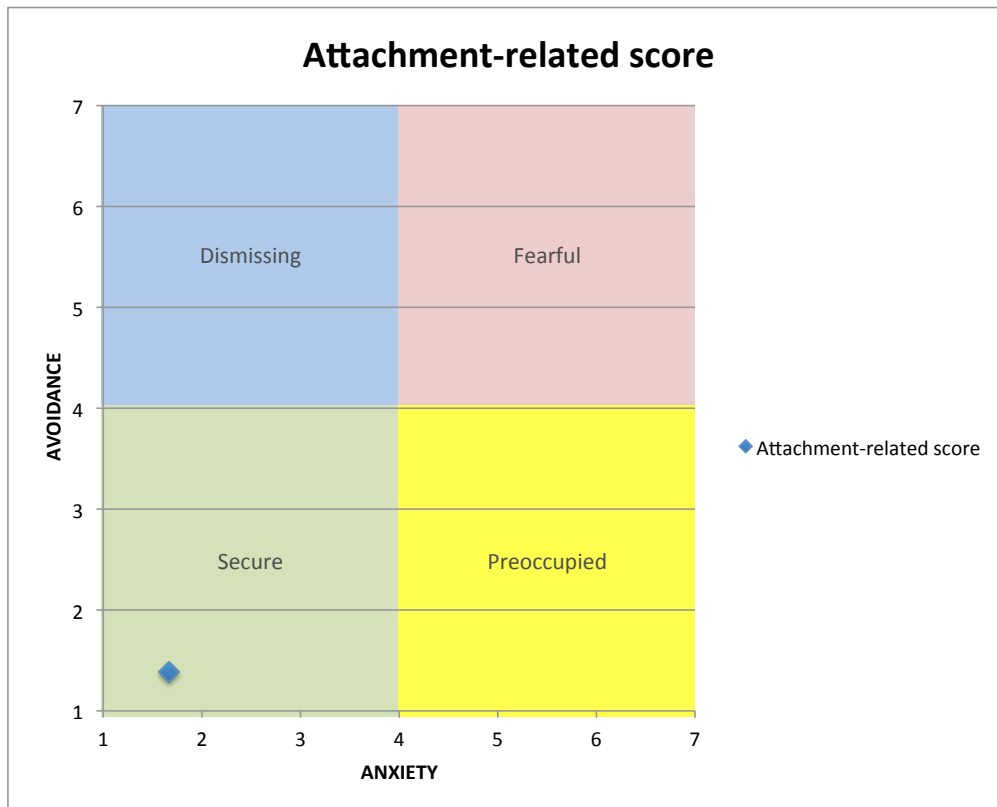
In comparison to the ECR norms provided on Fraley’s webpage, Ali scored higher than the average anxiety score of 1.21, and higher than the average avoidance score of 1.13 (Fraley, 2012). These norms are based on a sample of over 17,000 people who completed the ECR online, 73% of whom were female, with a median age of 27, and with 21% of the sample married (Fraley, 2012). Having compared the demographics of this sample size with Ali’s demographics – a married, first time mother in her early 30’s – Ali is not representative of the mode demographic profile of the sample size. Thus, it can be argued that her higher than average ECR scores may be accounted for by other factors, for example, being a first-time mother parenting a child with complex needs. Nonetheless, Ali’s ECR scores placed her in the secure quadrant of adult romantic attachment styles.

Moreover, when compared to her PSI subdomain score on ‘Spousal/Parenting Relationship’, Ali’s ECR scores matched her low score in that PSI subdomain, which indicated that, overall, her relationship with her husband Ben was a supportive one. These quantitative results also corroborated with the interview responses. In her interviews, Ali described Ben as emotionally supportive and aware of her needs. But, Ali also admitted her frustration towards Ben, perceiving him not to be supportive of Rosa’s therapy, and not comprehending how much effort was required with Rosa’s therapies. Likewise, Sarah’s interview revealed that she believed that with regards to parenting Rosa, Ali and Ben were not on the same page: “I can see that they’re at very different, phases with it all,

and whilst he's very supportive he doesn't get where she's coming from and she doesn't get where he's coming from, and I can see that there's a bit of work".

Figure 4.3

*Case Study 1 Mother's Experiences in Close Relationships Score.*



Measuring the primary caregiver's adult romantic attachment style had significant implications for this study. This is due to the link between a person's adult romantic attachment style and caregiving style, where a secure adult who is sensitive and attuned to their romantic partner is also likely to behave in a sensitive and attuned way in their role as the caregiver and attachment figure of their child (Fraley & Shaver, 2000; Rholes & Simpson, 2004; Rholes et al., 2006; Zayas et al., 2011). Thus, based on her ECR scores, Ali was likely to have low anxiety and low avoidance in her relationship with her child (Rholes & Simpson, 2004; Rholes et al., 2006).

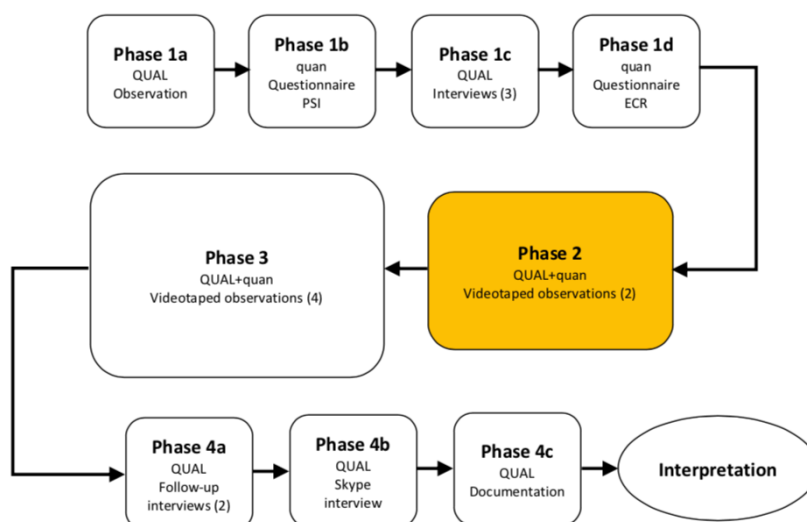
**Limitations.** A limitation of the ECR, is that the data from its normative population, as provided by the website, is not a controlled population (Fraley, 2012). Rather, it is simply data derived from any person who has completed the ECR online. As stated, 73% of this population were female, with an average age of 27 (Fraley, 2012). This clearly is not representative of the average world population, nor representative of an Australian population. Another drawback is that this population is not representative of the study's population of infants with HL-CN and their caregivers, and therefore may only provide a limited interpretation.

**Implications.** Due to the limitations of the ECR's online database, caution should be taken when making comparisons and conclusions of CS1's results, based on this data. Also, similar to the PSI, the ECR is a quantitative instrument that provides quantitative data to support the study's main qualitative instruments. As an instrument that measures attachment style, data derived from the ECR were directly compared with the data obtained from the video-based assessments measuring the attachment constructs of sensitivity and attunement. In the following two phases (Phase 2 and Phase 3) of video data collection and analysis, the researcher compared Ali's ECR results with the findings gathered from the CARE-Index and researcher's own video analysis, thus triangulating multiple sources of evidence to strengthen the conclusions made (Yin, 2018).

## **Phase 2**

Phase 2 of the research involved collecting videotaped observations to pilot qualitative and quantitative methods of analysing the video data. The researcher analysed the observations through qualitative descriptions and her own video-coding scheme.

## Videotaped Observations.



**Collection.** Videotaped observations were conducted in the participants' home during therapy sessions on a Friday morning. Two cameras were used: an iPhone 6 and a Canon SLR. The researcher held the iPhone 6 and used it to capture a close-up or medium shot of the participants. The Canon camera was on a tripod and positioned in the back right-hand corner of the room, and captured a wide-angle shot of the participants and their environment. The participants were Rosa, her mother Ali, and the service provider Sarah. Videos were taken of two sessions, with each session lasting approximately 1 hour. One week separated the first and second videos.

**Analysis.** Video analysis focussed on the behaviours of the infant, caregiver and service provider during the ECI therapy sessions. Videos were uploaded onto a computer then initially analysed qualitatively followed by a quantitative analysis of behavioural constructs using video codes.

First, the researcher watched the video to gain an overall sense of the structure of the therapy session, observing the changes in activity or toys, as well as the positioning of the participants. Noteworthy interactions that emerged from this viewing were noted in the researcher's logbook. The researcher then watched the two videos with Louise – the ECIC's coordinator and key informant for the study – and together they analysed and discussed key observed behaviours and interactions of the

participants. Inter-rater agreement was achieved through this collaborative process, with the researcher and Louise agreeing on the salient behavioural constructs and video codes that emerged from the video recordings. Following this, the researcher wrote up qualitative descriptions for each of the two videos based on the logbook notes and discussion with Louise.

Next, the researcher created a video-coding scheme (see Appendix E). This scheme was based on the discussion with Louise, the key constructs that emerged from the interview responses in the previous phase, as well as the academic literature on attachment, infants with HL-CN, and ECI therapies. In total, 40 codes were created by the researcher to analyse the behaviours and interactions of the child, service provider and mother.

Thirdly, the researcher analysed the two videos through Vcode and Vdata, a set of publicly-available applications for video annotation (Hagedorn, Hailpern, & Karahalios, 2008). Vcode was the application used to analyse videos for behaviours, which were coded along a timeline, and Vdata was used to extract and examine the data (Hagedorn et al., 2008). In Vcode, two types of coding events were used to mark behaviours: ranged events, which marked the start and duration of a behaviour, and momentary events, which marked a behaviour occurring at a single point in time (Hagedorn et al., 2008). Both coding events were measured in seconds and milliseconds. An example of a ranged event was 'Joint attention' - Child and Mother or Child and Service Provider are engaged together in an activity, with or without a toy e.g. Service Provider and Child playing with rattles. And an example of a momentary event was 'Follows child's lead' - Mother or Service Provider follow the Child's interest or interaction e.g. Child picks up rattle and starts shaking it, Mother also picks up a rattle and starts shaking it.

Based on an appraisal of the most significant constructs within the fields of literature noted earlier, the interview responses, as well as those that emerged from the video data, the researcher organised the codes into six categories: *Attachment*, *DIR/Floortime*, *Auditory-verbal therapy*, *Interactional quality*, *Other therapy*, and *Service Provider and Mother relationship*. Within these categories, three codes were ranged events: in the *Attachment* category – 'face to face', in the

*DIR/Floortime* category – ‘joint attention’, and in the *Auditory-verbal therapy* category – ‘pausing and waiting’. All other codes were momentary events.

The researcher uploaded each video onto Vcode and watched each video several times and marked whenever different codes occurred. Data were then exported from the Vcode to the Vdata software, which displays the raw data from the coded videos, showing where each individual code was coded within the whole video. In order to find trends in the raw data, the data were exported to a Microsoft Excel spread sheet. Using Excel, the codes were first converted from milliseconds to seconds, then organised chronologically. Momentary events were grouped together to count their frequency, the duration of ranged events was then converted from milliseconds to seconds. The researcher used these data to look for trends and to create charts (see Figures 4.4 to 4.21) for each video that was coded.

### ***Results.***

***Qualitative descriptions.*** The results of the qualitative analysis are based on the researcher’s individual viewing of the videos, and on the joint viewing with Louise (see p. 101, ‘Phase 2 Videotaped Observations (Initial)’, Chapter 3 Methodology). Both the researcher and Louise concluded that, although Sarah and Ali were sensitive and attuned to Rosa, there was scope for improvement. The researcher and Louise noted how Sarah scaffolded most of Ali and Rosa’s playful interactions. While Sarah was modelling strategies and ways to interact with Rosa for Ali, she could have given Ali more opportunity to interact and play with Rosa. The researcher also observed how Ali seemed nervous or hesitant in her interactions with Rosa, evidenced by her looking away, biting her nails, and wringing her hands at times. These behaviours could also be accounted for simply having cameras recording her and her child. However, the researcher also noticed how Ali appeared to be more comfortable sitting behind Rosa and letting her interact with Sarah, rather than with herself. Ali would not sit directly facing Rosa unless prompted by Sarah. Moreover, Louise noted how Sarah and Ali hardly lowered their posture to be on the same level as Rosa. For example, they

would be sitting next to Rosa and facing her, however did not bend lower to have their faces on the same level as Rosa's, in order to be more attuned to her cues. Thus, these observed behaviours led Louise and the researcher to conclude that both Sarah and Ali could have done more to develop Ali and Rosa's interactions with each other. In particular, Sarah could have done less with Rosa, and stepped back to give Ali more time to play and interact with Rosa in her own way.

Interestingly, at the start of the second videotaped lesson, Sarah made the comment to Ali that the last video taken could be shown to other parents on what to do at therapy sessions. Therefore, Sarah noted that for this particular therapy session, the focus would be on Ali and Rosa interacting, while she stepped back a bit more. From these comments, it appeared that Sarah believed that Ali and Rosa were doing a great job playing and interacting with each other. This view is in contrast to that of the researcher and Louise's analysis of the two videos, as previously noted.

***Video codes.*** Results from the Vcode and Vdata quantitative analysis (see Figures 4.4 to 4.21) are presented in the following sections. Codes have been separated into five code categories: *Attachment*, *DIR/Floortime*, *Auditory-verbal therapy*, *Interactional elements*, and *Service Provider and Mother relationship*. The code category *Other therapy* was taken out due to the lack of codes that emerged from this category.

Regarding the *Attachment* codes, Rosa and Ali had less occurrences of 'face to face', compared to Rosa and Sarah (see Figure 4.4). In Figure 4.5, there is an increase between Rosa and Ali's 'face to face' total and a decrease between Rosa and Sarah. This could be accounted for by Sarah's decision that the focus of the second therapy session was on Ali and Rosa's interactions. However, when the duration of Ali and Sarah's 'face to face' interactions with Rosa are compared, a different picture emerges (see Figures 4.6 to 4.9). In video 2, though Ali's 'face to face' interactions with Rosa were greater in number, Sarah's 'face to face' interactions with Rosa were, on average, longer in duration. This suggests Rosa's preference for Sarah during therapy sessions.



Figure 4.4

Case Study 1 Phase 2 Video 1: Attachment Codes.

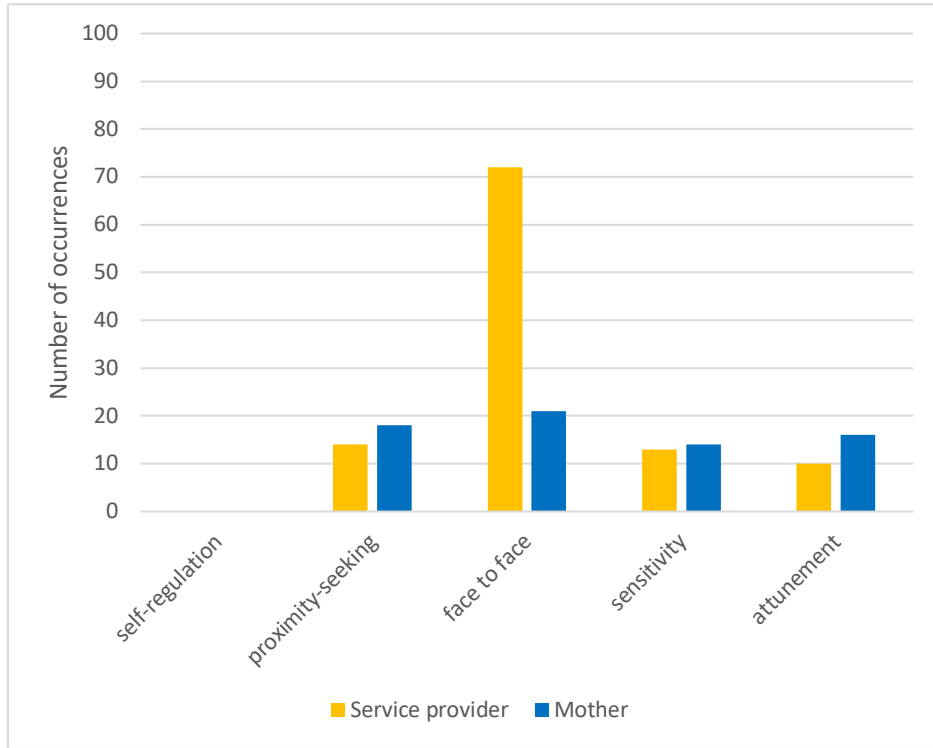


Figure 4.5

Case Study 1 Phase 2 Video 2: Attachment Codes.

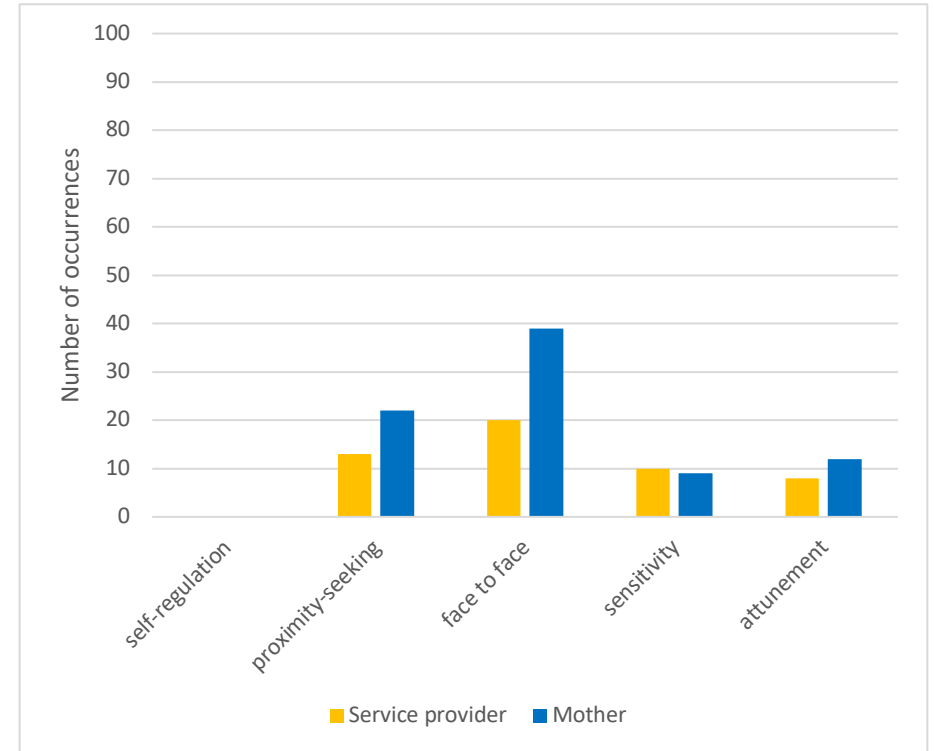


Figure 4.6

*Case Study 1 Phase 2 Video 1: Face to Face Service Provider and Child.*

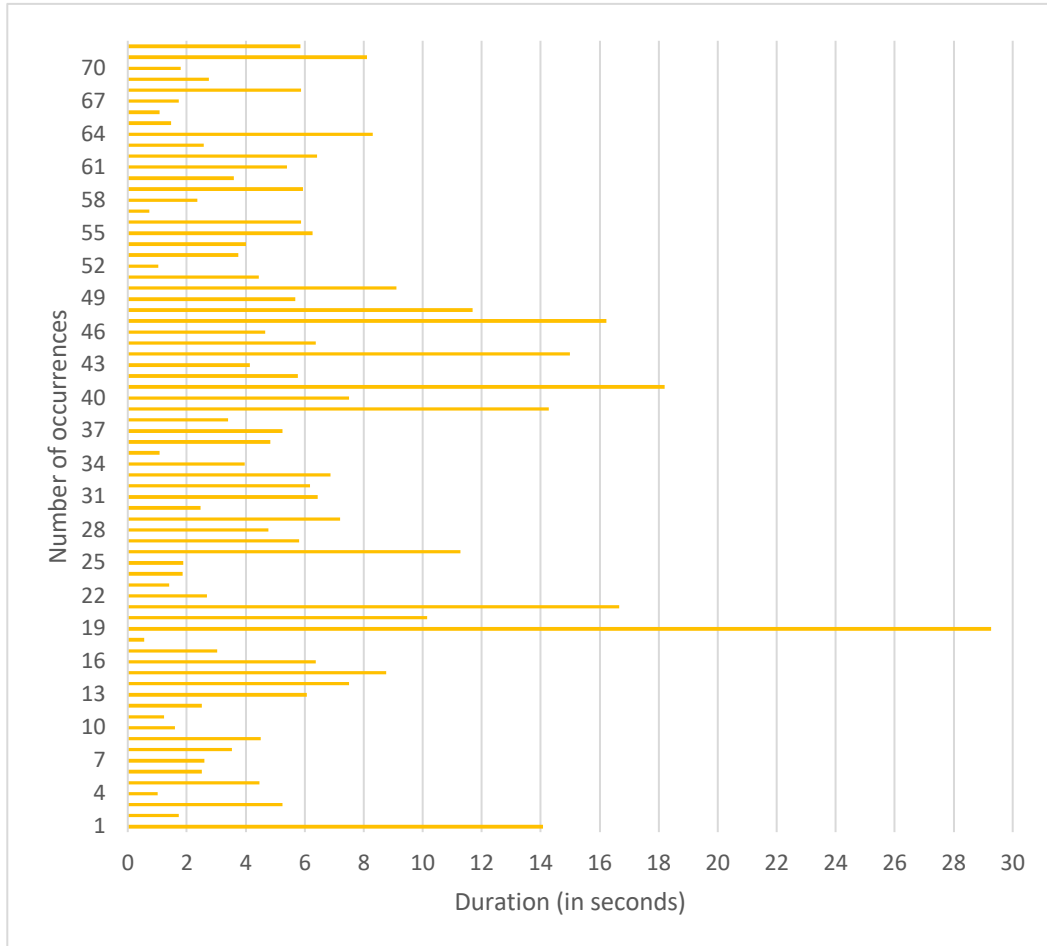


Figure 4.7

Case Study 1 Video 2: Face to Face Service Provider and Child.

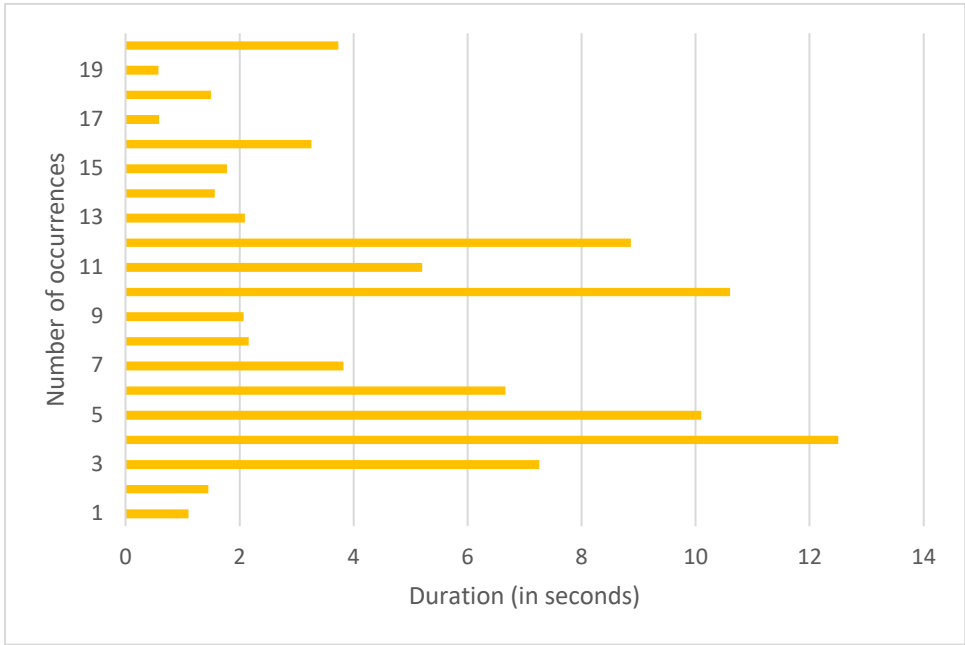


Figure 4.8

Case Study 1 Phase 2 Video 1: Face to Face Mother and Child.

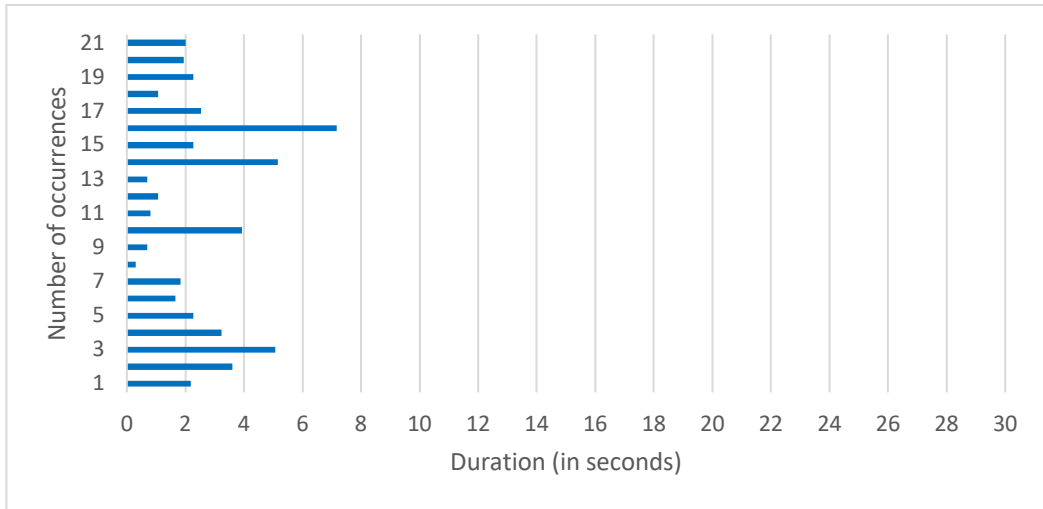
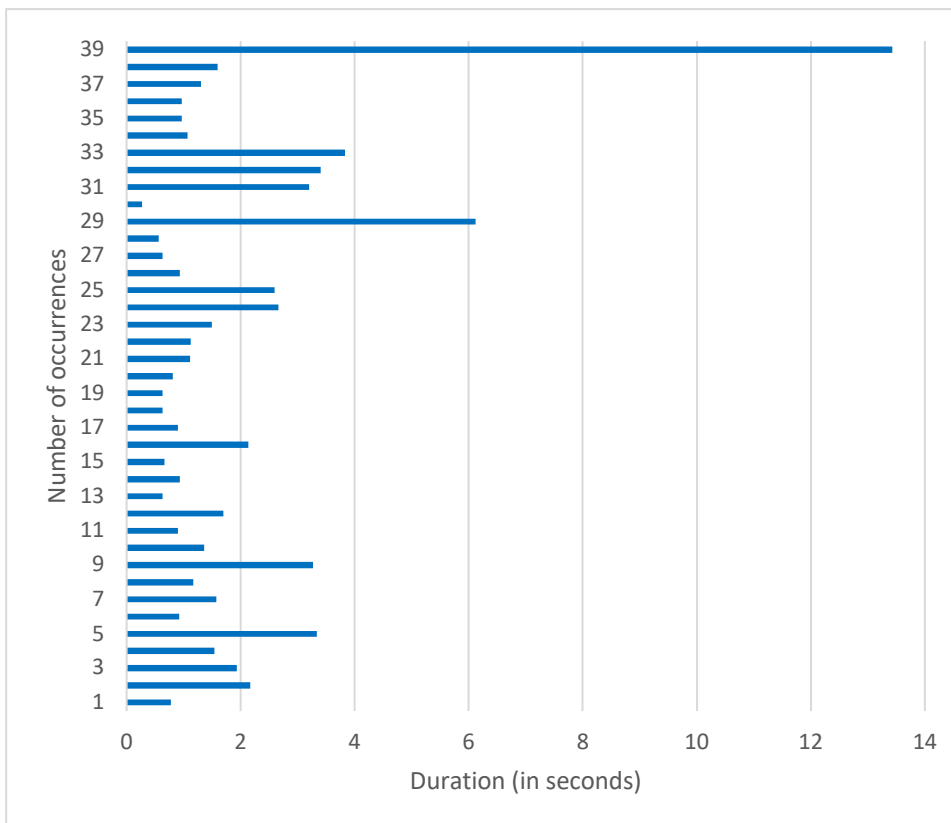


Figure 4.9

Case Study 1 Phase 2 Video 2: Face to Face Mother and Child.



For the *DIR/Floortime* code category (see Figures 4.10 and 4.11), in video 1, Sarah had a greater number of ‘turn-taking’ moments with Rosa than Ali, but in video 2, Ali had the greater amount. Across the two videos, Ali achieved the most amount of ‘turn-taking’ with Rosa. In Figures 4.10 and 4.11, Ali was coded as having more occurrences of ‘joint attention’ with Rosa, than Sarah with Rosa (see Table 4.3 for a definition). In terms of duration, on average in video 1, Sarah and Ali spent around the same time in ‘joint attention’ with Rosa – 17 seconds (see Figures 4.12 and 4.13). This was the same for video 2, with Rosa spending an average of 9 seconds in ‘joint attention’ with both Ali and Sarah (see Figures 4.14 and 4.15).

Figure 4.10

Case Study 1 Phase 2 Video 1: DIR/Floortime Codes.

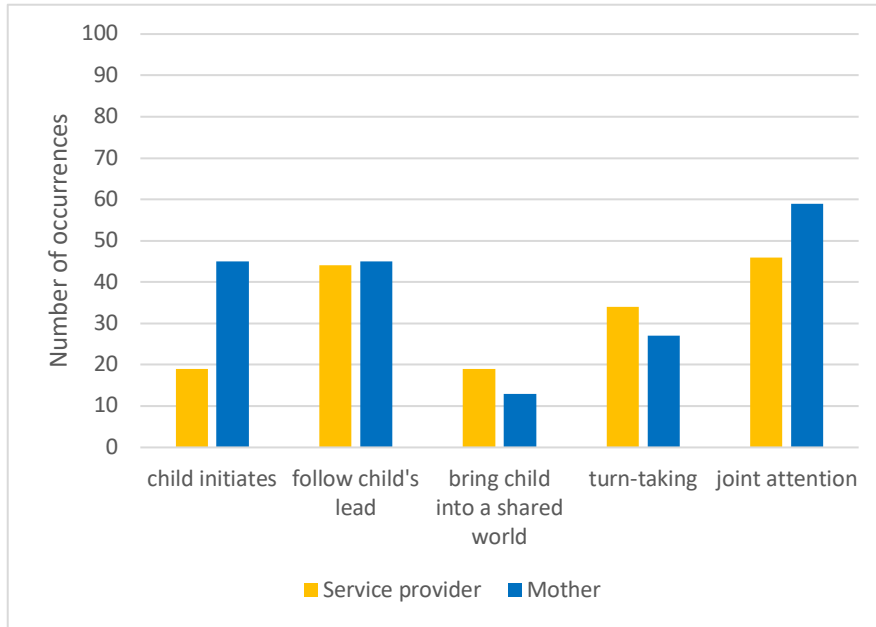


Figure 4.11

Case Study 1 Phase 2 Video 2: DIR/Floortime Codes.

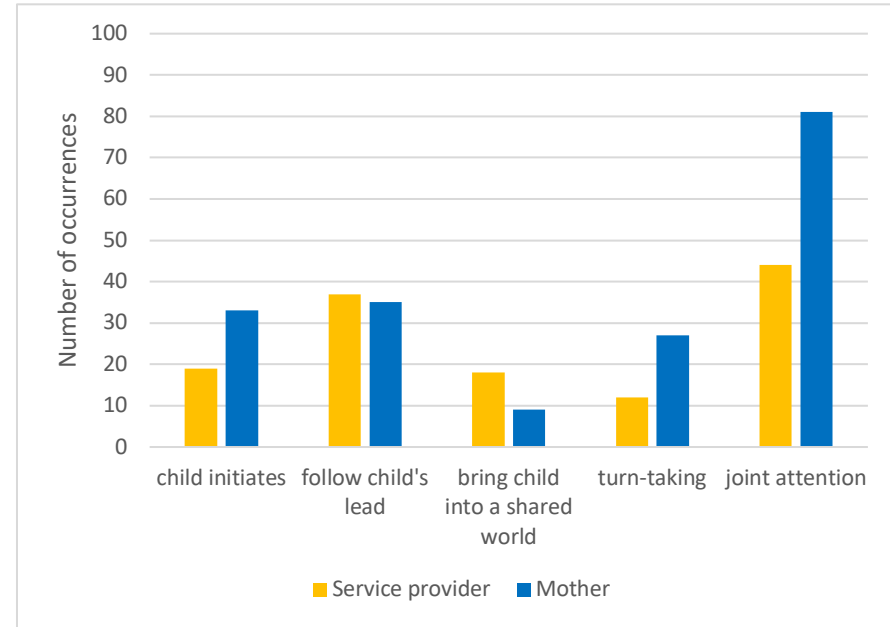


Figure 4.12

Case Study 1 Phase 2 Video 1: Joint Attention Service Provider and Child.

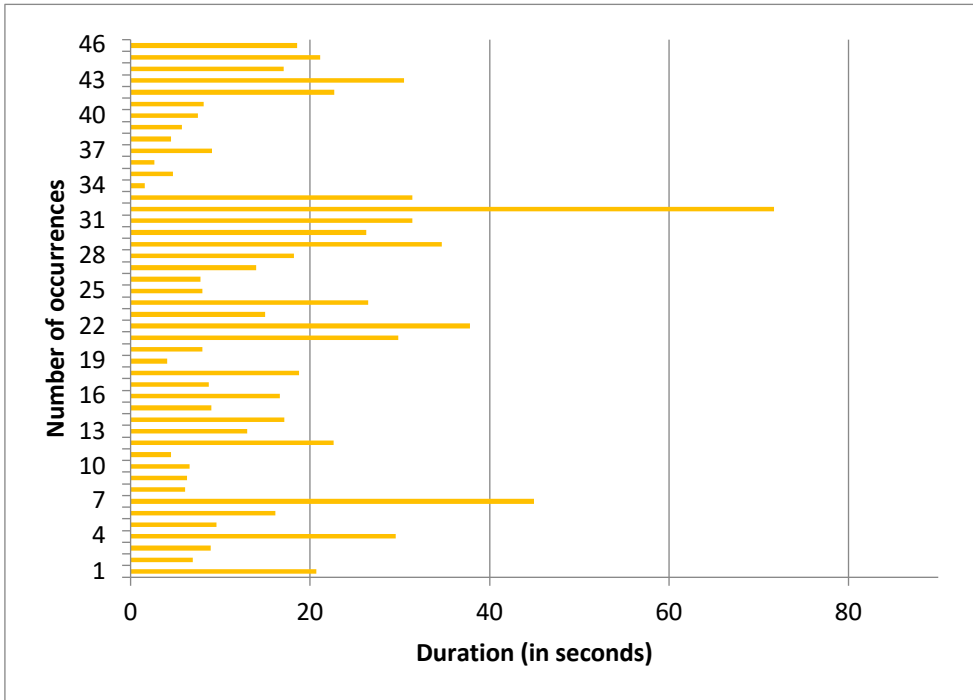


Figure 4.13

Case Study 1 Phase 2 Video 1: Joint Attention Mother and Child.

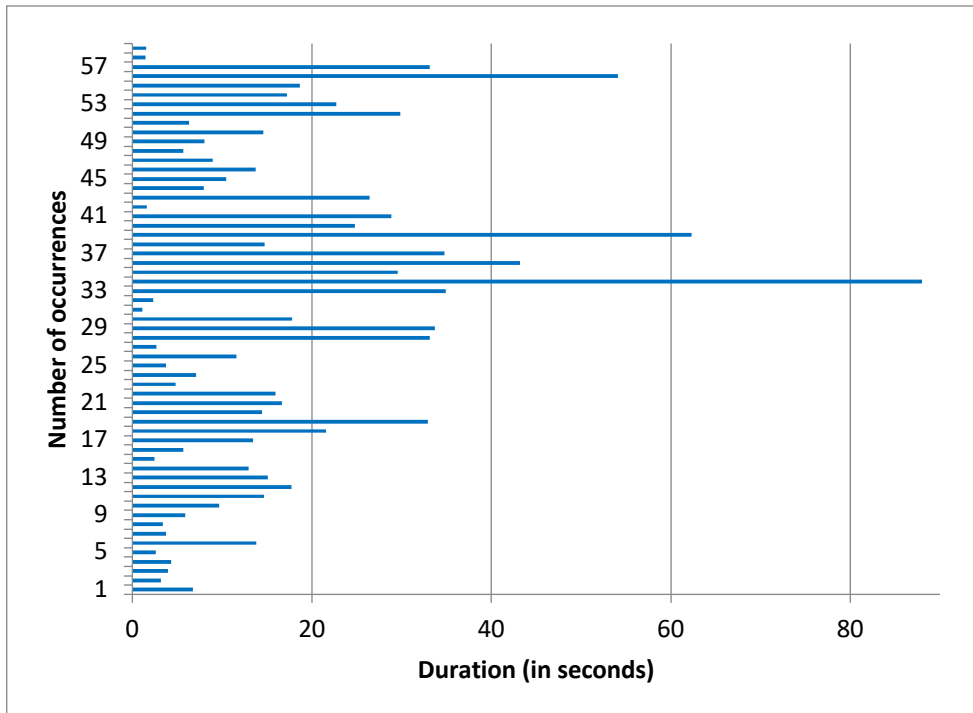


Figure 4.14

Case Study 1 Phase 2 Video 2: Joint Attention Service Provider and Child.

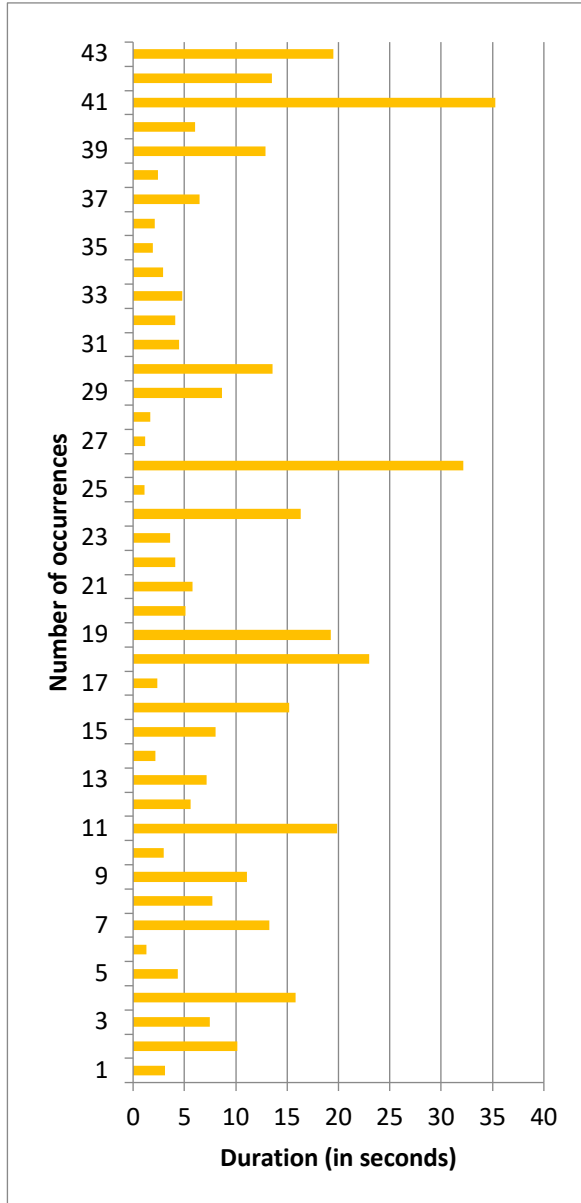
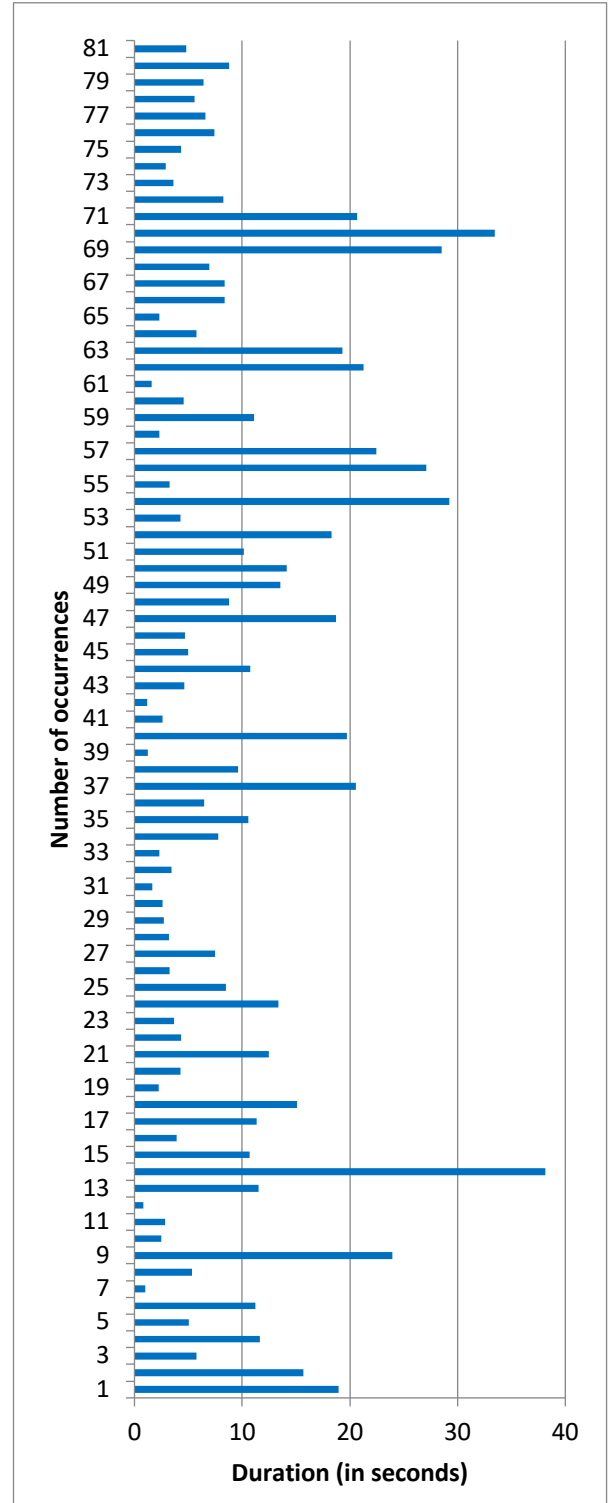


Figure 4.15

Case Study 1 Phase 2 Video 2: Joint Attention Mother and Child.



For the *Auditory-verbal therapy* code category (Figures 4.16 and 4.17), Rosa was coded as vocalising in response to, or towards Sarah, more than Ali in video 1. However, in video 2, the opposite was true. For ‘child gestures’, Rosa was coded as having gestured in response to, or towards Ali more than Sarah in both videos. Figures 4.16 and 4.17 also show Sarah’s high usage of ‘acoustic highlighting’. In comparison, Ali used ‘acoustic highlighting’ fewer times, though her usage showed an increase in video 2. Ali was coded using ‘motherese’ more than Sarah, across both videos. Looking specifically at Ali’s use of ‘acoustic highlighting’, ‘ling sounds’, ‘motherese’ and ‘singing’, from video 1 to video 2, there was an increase in the total number of these codes. However, Rosa’s total responses to Ali, did not increase a significant amount but rather remained about the same. In other words, although Ali’s use of auditory-verbal therapy techniques had increased (namely ‘acoustic highlighting’), Rosa’s responses had not.



Figure 4.16

Case Study 1 Phase 2 Video 1: Auditory-verbal Therapy Codes.

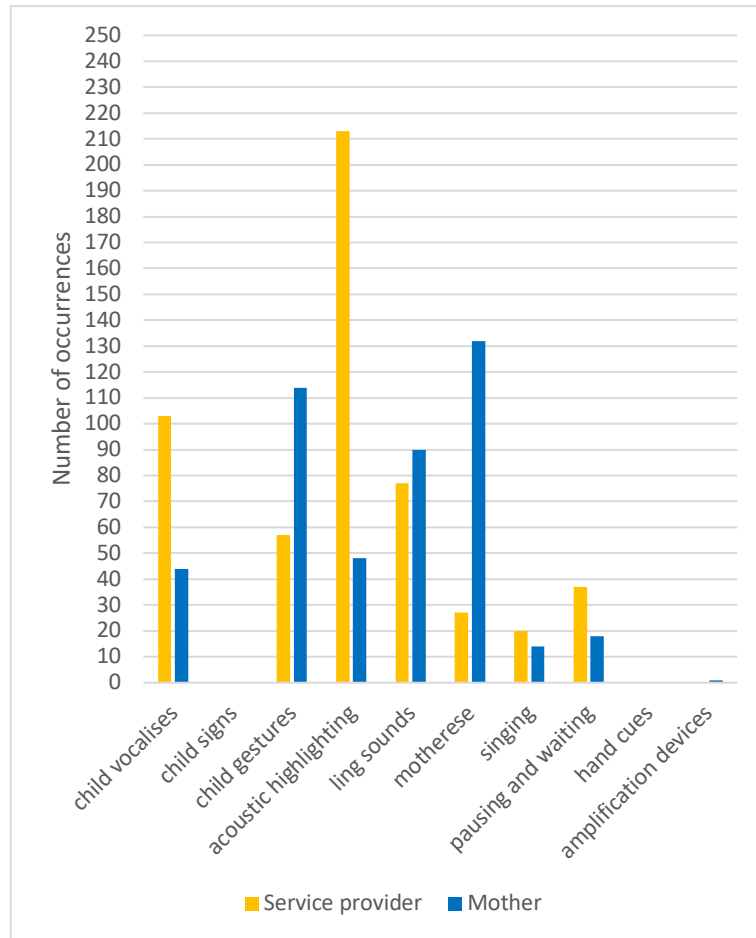
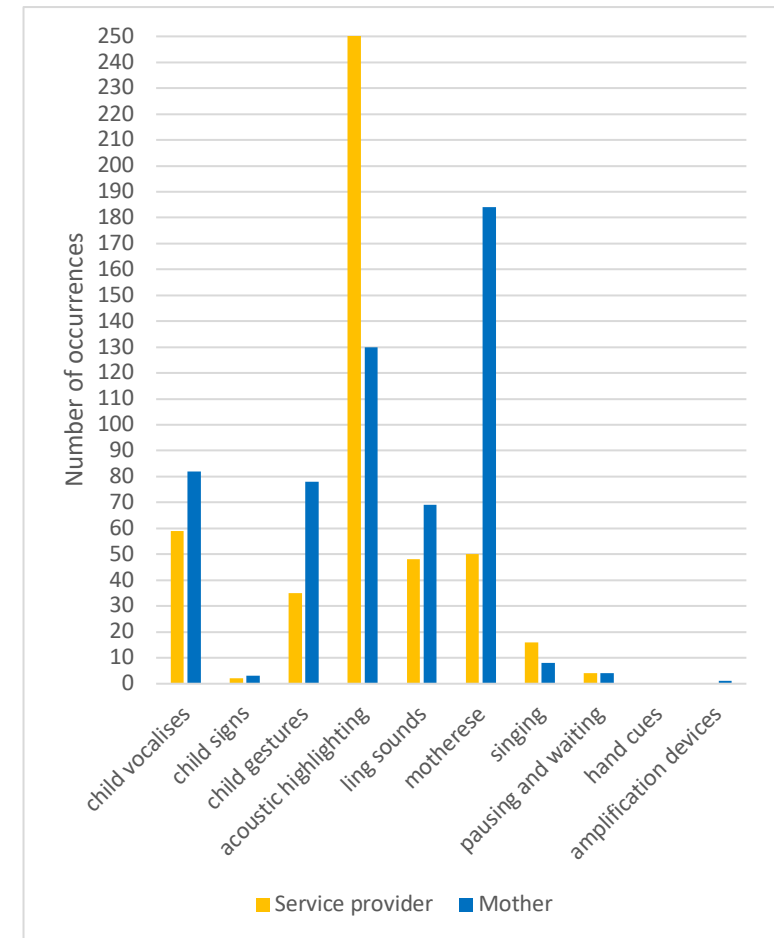


Figure 4.17

Case Study 1 Phase 2 Video 2: Auditory-verbal Therapy Codes.



Regarding their ability to pause and wait, Sarah paused and waited for Rosa during their interactions, more times than Ali (see Appendix L). Though in terms of averages, Sarah and Ali paused and waited for approximately the same duration in video 1, 4 seconds, and in video 2, 6-7 seconds (see Appendix L). For the code category of *Interactional elements*, (see Figures 4.18 and 4.19) salient differences were in the number of times Sarah and Ali used ‘praise’ and ‘instruction’ when interacting with Rosa. In both videos, Sarah praised Rosa more times than Ali. Regarding instructions, Ali directed Rosa more times than Sarah.

Figure 4.18

*Case Study 1 Phase 2 Video 1: Interactional Elements Codes.*

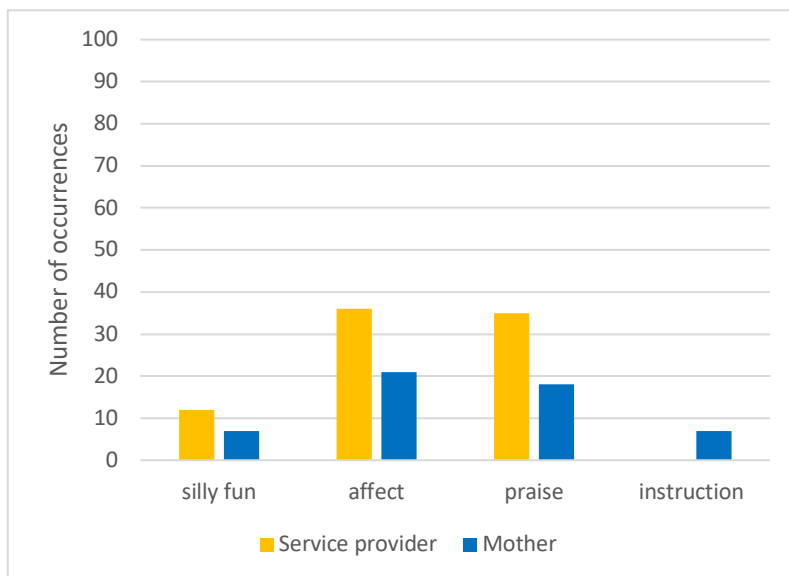
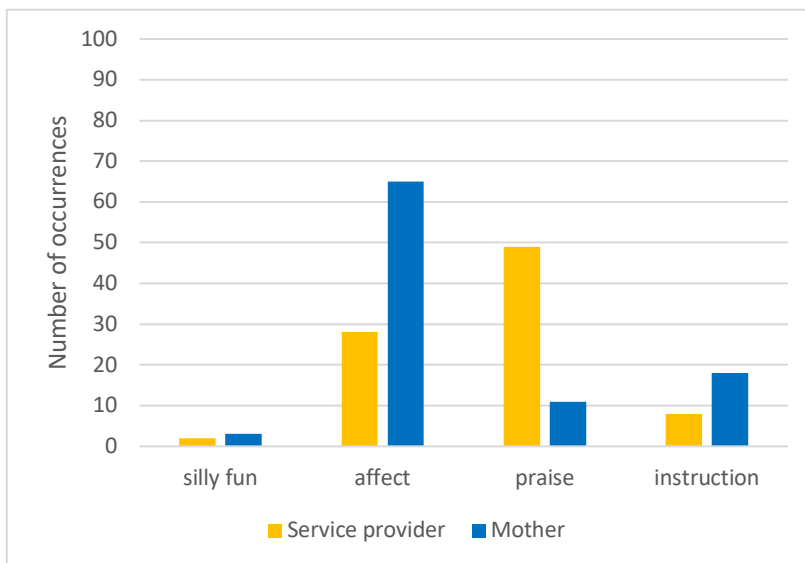


Figure 4.19

*Case Study 1 Phase 2 Video 2: Interactional Elements Codes.*



The last code category – *Service Provider and Mother relationship* – consisted of codes that attempt to capture the interactions between Sarah and Ali during therapy sessions (see Figures 4.20 and 4.21). Of salience is the decrease in occurrences of Sarah modelling, which may suggest Ali’s growth in early intervention techniques as well as her sensitive interactions with Rosa. There was also a decrease in Ali carrying out the therapy prompted by Sarah, however interestingly, there was no increase in her doing therapy unprompted by Sarah.

Overall, the major findings show Sarah’s expertise in early childhood intervention techniques and strategies, evidenced by Rosa being engaged by Sarah (e.g. amount of face to face time together). The data also reflect Sarah’s ability to model these for Ali, as evidenced by Ali’s improvement in her use of the techniques (e.g. her increased use of ‘acoustic highlighting’ across videos 1 and 2).

Figure 4.20

Case Study 1 Phase 2 Video 1: Service Provider and Mother Relationship.

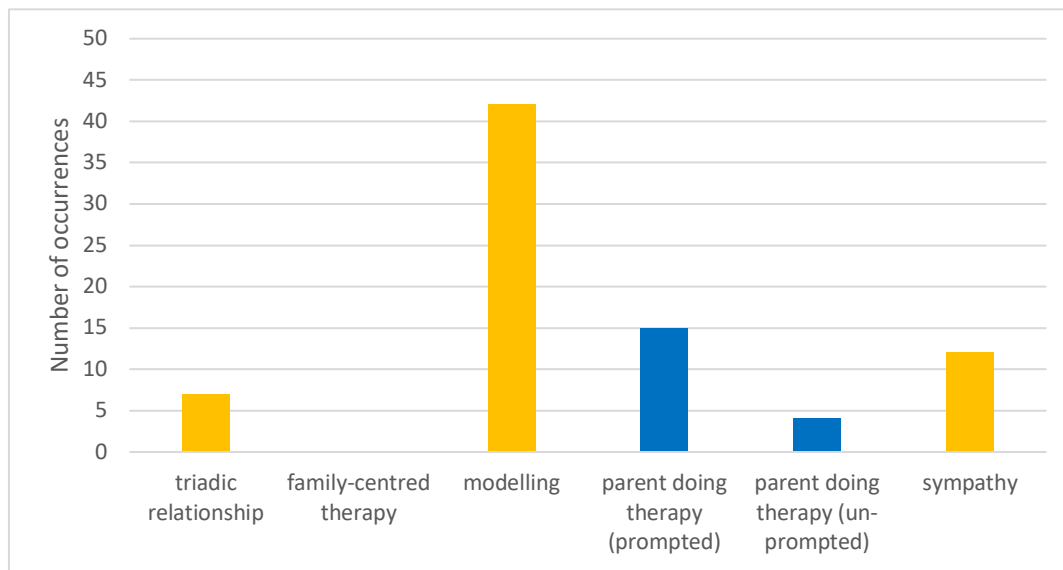
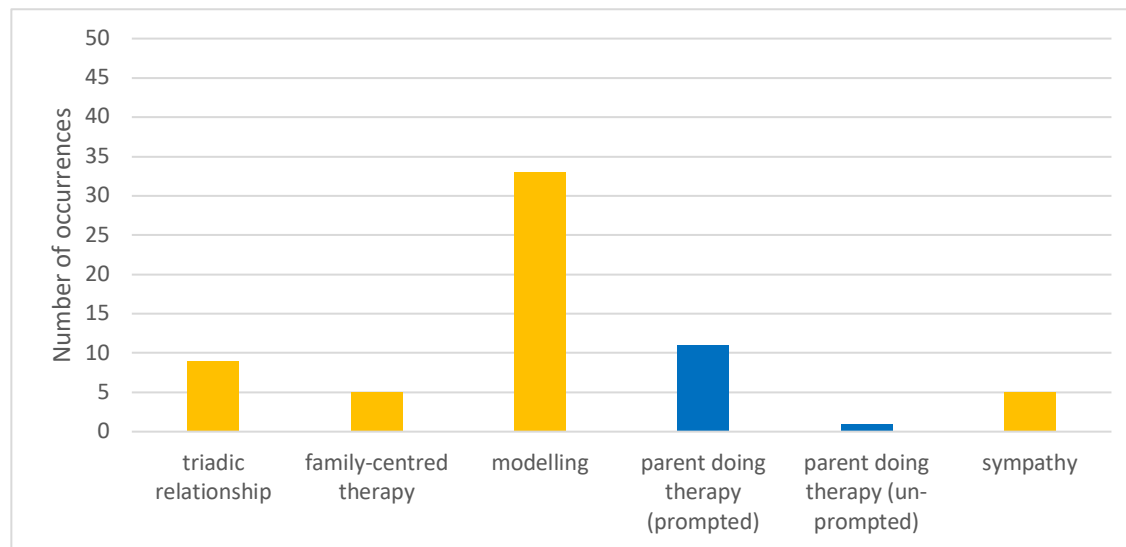


Figure 4.21

Case Study 1 Phase 2 Video 2: Service Provider and Mother Relationship.



**Limitations.** The first video was taken using a poor-quality Canon camera, which limited the researcher's ability to view and analyse the session from a wide-angle shot. Also, the iPhone 6 did not have a tripod, therefore some parts of the video taken was poor in quality. Moreover, the sound quality was not optimum as no microphone was used.

In terms of coding and analysis of the videos, upon coding the two videos in Phase 2, the researcher found that the process was too lengthy. Furthermore, a number of the video codes were

either too abstract, redundant or deemed unnecessary. For example, the researcher questioned the purpose of counting all occurrences of other therapies used; whether or not this helped to understand the attachment relationships that were forming.

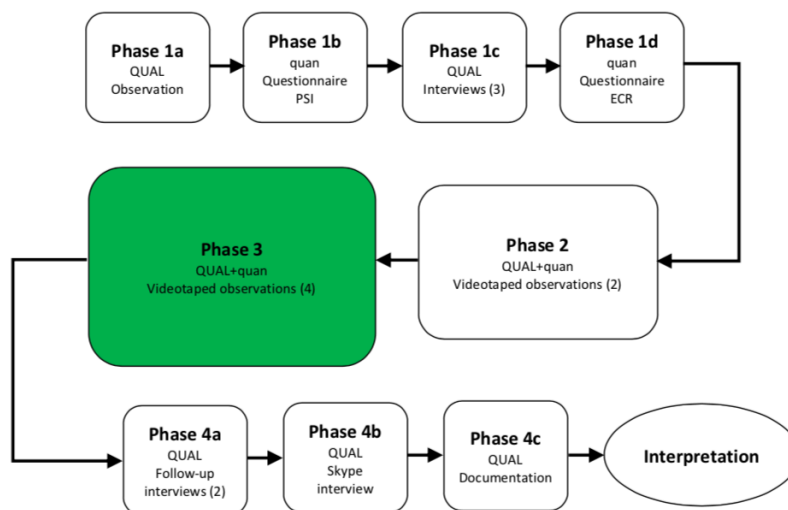
***Implications.*** The researcher ensured that better video and audio equipment was used for Phase 3, including a microphone system, an iPhone tripod, and better cameras for different camera angle shots. These Phase 2 videos were taken at the participants' home, therefore any factors related to a home environment need to be considered when comparing these videos with the subsequent videos taken at the ECIC. For example, the presence of relatives in the second Phase 1 video was an unexpected variable, whereas during the Phase 3 videos, any people to be present during the therapy session were advised beforehand.

Due to the large number of codes, as well as some codes that did not emerge during coding, the researcher chose to revise the coding scheme with the help of Louise, the key informant. Thus for subsequent video coding, 40 codes were reduced down to 18 codes (see Appendix M for the revised video-coding scheme). These codes were more specific and focussed on the attachment behaviours exhibited by the infant, and the caregiving behaviours exhibited by the mother and service provider. More abstract codes such as 'modelling' or the code category *Other therapy*, were either taken out or analysed qualitatively, with results presented as a written discussion of any trends that emerged across the videos over time. The results of the Phase 3 videos using this revised coding scheme are detailed in the following section.

### ***Phase 3***

Phase 3 videotaped observations were collated to analyse the interactions and behaviours of the infant with HL-CN, her mother and service provider. Analysis techniques included: the *Child-Adult Relationship Experimental Index* (CARE-Index) (Crittenden, 2008), qualitative descriptions, as well as a revised video-coding scheme, following the pilot video-coding scheme used in Phase 2.

## Videotaped Observations.



**Collection.** Three types of cameras were used to video record during Phase 3 (for a detailed description see p. 101 in Chapter 3 Methodology). Each of the video-recording sessions was taken during the scheduled therapy session of the infant on a Friday morning, at the ECIC. Videotaping occurred four times over a period of 4 months, with approximately 1 month separating each video recording. For the first recording, only a 10-minute play interaction between mother and infant, before the therapy session, was recorded. Neither the researcher nor the service provider was in the room during this video recording. Following this 10-minute play interaction, the service provider and researcher entered the room, and the therapy session commenced as usual. This first video recording differed from subsequent video recordings as it was to be analysed using CARE-Index. It followed the CARE-Index video recording protocols, which involved taping mother-infant play for 3 to 5 minutes, with or without toys, at the participant's home, in a laboratory setting, or a clinical setting (Crittenden, 2008).

For the three subsequent recordings, the child's whole therapy session was videotaped as they were to be analysed using the researcher's coding scheme. Present during these video-recorded sessions were: the mother, the child, the service provider, and the researcher. During the video recording of therapy sessions, the researcher sat behind either the Canon or Samsung cameras, which

were positioned in the left and right corners of the room to capture side angles of the participants. The researcher adjusted the Canon and Samsung cameras to follow the participants' movements.

*Analysis.* The videos recorded during the third phase were analysed using the CARE-Index (Crittenden, 2008), qualitative descriptions written by the researcher, and the researcher's own quantitative coding scheme (discussed below) derived from constructs that emerged in the interviews and the academic literature on attachment and infants with HL-CN. Each video recorded session was analysed separately.

*Child-Adult Relationship Experimental Index (CARE-Index).* This instrument was used to analyse video 1 – the 10-minute mother-infant play session. The CARE-Index measures mother-infant interaction, based on a 3 to 5-minute videotaped play interaction (Crittenden, 2008). It assesses mothers on: sensitivity, control and unresponsiveness, and measures infants on: cooperativeness, compulsivity, difficultness, and passivity (Crittenden, 2008). Specifically, the CARE-Index defines sensitivity as “adult sensitivity in play is any pattern of behaviour that pleases the infant and increases the infant's comfort and attentiveness and reduces distress and disengagement” (Crittenden, 2010, p.8). The researcher was especially interested in the sensitivity score for the mother, as the literature attests to the causal link between caregiver sensitivity and attachment security (Bakermans-Kranenburg et al., 2003).

An external coder was asked to code a 5-minute segment from the 10-minute mother-infant play interaction, as outlined by the CARE-Index video recording protocols (Crittenden, 2008). The researcher had previously attended a video coding training session led by the external coder, in order to learn more about the CARE-Index. The CARE-Index training ran for several weeks and provided the researcher with valuable knowledge and insight on how to analyse caregiver sensitivity, as well as the interactional synchrony between mother and infant. Due to the importance of caregiver

sensitivity to secure attachment, this training with its focus on sensitivity, proved invaluable to the research study, equipping the researcher with the skills to analyse mother-infant interaction.

The external coder was chosen for her expertise in using this measurement tool, as well as to provide an unbiased lens, adding to the reliability of the study (Creswell, 2018; Yin, 2018). Moreover, the CARE-Index has been used as an effective analysis tool in other mother-infant studies (e.g., Crittenden & Bonvillian, 1984; Leadbeater, Bishop, & Raver, 1996; Leventhal, Jacobsen, Miller, & Quintana, 2004). The segment taken was from the second half of the 10-minute play interaction of the mother and child, and included the toy. The external coder was blind to the aims of the research study, the participants' profiles, and knew only the child's age and that she had a hearing loss.

***Qualitative descriptions and video codes.*** Qualitative and quantitative methods were used to analyse videos 2, 3 and 4. These videos were recordings of the entire therapy session. The researcher coded the videos to a point of saturation to ensure accuracy when coding the behaviours. While viewing the videos, the researcher wrote a description of the therapy sessions, and noted down any interactions, behaviours or dialogue that were of significance. In particular, the researcher noted any ECI strategies and techniques that were used by the service provider or mother. Having emerged as key constructs, the researcher focussed on the constructs of 'modelling' and 'empathy' to help analyse the relationship between the service provider and mother. Following this qualitative analysis, the researcher then coded the video sessions using the list of behavioural codes.

This list of codes was generated based on the literature and empirical evidence surrounding attachment and infants with HL-CN, as well as notable constructs that emerged from the interview responses in Phase 1. The codes were revised after using the original coding scheme to analyse the Phase 2 videos. After consulting Louise (the key informant), and reviewing which codes were not significant to the study, the 40 codes of the original coding scheme were condensed into 18 codes (see Appendix M). Each time one of the behavioural codes was observed, the researcher would mark this occurrence. Any trends in the coding that emerged across the videos were also noted.



**Results.** Results of the videos will begin with video 1 which was analysed using the CARE-Index. This is followed by the qualitative results of videos 2 to 4, followed then by the quantitative video coded data of these same videos.

### ***CARE-Index.***

The researcher chose Phase 3 video 1 – the 10-minute mother-child play interaction – to be analysed using the CARE-Index, having best fit the video-recording parameters as indicated by the CARE-Index manual. Adams, the external coder (a pseudonym is used) placed the mother and child in the upper high-risk group in the CARE-Index, and described the risk in the relationship as: “the development of a struggle between mother and baby which limits the developmentally necessary information about language and communication that the baby can access” (B. Adams, personal communication, August, 1, 2016).

The coder went on to describe the quality of play interaction during the video:

The baby is not looking at her mother much of the time, and the mother responds much more to the baby’s negative cues (for example by getting the second duck, and putting both ducks aside) than she does to any positive cues. The baby is doing very little – the activity is largely the mother doing things while the baby watches. The baby is more active when the mother is not watching – for example she touched the first duck’s beak while the mother went to get the second duck. (B. Adams, personal communication, August, 1, 2016)

The CARE-Index assesses the mother’s sensitivity using a 14-point scoring system. These 14 points are allocated across four types of descriptions: sensitive, control, unresponsive (active) and unresponsive (passive). In terms of scores on the scales assessed, the mother received 4 for sensitive,

0 for control and 10 for unresponsive (active). In other words, the mother's main pattern was unresponsive active, meaning that she was responding to the infant in her mind, though was not using the information from her actual infant to guide her behaviour. An example of this was when Ali instructed Rosa to pull a sheet off a toy, though did not give her time to do so. Ali said brightly "you can do it, Rosa do" but Rosa did not react and so Ali went on to say "ah ah" and started to pull off the sheet. Rosa then reached for the sheet then feebly pushed it away, and moved her body down and sideways as Ali pulled it off. Furthermore, the coder noted that while the mother's behaviours (e.g. naming objects, counting down, repetition) were developmentally appropriate, she was not doing them in synchrony with the infant, and so could not use them to scaffold the infant's development.

For the infant scales assessed, the infant scored 3 points of cooperative, 0 points of compulsive, 4 points of difficult, and 7 points of passive. Therefore, the infant's main pattern was passive and difficult. According to the coder, the infant's lack of initiative and involvement reflected the passive pattern, and her refusal to respond to her mother's invitations, and the negative tone of her voice and face were coded difficult. Rosa's passive and difficult behaviours suggest that she did not find her mother engaging, and was resisting Ali's attempts to interact with her. In terms of their developing attachment, this could prove problematic as the pair were not attuned to each other's signals.

According to the external coder, the best part of the interaction "were the small moments when the mother and baby looked at each other" (B. Adams, personal communication, August, 1, 2016). However, she commented that this did not lead to a "broader connection" between the two. The mother was focussed on trying to use language during their play interaction, but because the child was not attending to her mother, the coder noted that the child received little benefit from this. The child was more focussed on "the affective elements of their relationship, and eliciting predictable signals from her mother" (B. Adams, personal communication, August, 1, 2016).

The coder described the mother as giving mixed signals to her child. For example, when Rosa gestured to a different activity instead of paying attention to the current activity, Ali responded to this "negative signal", which the coder described as having "not improve[d] the overall interaction".

Another example was when Ali said that Rosa was able to do something, though proceeded to do the activity for her and said “ready?” yet did not pause to allow Rosa time to look up towards her and the activity. The coder commented that these mixed signals “increase the child’s frustration, and mean that her negative communications have more power than cooperative behaviours, as her mother stops what she is doing to attend to these”. Interestingly, the coder commented: “it was very striking that the baby’s limited exploration was more evident when her mother was not looking” (B. Adams, personal communication, August, 1, 2016).

To increase the quality of interaction between the mother and infant, the coder recommended that a therapist work individually with the mother to help her slow down her interaction and watch for the infant’s signals. She also noted that Ali’s overbright affect might have added to the difficulty, as it was very discrepant from Rosa’s affect. The coder suggested that the mother needed “a safe and encouraging environment and possibly some therapeutic work around her own expectations of parenting and representations of her child to enable her to ‘tone down’ her presentation so that baby is not so overwhelmed” (B. Adams, personal communication, August, 1, 2016).

These results support the conclusions drawn from the analysis of the Phase 2 videos. That is, that the interactions between Rosa and her mother Ali had room for improvement. Moreover, Ali’s sensitivity assessment reflects her preoccupation with Rosa’s therapy and progress, and not with Rosa herself, as discussed by Sarah in the Phase 1 interviews. As the CARE-Index coder noted, Ali was responding largely to the infant in her mind, and not to the behaviours and cues that Rosa was actually giving during the playful interaction.

***Qualitative descriptions.*** Key constructs that were used to analyse the videos 2 to 4 included: ‘emotion regulation’, ‘anxiety’, ‘misattunement’, ‘empathy’, ‘active listening’, ‘parent-led therapy’, ‘child-centred therapy’, ‘coaching’, and ‘modelling’.

*Video codes.* Results of the video coding analysis for each videotaped session are displayed in Figures 4.22 to 4.45. Each therapy session lasted for 40 to 50 minutes. Eighteen codes were used to video analyse videos 2-4 (see Appendix M). The 15 momentary events (codes) were categorised into three categories: ‘Facial expression and body language’, ‘Circles of communication’ and ‘Vocal interaction’. The remaining codes were ranged events: ‘pausing and waiting’, ‘joint attention’, and ‘shared connection’. Interactions and behaviours between participants were analysed using these codes.



In video 2, Sarah and Ali began to work together when they played with Rosa, showing a move towards parent-led therapy, rather than the service provider-led therapy seen in the Phase 2 videos. Parent-led therapy is therapy where the parent takes the lead in the decisions and actions made during the therapy session, with the service provider supporting the parent. This is opposite to service provider-led therapy, where the service provider takes charge of the therapy session with her own goals in mind. In the Phase 2 videos, Sarah introduced an activity or toy, and passed it onto Ali for her to play with Rosa. Another example was when Sarah read an animal book to Rosa, she gave Ali a bag full of animal toys. Whenever Sarah would read about a certain animal, Ali would take out the corresponding animal for Rosa to explore. Here we see Sarah ‘coaching’ Ali in that she prompted her when to interact with Rosa.

An important construct observed was child-centred therapy. This type of therapy is focussed on the child and the service provider and parent follow the lead of the child during the therapy session. Sarah would often follow Rosa’s lead or interest, either following her gaze to an object, or copying her babbling and games. For example, Rosa played the “where is it?” game a number of times, where

she would hide a toy behind her back and sign “where?”. Sarah and Ali would frequently copy Rosa when she did this. Whenever Rosa said a word, or tried to articulate a word, Sarah would repeat the word, or shape Rosa’s utterance into a word related to the activity they were doing.

Sarah was adept in coaching Ali in speech and language therapy techniques. For example, when playing with a toy snake, Sarah could hear Rosa faintly saying “sss, sss, sss”, and cued Ali into this. Sarah would use acoustic highlighting, either emphasising certain vowels in a word by raising the pitch of her voice, or saying sounds softly. In response, Rosa would often try to imitate Sarah, and though she did not always articulate the word, she was able to babble using the same pitch and intonation as Sarah. While Ali often used motherese when speaking to Rosa, she did not always use acoustic highlighting as Sarah did. For example, when playing with bubbles, Ali repeatedly said “pop!” loudly, though Rosa did not imitate her. Seeing this, it seemed that Sarah decided to change her tone and say, “pop” softly instead. Sarah cued Ali into this and suggested she blow the bubbles off of Rosa’s hands – an example of ‘modelling’. This appeared to engage Rosa a lot as she tried to pop the bubbles.

One instance where Sarah and Ali did not follow Rosa’s lead was during water play with ducks. Both caregivers kept trying to encourage Rosa to put the ducks in the water. However, Rosa simply wanted to play with the water, splashing with her hands. Eventually Sarah realised what Rosa was interested in, but Ali kept instructing Rosa to put the ducks in the water. Ali appeared to be anxious and perhaps frustrated as Rosa continued to play with the water. Her concerned facial expression, biting her nails, and her persistence showed that she did not seem satisfied with Rosa playing “splash”. Rosa eventually followed her mum’s instructions, but then took all the ducks out after she completed what her mum wanted her to do. This was one example of ‘misattunement’ to the child’s behavioural cues. Another example of ‘misattunement’ was in the area of Ali’s facial expressions and vocalisations. She would frequently have overly positive and excited expressions, as well as high-pitched vocal intonation. This would not have been problematic if Rosa expressed a similar level of positivity, however often Rosa would have a flat affect.

Interestingly, there were at least four moments where Ali and Rosa were playing, and Rosa would either turn away from her mother, or reference Sarah. This sometimes occurred when Sarah would speak, and Rosa would turn towards her immediately, even if she was engaged in play with her mother. This behaviour could also have been an example of ‘self-regulation’, where Rosa averted her mother’s gaze, or turned away from her at times when she was overstimulated.

Regarding their attunement to Rosa’s affect, Sarah and Ali were able to engage Rosa and tune into her wants and emotions more so than in the previous two videos in Phase 2. Rosa and Sarah shared a couple of moments together where they looked like they were attuned and engaged. Ali and Rosa also shared a couple of moments of engagement. Ali often seemed concerned with making sure that Rosa followed their instructions, for example, making sure Rosa put the toy duck in the water. During this instance, Sarah gently reminded Ali that Rosa was still interested in splashing the water with her hands, then in putting the duck in the water. Sarah and Ali also noticed when Rosa’s mood changed. For example, Sarah commented that she thought Rosa looked a bit worried about the toy frog. This example reveals Rosa’s ‘anxiety’ and thus developing ‘self-regulation’, and how Sarah was able to tune into this, as well as some ‘anxiety’ experienced by Ali. Sarah coached and often encouraged Ali in her play interactions with Rosa. One example was when Sarah heard Rosa make the ‘shh’ sound, and she then looked at Ali to check that she had heard her too. This seemed to affirm Ali and her efforts with Rosa.

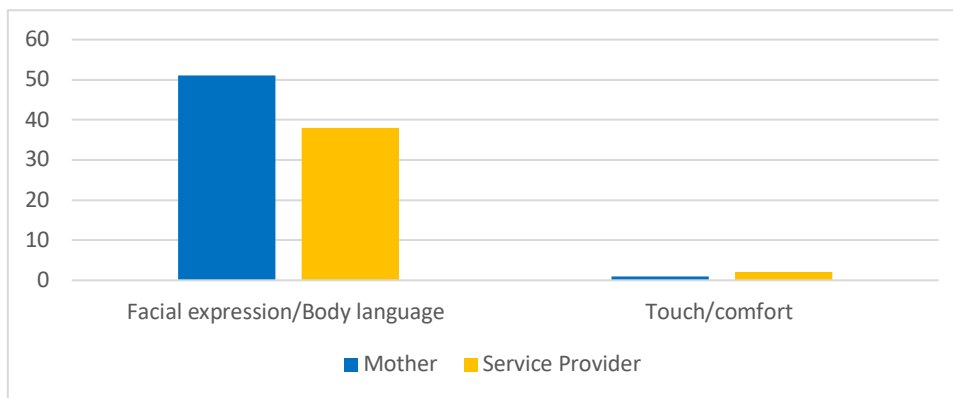
Overall, video 2 showed Sarah and Ali working together a lot more when compared with the Phase 2 videos. In comparison to the Phase 2 videos, this video had more interaction between just Ali and Rosa, with Sarah stepping back to a more supportive role. Sarah still coached and modelled for Ali, often prompting her to interact with Rosa.

## Video codes

As seen in Figure 4.22, Rosa's mother Ali was coded as having more occurrences of 'Facial expression/Body language' than Sarah. This trend appears to continue in videos 3 and 4 (see Figures 4.31 and 4.34).

Figure 4.22

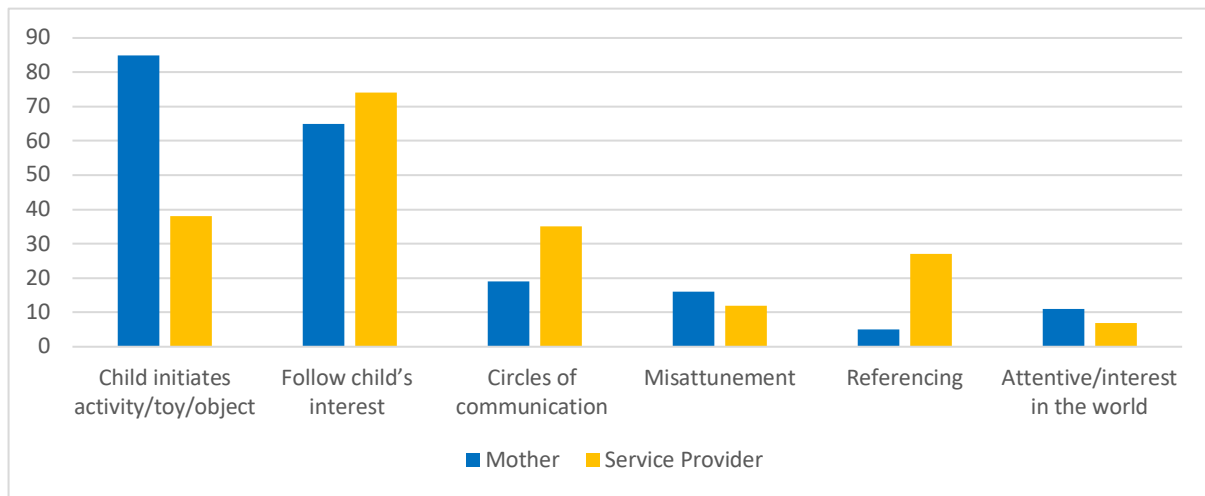
*Case Study 1 Phase 3 Video 2: Facial Expression and Body Language.*



Regarding the category 'Circles of communication', (see Figure 4.23 below), a major trend that emerged was Rosa and Sarah completing several circles of communication. Another trend indicates that Ali had more instances of 'misattunement' towards Rosa in comparison to Sarah. These results show Sarah's expertise in using DIR/Floortime. It also showed Ali continuing to learn how to read her daughter's behavioural and affective cues, with the instances of completed circles of communication between Ali and Rosa remaining much the same across the three videos (see Figures 4.23, 4.32, and 4.35).

Figure 4.23

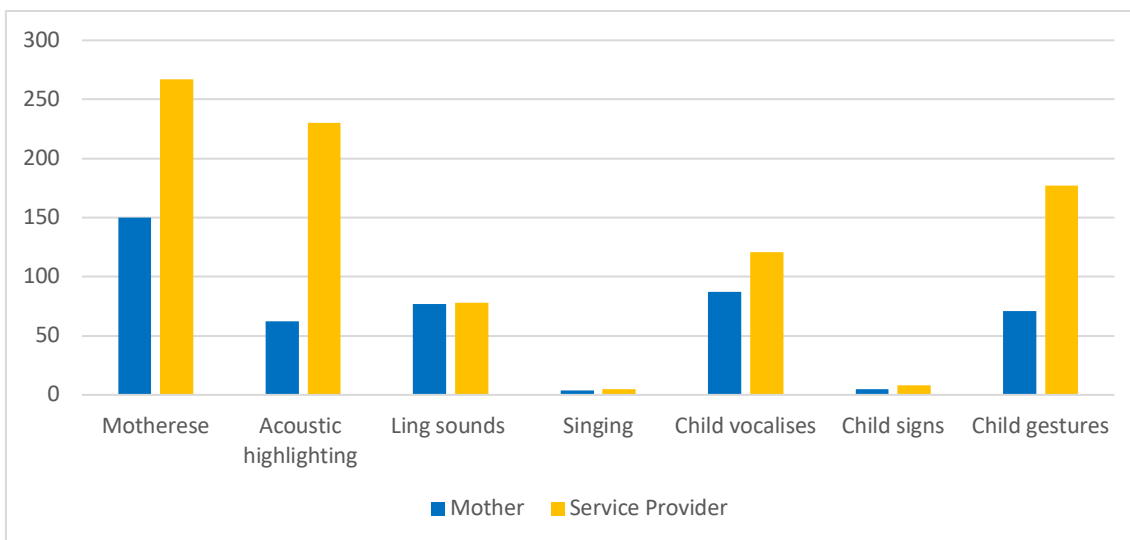
Case Study 1 Phase 3 Video 2: Circles of Communication.



For the code category 'Vocal interaction', in video 2, Sarah is shown with a greater amount of all codes in comparison to Ali. Moreover, Rosa is shown responding to Sarah more times than she does to her mother Ali.

Figure 4.24

Case Study 1 Phase 3 Video 2: Vocal Interaction.





In video 2, Figures 4.25 to 4.28 show that Sarah gave Rosa more time to process or respond, shared more times in ‘Joint attention’ with her, as well as more times of ‘Social connection’, in comparison with Ali.

Figure 4.25

*Case Study 1 Phase 3 Video 2: Pausing and Waiting for Mother.*

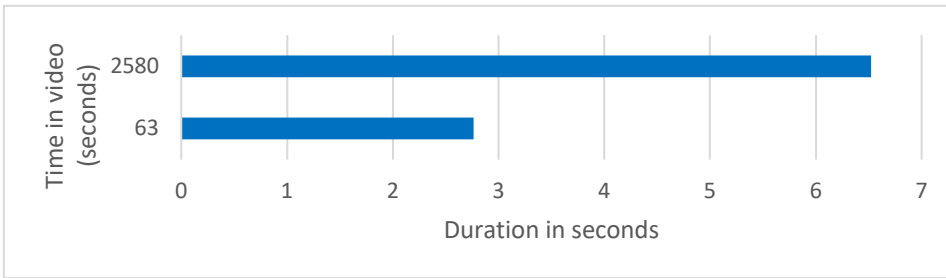


Figure 4.26

*Case Study 1 Phase 3 Video 2: Pausing and Waiting for Service Provider.*

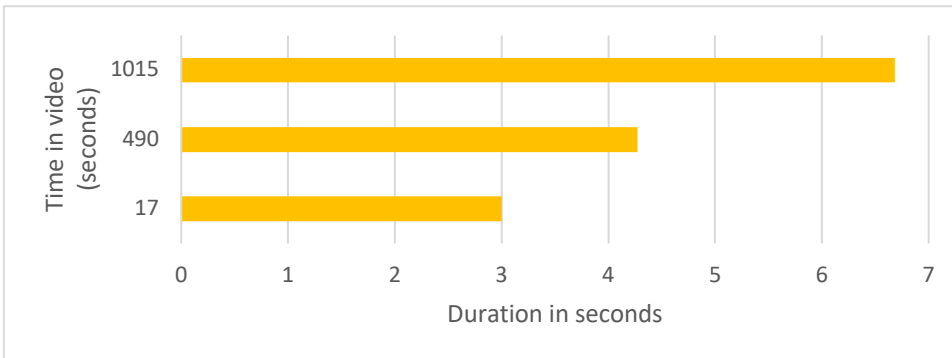


Figure 4.27

Case Study 1 phase 3 video 2: Joint attention between Mother and Child.

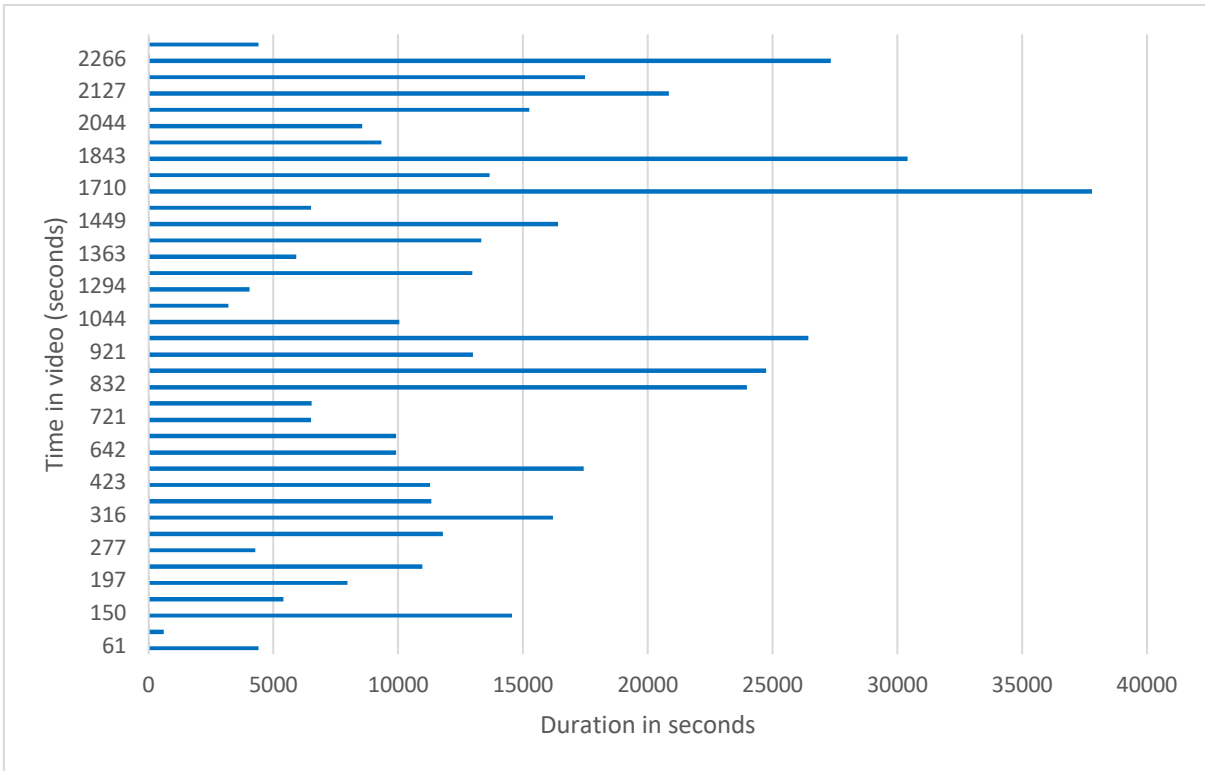
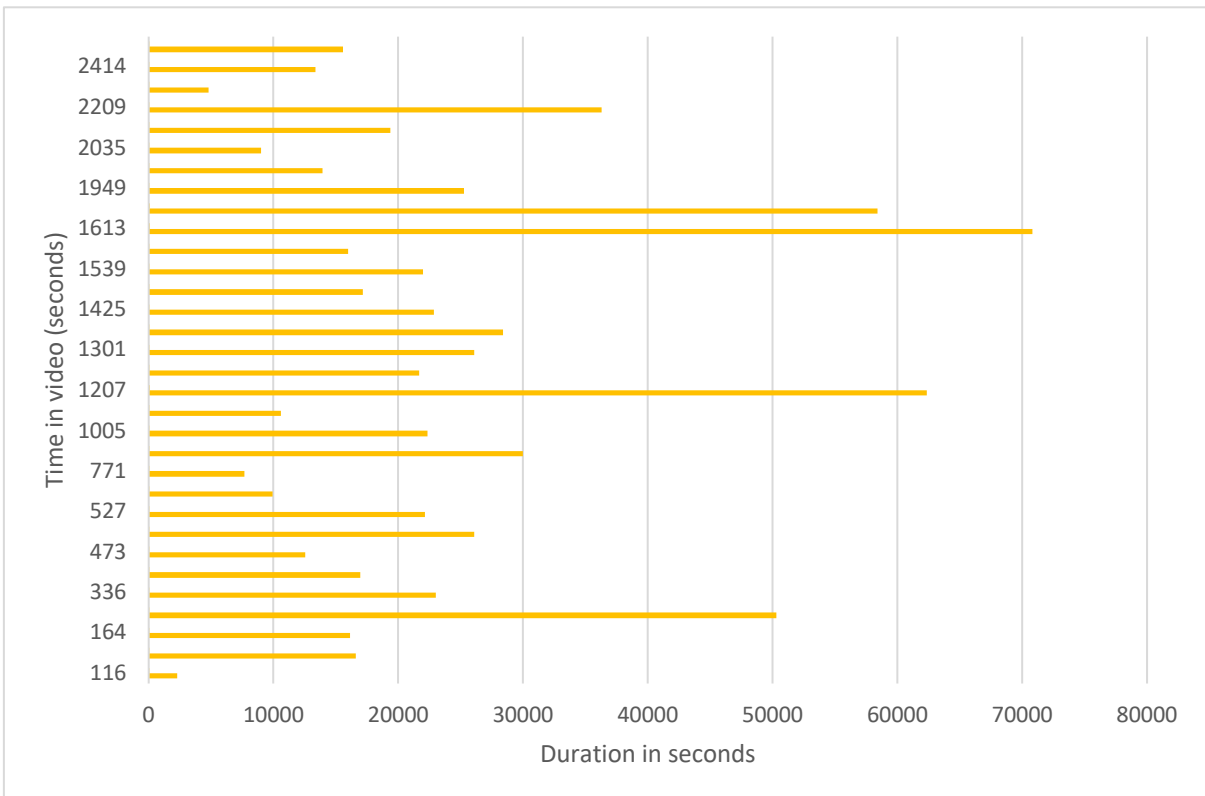


Figure 4.28

Case Study 1 Phase 3 Video 2: Joint Attention between Service Provider and Child.



Finally, video 2 also reveals that Rosa and Sarah experienced more social connection than Rosa and Ali (Figures 4.29 and 4.30).

Figure 4.29

*Case Study 1 Phase 3 Video 2: Social Connection between Mother and Child.*

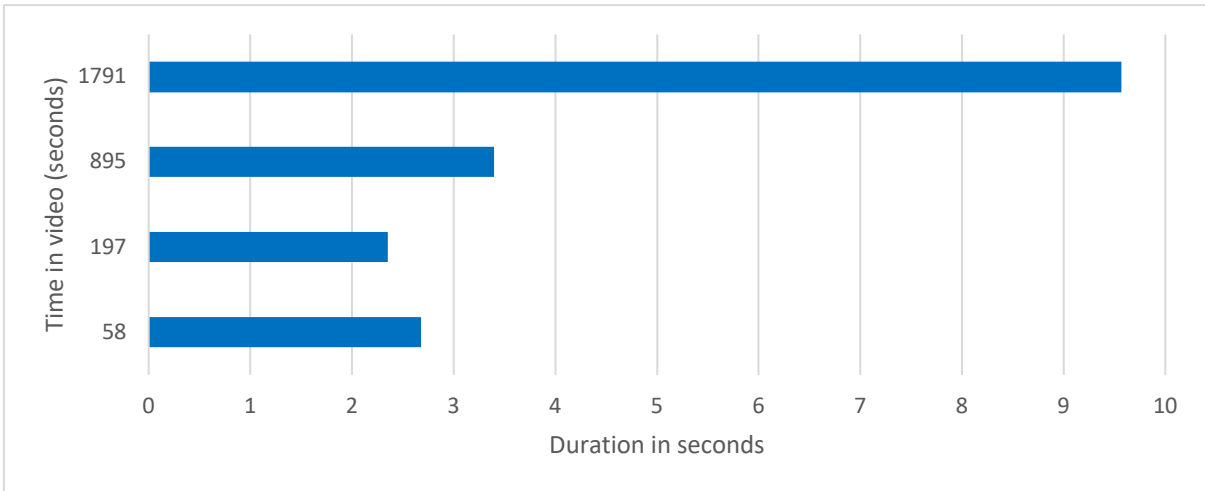
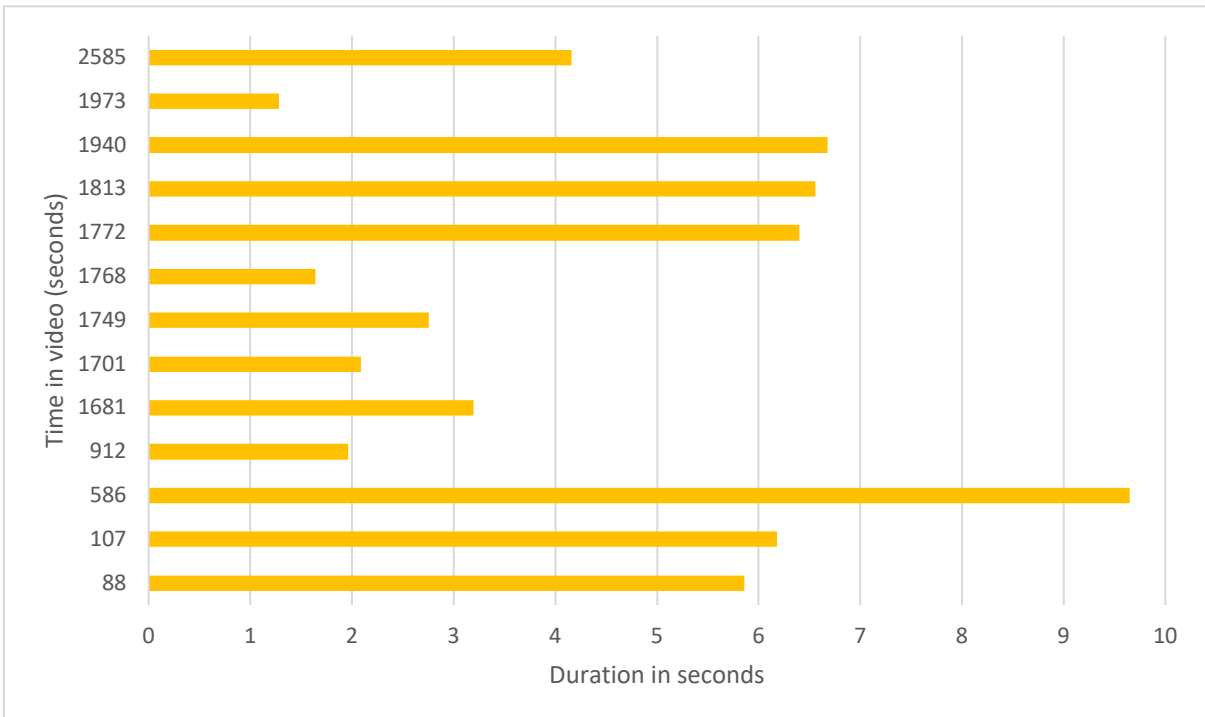


Figure 4.30

*Case Study 1 Phase 3 Video 2: Social Connection between Service Provider and Child.*





In video 3, key constructs that emerged following analysis were: following Rosa's lead, Rosa asking for help, turn-taking and pausing, Ali focussing on Rosa following instructions and doing things on her own, Rosa's emotions, Sarah following Ali's suggestions, modelling play for Rosa, and shaping Rosa's vocalisations into words.

One example showed how Ali and Sarah followed Rosa's lead for most of the therapy session, often pausing and waiting to see what Rosa was interested in. Ali and Rosa started off by playing with the duck-in-a-ball toy, and Sarah joined in. Ali started shaking the duck, and Rosa attempted to copy her mum by touching the duck in a ball, and then shaking her whole body. Ali repeated the shaking, though only after she waited for Rosa to give her a signal to shake it, which showed evidence of pausing during joint attention, and following the lead of the child. Ali and Sarah encouraged Rosa to shake the ball on her own. When Rosa was unable to shake the ball, Sarah saw this as an opportunity to suggest that Rosa ask her mum for help in shaking the ball. Rosa then tried to ask mum for help: "mmm mmm mmm!", which Sarah copied and moulded as "mum mum mum!". Other examples of shaping Rosa's vocalisation into words was when she exclaimed "maa maa!" while holding the toy sheep, to which both Sarah and Ali exclaimed "baa baa!". Interestingly, though Rosa was not able to copy words exactly, her vocalisations had the same pitch and tone as Sarah and Ali's.

Another example of following Rosa's interest in play, was when she initiated a hiding game, where she would roll away the ball and then sign "where?" with her hands, and try to say "where?". Ali and Sarah imitated Rosa, and also signed and said "where?". Sarah brought out a scarf to use during the hiding game. It seemed that this was an activity that they often did as Ali knew exactly what to do when handed the scarf. Ali used the scarf to cover the ball and both Sarah and Ali asked

Rosa where the duck in a ball was. Rosa signed “where?” to show that she had comprehended their question.

Rosa was able to listen to her mother’s instructions and began to pull the scarf off when Ali asked her to, which was a good example of the child following instructions. Ali seemed at times to be preoccupied with Rosa following her instructions and doing things independently, and exclaimed “Yeah you can do it” on more than one occasion. There was also some mismatch in Ali and Rosa’s vocal turn-taking, with Ali seeming too quick to respond to Rosa’s vocalisations, at times overlapping her utterances, showing ‘misattunement’. Again, there were moments where Rosa seemed overstimulated by her mother, and referenced Sarah in the middle of their interactions. One example was when Ali asked Rosa to pull the scarf off by herself, and Rosa responded with vocalisation gestures, perhaps indicating the task to be too challenging. She then reached for the scarf and turned towards Sarah instead. One other instance was when Ali asked Rosa “Shall we put it [the sock] on your foot?”, to which Rosa responded by looking and turning away. Another example was during the sock play. Rosa turned away from Ali when Ali used the sock puppets to tickle her, which her mother acknowledged but laughed instead and did not comfort Rosa immediately. Sarah’s response to Rosa sounded more sympathetic. There were also a few times where Sarah had to re-direct Rosa’s attention towards her mum, encouraging infant-mother interaction.

Overall, Ali appeared to have a good sense of Rosa’s emotional state. During peek-a-boo play with a scarf, Rosa stopped trying to pull the scarf off, and so Ali helped her daughter pull the scarf off. In this instance, Ali was able to read her daughter’s signals and emotions, and responded to Rosa’s change in mood towards the game. This was a good example of Ali helping Rosa develop her ‘self-regulation’.

Similar to video 2, Sarah and Ali were able to engage Rosa in play interactions for long periods of time, and followed her interests. When Rosa lost interest in the duck, Sarah followed Rosa’s lead and asked Rosa if she wanted her to hide behind the scarf. In response, Rosa rolled away the duck in a ball and turned towards Sarah who proceeded to hide herself behind the scarf. Rosa seemed to enjoy

the game and laughed whenever Sarah moved behind the scarf. When asked, Rosa was hesitant to pull the scarf off and so Sarah cued Ali in to help Rosa pull the scarf. Sarah then gave Ali and Rosa a turn to play the 'hide-behind-the-scarf' game. They continued to play this game for 20 minutes. Variations were made when Rosa pointed towards her foot and Sarah decided to hide her feet. Sarah always cued Ali in on when to have a turn in playing the hiding game with Rosa. The hiding game with Rosa's foot and sock continued for most of the session, testament to Rosa's long attention span, as well as both Ali and Sarah's ability to engage Rosa in an activity for a sustained period of time.

Compared to previous videotaped observations, Ali appeared more confident and had more suggestions. For example, when Ali saw that Rosa was pointing towards the scarf, Sarah thanked her for the suggestion and so incorporated the scarf in playing with Rosa. More so, in contrast to previous videotaped observations in Phases 2 and 3, there were more opportunities for Ali to play with Rosa. There were, however, times where Ali appeared anxious about what Rosa was able to do on her own, for example when Rosa would pick up the wrong farm animal, and Ali remarked that they had not played with this animal before. Another example was when Ali peered into the bag of toy animals and remarked "I don't think you've done the rest of the animals so you might have a bit of trouble with the rest of them". Sarah responded saying, "That's alright", to reassure Ali. Ali's instructional tone also came out a number of times during this session. Rosa gestured towards the bag of animals, but Ali said "We have to turn the page" twice, perhaps showing a preoccupation with 'doing things the right way'. She then asked again, in a firmer tone "Are you going to turn the page?", and did not wait for Rosa to respond but turned the page for her. This is problematic because while Ali communicated to Rosa the importance of following her instructions, she also did not allow Rosa the space and time to do so. During this interaction, Ali's anxiety was evident through her disappointed looks, tone of voice, and nail biting.

At this point, Sarah explained that they needed to start modelling play for Rosa. Both Ali and Sarah had noticed that Rosa became anxious and uncertain when she was introduced to a new toy, and therefore needed modelling on what to do with the toy. Sarah seemed aware of Ali's worries and

was able to reassure her, and in this instance, provided a solution for why Rosa was not able to pick the right farm animal. Ali and Sarah seemed to work better together as well, and at times Sarah did not need to cue Ali in on when to interact with Rosa. They ran the therapy session as partners with Sarah drawing on Ali's knowledge of Rosa, and Ali learning from Sarah's coaching.

## Video codes

Figure 4.31 shows that Rosa's mother had more counts of 'Facial expression/Body language' and 'Touch/comfort' than Sarah. However, in the code category of 'Circles of Communication', Sarah had the greater number of counts (see Figure 4.32). Furthermore, Ali is shown as having a greater number of occurrences of 'Misattunement' in comparison to Sarah (Figure 4.32).

Figure 4.31

*Case Study 1 Phase 3 Video 3: Facial Expression and Body Language.*

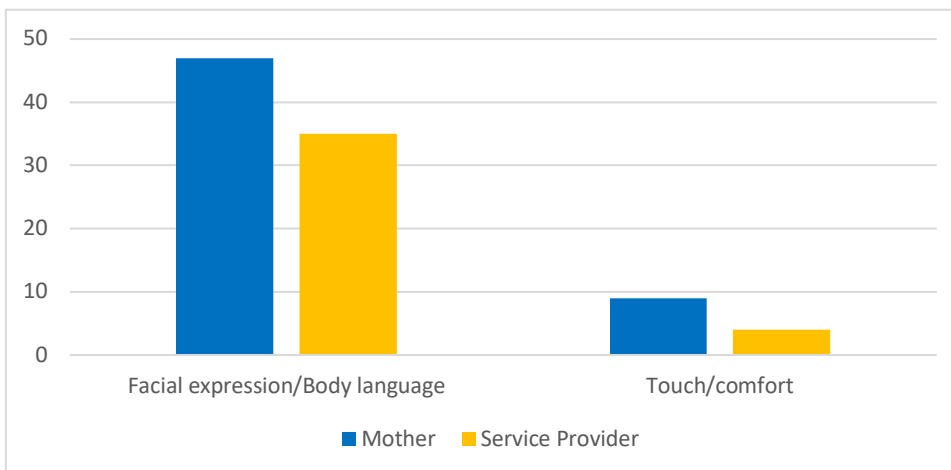
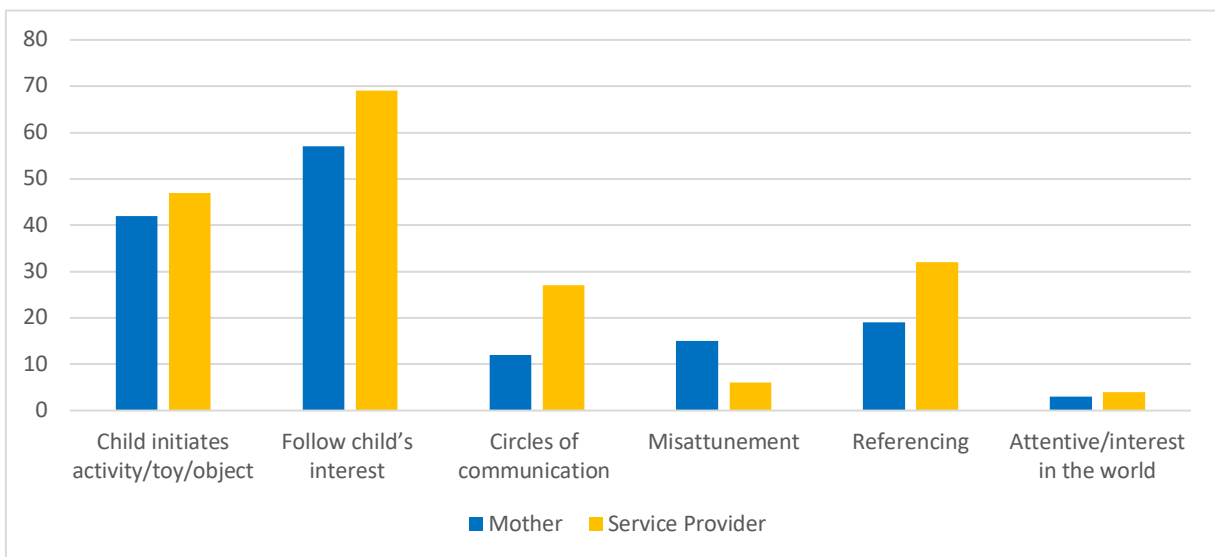


Figure 4.32

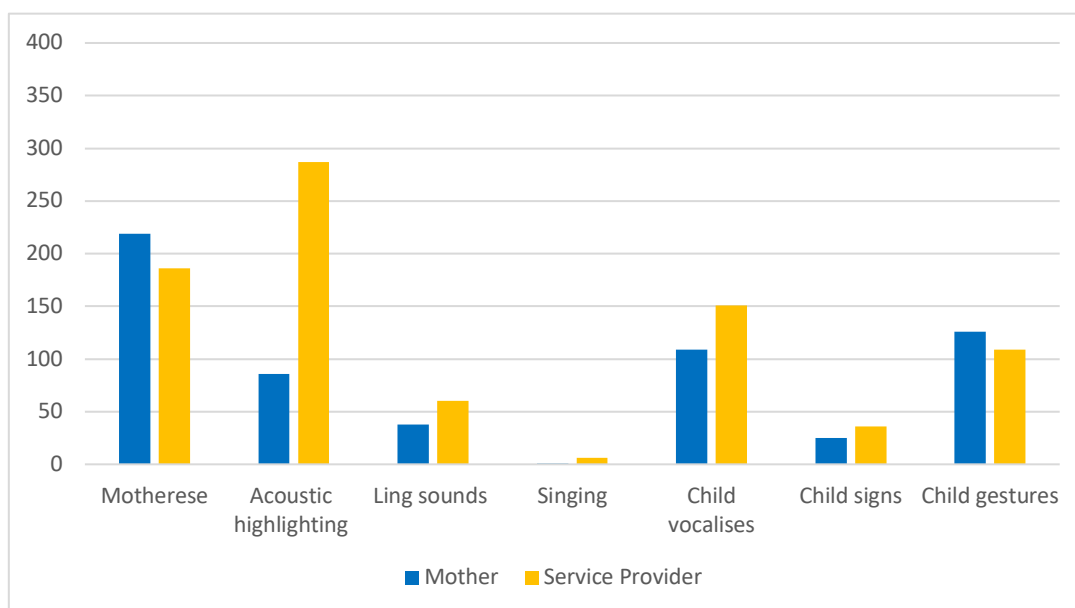
*Case Study 1 Phase 3 Video 3: Circles of Communication.*



As seen in Figure 4.33, in video 3, Ali is coded with more counts of ‘Motherese’ and more counts of Rosa responding to her through ‘Child gestures’. This is in contrast to video 2 where Sarah is coded with more counts (see Figure 4.24).

Figure 4.33

*Case Study 1 Phase 3 Video 3: Vocal Interaction.*





In terms of ranged events, in video 3, there were no counts of Ali pausing and waiting for Rosa, whereas Sarah is shown as having nine counts (see Appendix N). Sarah had six counts of ‘Social connection’ with Rosa, twice more than Ali (see Appendix N). Lastly, while Ali had a greater number of occurrences of joint attention with Rosa (32 compared to 29 for Sarah), in total, Sarah had a greater duration of time spent in joint attention with Rosa – 16 minutes and 30 seconds compared to Ali’s 9 minutes and 35 seconds (see Appendix N).



In video 4, key constructs that emerged included: the child’s vocalisations; following the child’s lead; the child’s emotion regulation; the partnership between mother and service provider; the mother’s focus on her child’s progress; the mother’s anxiety, and, the interaction between the mother and child. The quality of Rosa’s vocalisations appeared to have improved compared to other videos. Notably, Rosa responded to both Sarah and Ali’s use of acoustic highlighting, e.g. Sarah said “caaar!”, to which Rosa responded with “caaa!” and though she could not pronounce the “r” sound, her vocalisation was the same in tone, pitch and duration as Sarah’s. Other examples included Rosa imitating Ali and Sarah when they said “Up! Up! Up!”, and again though she did not pronounce the word “up!”, she was able to imitate Ali and Sarah in their intonation, pitch and duration. Throughout the session, Rosa used familiar words and gestures, such as signing and vocalising “where?”, vocalising “more”, and saying “Brrmm! Brrmm!” meaning ‘car’.

In terms of following Rosa’s lead, Sarah and Ali focussed on Rosa’s interests, though interestingly, at times pushed her to move on to toys and activities that were not so familiar to her. For example, when reading a book on animals. Rosa preferred animals she was familiar with, such as the fish or the bird. Other animals she was not familiar with were the cat and dog, and she would

quickly turn the page and throw these animals away. Sarah and Ali persisted with these less familiar animals, until Rosa gave clear signals that she was not interested, for example by turning to the next page.

One important construct that emerged was Rosa's emotion regulation. The activity with Humpty Dumpty was a good example of this. Whenever the Humpty Dumpty song was sung, Rosa would start crying at the part where Humpty was about to fall. Sarah and Ali decided to re-frame Rosa's negative experience of this by replacing "fall" with "jump", and emphasised how much fun Humpty had each time he jumped off the wall. This worked well and after some repetition, Rosa was no longer upset with Humpty Dumpty falling, as she had fun jumping with Humpty instead. Importantly, during this interaction with Humpty, Rosa showed her anxiety and turned towards her mother, or moved closer to her. This showed how Rosa was now able to use Ali as a safe haven during novel times. Sarah also used Rosa's proximity to Ali as a way to help her feel safer. Sarah suggested that Ali place Rosa on her knees when they sang Humpty Dumpty. This worked well, and Rosa was able to engage with the activity better. Sarah's comments when Rosa was upset showed her attunement to Rosa's emotions: "We don't want you to feel sad. We want you to feel safe". Furthermore, Sarah asked Rosa if she wanted to have a turn jumping off the wall like Humpty. Rosa scrunched up her face, which Sarah noticed and remarked "Or are we pushing the friendship? Yeah maybe not". Thus, both Ali and Sarah show a good level of attunement to Rosa's affective states. In this example, it seemed that Sarah and Ali were working together to build Rosa's self-regulation. This was also a great display of Sarah and Ali working together to teach and play with Rosa. At other times, Ali would take the lead and Sarah played a more supportive role, such as when Sarah handed Ali a blanket, and Ali chose to play peek-a-boo with Rosa and the car.

Finally, an important construct that emerged from the video analysis was Ali and Rosa's interaction. Rosa again used Ali as a secure base, for example when introduced with a new toy she was unfamiliar with, Rosa would hesitate, look back at her mother who was sitting behind her, then continue to explore the toy. Other times, Rosa would reach for Ali's hand, which both Ali and Sarah

interpreted as Rosa asking for Ali's help with the toy or activity. In this way, Ali was also Rosa's safe haven, available to Rosa whenever she needed support when exploring something unfamiliar or difficult.

Another significant construct to emerge was Ali's focus on Rosa's progress. Throughout the session, Ali seemed focussed on Rosa being able to do things 'right'. Often Rosa would try to turn the page before matching the animals, and Ali would stop her and insist she play with the toy animal, or make the animal noises. Another example were Ali's comments such as "Took you a while but you got there", and "good enough", in response to Rosa not being able to complete the task straight away. This suggests Ali's focus on Rosa's developmental progress. Again, Ali's anxiety surrounding this was evident through her nail biting and a comment towards herself: "I would've failed that one", showing her results-driven attitude.

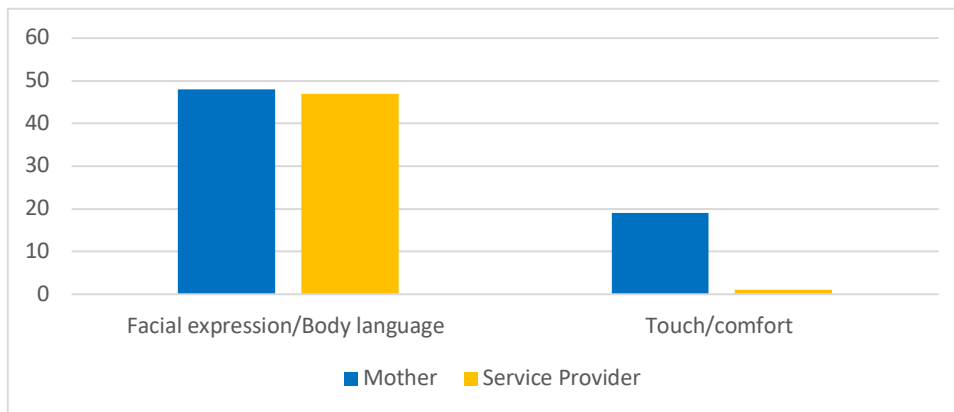
Sarah's expertise in coaching and early intervention was highlighted in her ability to listen and follow the parent's suggestions. Sarah took the time to listen to Ali telling her about all the animals that Rosa knew the name of. Sarah actively listened, and praised both Ali and Rosa on the things Rosa was progressing with at home. Sarah also took note of Ali's suggestions and knowledge of Rosa, for example, when Ali described Rosa's word for 'nose'.

## Video codes

Video 4 continues the same trend found in videos 2 and 3, with regards to the category of 'Facial expression and Body language' (Figure 4.34).

Figure 4.34

*Case Study 1 Phase 3 Video 4: Facial Expression and Body Language.*



Similarly, Figure 4.35 shows that Ali had more occurrences of 'Misattunement' than Sarah, as was the case in video 2 (see Figure 4.23) and video 3 (see Figure 4.32). Again, Sarah is shown to have completed more 'Circles of communication' with Rosa in comparison to Ali (Figure 4.35).

Figure 4.35

*Case Study 1 Phase 3 Video 4: Circles of Communication.*

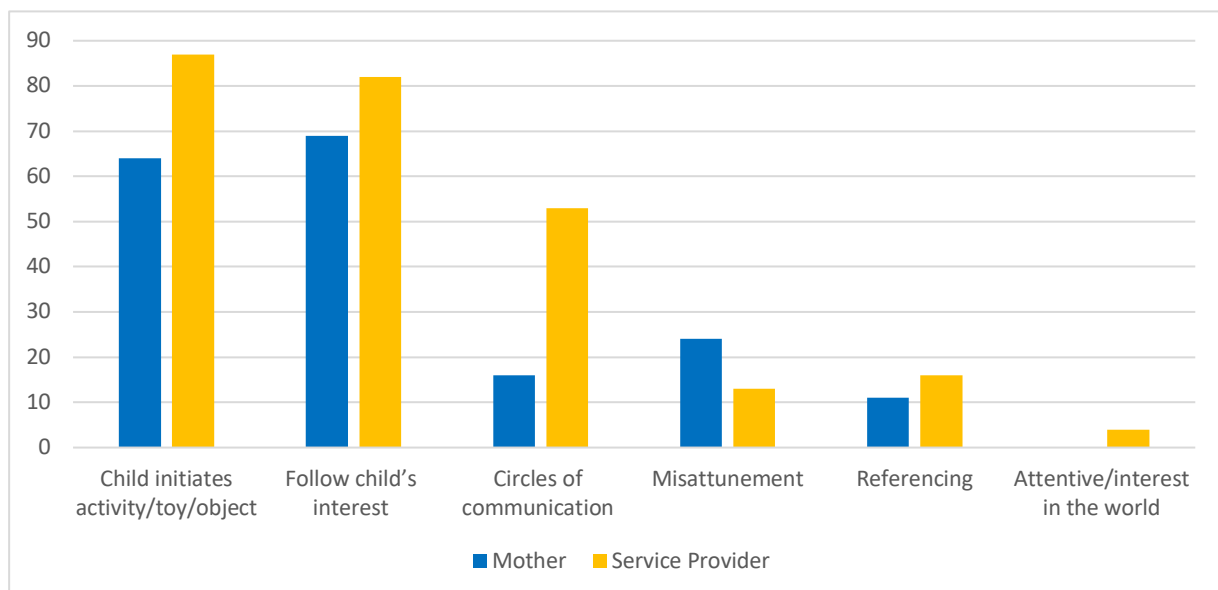
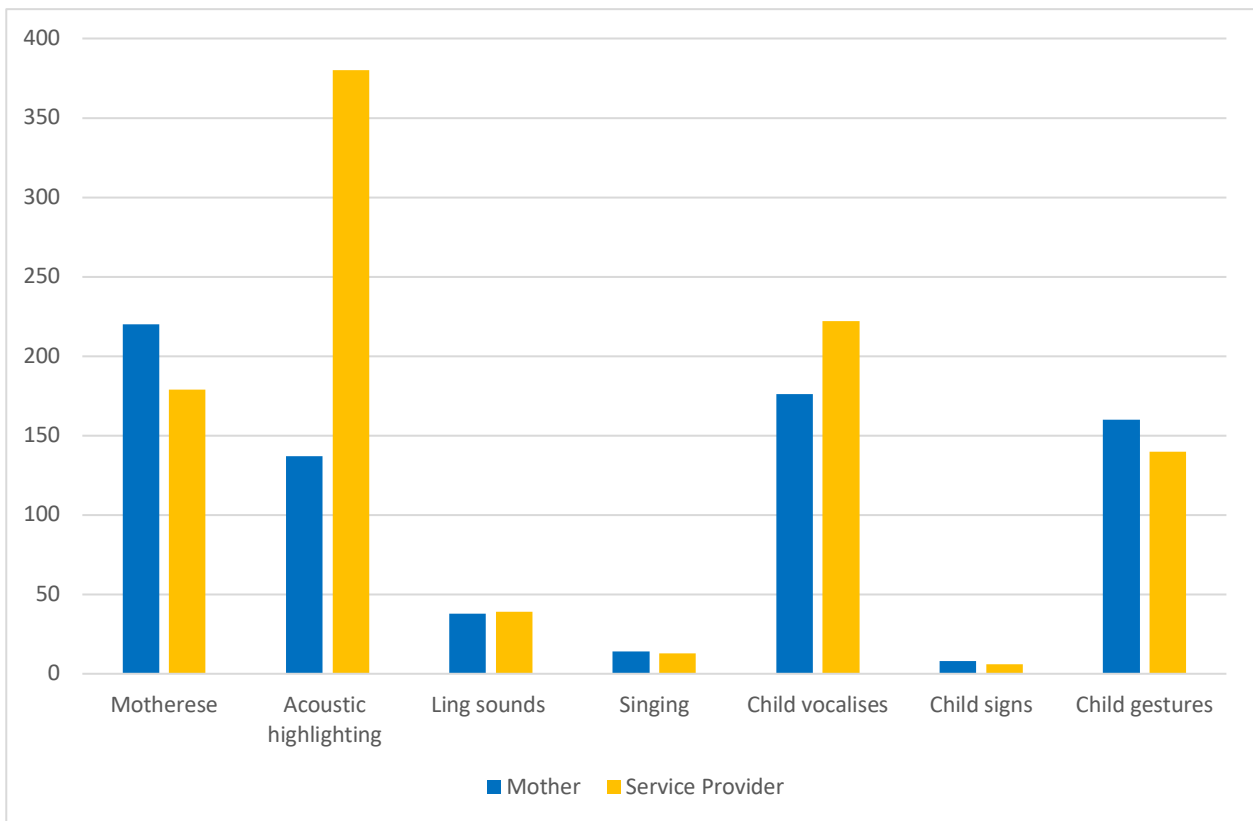


Figure 4.36 shows an increase in Ali's use of 'Acoustic highlighting', when compared to video 2 (see Figure 4.24) and video 3 (see Figure 4.33). Similar to video 3 (see Figure 4.33), in Figure 4.36, Rosa is also shown to gesture towards her mother more times than she does to Sarah.

Figure 4.36

Case Study 1 Phase 3 Video 4: Vocal Interaction.



Regarding the ranged events of ‘Pausing and waiting’, ‘Social connection’, and ‘Joint attention’, in comparison to Ali, Sarah was coded with more occurrences of all these ranged events (see Appendix N). Notably, there were no occurrences of ‘Social connection’ between Ali and Rosa for video 4.

### ***Summary of video analysis***

Using three methods of video analysis provided both quantitative and qualitative means to make sense of the video data. The CARE-Index results provided a measure of the quality of the mother’s sensitivity, and of the infant’s responses, and indicated that Ali and Rosa’s relationship was at-risk.

The qualitative analysis of the three videos showcased a number of key constructs surrounding Rosa’s relationship with her mother and service provider. These include: ‘following the child’s lead’, ‘emotion regulation’, ‘anxiety’, ‘misattunement’, ‘partnership between parent and provider’, ‘active listening’, ‘empathy’, ‘child following instructions’, ‘modelling’, ‘coaching’. The qualitative

descriptions also provided information on more abstract constructs, such as ‘empathy’, ‘anxiety’, ‘coaching’ and modelling’. They also provided more detail on the construct ‘misattunement’, giving concrete examples from the video. The constructs of ‘emotion regulation’ and ‘misattunement’ reveal some dimension of Rosa’s developing attachment relationships. Both Sarah and Ali were able to demonstrate awareness of Rosa’s emotional states, shaping play interactions to help Rosa regulate her negative emotions.

The quantitative video coding focussed on measurable behavioural constructs, such as the use of ‘acoustic highlighting’, and the completion of ‘circles of communication’. In sum, the results of the quantitative video coding showed that Rosa tended to respond to Sarah more than her mother, through vocalisations, sign language, and gestures. However, a major trend observed was that Ali showed improvement in her use of ‘Acoustic highlighting’ across the three videos. This is important as ‘Acoustic highlighting’ is an auditory-verbal technique that is specifically used to help children with hearing loss develop listening and communication skills. It differs from ‘Motherese’, the naturalistic voice that adults use when speaking to infants and young children. Ali’s increased ability to use ‘Acoustic highlighting’ showed her responding more sensitively to Rosa’s needs. This is further confirmed in the increase of Rosa’s vocalisations towards Ali across videos 2, 3 and 4. Through Sarah’s coaching and modelling, Ali also improved in the areas of ‘Joint attention’, and ‘Following child’s interest’. This showed Ali had improved her sensitivity and attunement towards Rosa across the three videos.

The graphs also showed Sarah’s sensitivity and attunement towards Rosa, as well as her ability to cue Ali into Rosa’s signals and behaviours. Sarah showed few amounts of ‘Misattunement’ to Rosa’s behavioural and affective cues, and a large amount of time responding to Rosa promptly and appropriately through various modalities – facial expressions, body language, sign language, and vocalisations. Rosa responded well to Sarah, as indicated by the number of ‘Circles of communication’ they completed, as well as the ratio of times Sarah responded to Rosa’s initiating of a new activity or toy.

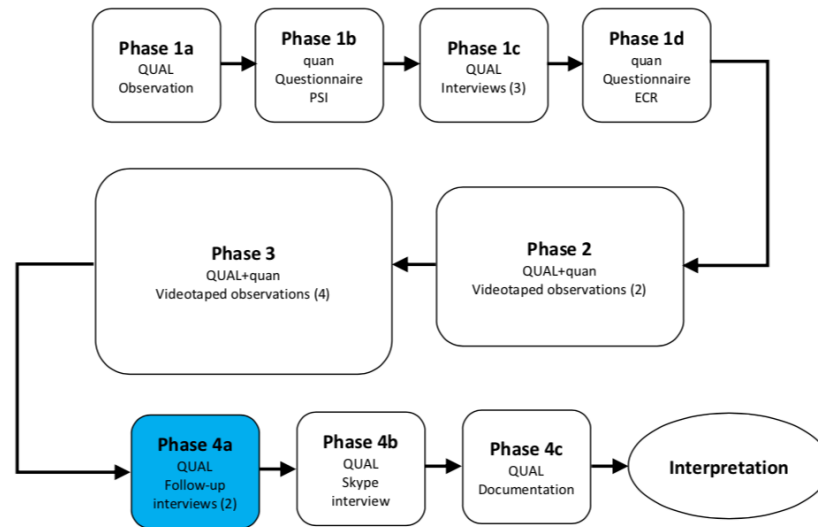
**Limitations.** A limitation of using the CARE-Index was that it had not been used for this specific population before, though the external coder noted that the CARE-Index did not discriminate with regards to the characteristics or disabilities of the infants being analysed. Furthermore, the researcher had intended to code the CARE-Index videos herself, following completion of the training she received. This inter-rater coding could have added to the reliability of using the CARE-Index coding analysis as part of the study. However, due to personal events, the researcher missed a few days of training and subsequently did not pass the video coding test that would have proved her to be a reliable CARE-Index coder.

**Implications.** Sourcing another external CARE-Index coder would only increase the reliability of the chosen video analysis techniques, seeing as over the years the CARE-Index has become complex for practitioners to use and score reliably (Svanberg, Barlow, & Tigbem 2013), To achieve rater reliability, practitioners need to undergo a considerable amount of training and practice (Svanberg et al., 2013). For the researcher's original coding scheme, sourcing another coder blind to the scoring of the other coder would help reduce bias and increase reliability (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009). Validity and reliability of the original coding scheme was ensured through repeated consultations and coding checks with the key informant Louise, that showed adequate agreement (Miles & Huberman, 1994).

#### **Phase 4**

Phase 4 included the following qualitative instruments: follow-up interviews with the service provider and mother, an interview with the father, and documentation. Findings from these instruments were converged with the findings from the instruments of previous phases.

#### 4a - Follow-up Interviews.



**Collection.** The purpose of the follow-up interviews was to explore any changes in the participants' understanding of attachment relationships, as well as for the researcher to receive feedback on how the study was conducted, as it was the pilot study. The follow-up interview with Sarah, the therapist, was conducted at the ECIC and lasted for approximately 30 minutes. The follow-up interview with Ali, the mother, was conducted at her home and was approximately 50 minutes in duration. The researcher used a voice-recording application on an iPhone 6 to obtain an audio recording of the interviews. To help respond to the study's research questions, the following topics were covered in the follow-up interviews: Rosa's developing attachment relationships; understanding attachment; Rosa's growth and development; the place of attachment in the ECIC's methodology; and social support. The researcher also asked for feedback regarding the research study.

**Analysis.** Analysis of the follow-up interviews followed the same procedures as the interview analysis from Phase 1 (see section in this chapter on interview analysis in Phase 1). The audio recordings were transcribed verbatim by the researcher. The interview transcripts were then uploaded into Nvivo for coding. The existing coding scheme from Phase 1 was used. Any new themes were coded in vivo.



**Results.** Nvivo analysis of the follow-up interviews will be discussed under the follow-up interview topics: *Attachment relationships; Understanding attachment; Child's growth and development; Attachment in early intervention; Social support; and, Feedback regarding the research study.*

**Attachment relationships.** When discussing Rosa's developing attachment relationships, Sarah spoke about Rosa's anxiety and how it was part of the growing attachment. Sarah noted that Ali appeared much more attuned to Rosa's emotions: "Ali is very aware. ... and handles it so beautifully, and just will quietly ... leave the toy that she's scared of, near Rosa and is very aware that ... if she just takes the pressure off, Rosa will come to it in her own time." Another aspect related to facilitating Rosa's attachment relationships was resilience and emotional self-regulation. Both Sarah and Ali spoke about how they were working together to build Rosa's resilience, and saw it as the next step in her developing attachment relationships.

**Understanding attachment.** Throughout her own interview, Ali demonstrated her improved understanding of attachment, noting the different attachment phases that Rosa went through, for example, a phase where Rosa didn't need to be close to her, and moving onto the next phase where Rosa needed to be able to see her to feel safe.

When asked if she had learnt anything more about attachment through the study, Sarah responded:

I've been much more aware, of my role, and probably have ... been more aware of that pulling back and the setting up the support for Ali, rather than actually taking over, which is probably my weakness. ... I've transferred that to my work with other parents.

Also, Sarah noted how it was not just about her relationship with the child, but also about developing her ‘attachment’ relationship with the parent by “tuning into their emotions” and “checking on my own emotional state”. Interestingly, Sarah noted the impact that focussing on attachment had on Rosa’s relationships with her and Ali: “I think if we hadn’t worked on the attachment I’m not sure that we would be quite so attuned with the anxiety as such.”

Moreover, when asked if she thought that hers and Ali’s understanding of attachment had any impact on Rosa’s attachment, Sarah remarked:

I suppose I don’t have ... anything really to go on, clinically, apart from the fact that the process has been so in-depth and ongoing, and that we’ve gotten so much out of that process that I can’t help feeling that ... it’s been highly beneficial to her. The empathy and the...intuition, that she is now showing at such an early age is extremely unusual for a child who is profoundly deaf, and has so many other issues. ... So, you can’t help but think that that process has ... brought that out in her.

In sum, both interviewees perceived that an improved understanding of the process of attachment had a positive impact on their attachment relationships. Importantly, Sarah’s understanding highlighted the significance of her role as service provider, and her relationship with both the child and parent, in facilitating attachment relationships.

***Child’s growth and development.*** When asked to comment on Rosa’s development, Ali remarked: “The way that she just learns things and absorbs things, and mimics ... it’s just mind-blowing so, I can’t believe how far her hearing’s come”. Likewise, Sarah agreed that Rosa was doing “extremely well ... beyond anything we would’ve imagined”. Another key issue discussed with Ali was Rosa’s empathy and how it was well developed for a child with a profound hearing

loss:

we were doing five little ducks, and Sarah started crying when one of the little ducks went away. And Rosa cried instantly. And that's when Sarah told me about the whole empathy side of kids with hearing loss ... and Sarah was BLOWN away that Rosa showed that empathy.

In regards to Rosa's stubbornness, Sarah noted that while Ali saw this characteristic as determination, she saw it as Rosa being anxious or hesitant to try new things, and as stated before, was working to help Rosa deal with her anxiety and fear. This difference in perception further shows that Sarah is more attuned to Rosa's emotions than Ali. Sarah's ability to recognise and tune in to Rosa's anxiety is significant as she is helping Rosa deal with her emotions, which Sarah commented was a key part of her attachment development. Overall, both Sarah and Ali were pleased with Rosa's development, and associated much of her progress with the work they had done on forming a secure attachment relationship with Rosa.

***Attachment in early intervention.*** Ali commented on how she believed that the ECIC's focus on attachment played an important role in Rosa's speech and language development: "she would not be achieving what she was if she didn't feel safe and happy and loved there". Ali also noted how Rosa responded best when sounds were connected with positive experiences:

when Ben comes home our front door makes the loudest noise when you open it, and every single time she even hears ... the bang, she jumps straight away, looks at the door and smiles, SO big ... so that sound means dad's coming through the door.

Furthermore, Sarah discussed the importance of also forming an attachment with the parent during therapy sessions, by being attuned to their emotional state, and knowing when to model for

the parent, support them or to step back. As part of helping parents, the researcher and Sarah also spoke about having a counsellor as part of the ECIC's team: "...if we had that here as an integrated part of the whole service ... and somebody that they get to know, and they trust... then I think that it would be invaluable." In summary, the interview responses suggested that participants believed attachment played an important part in Rosa's language and emotional development.

***Social support.*** In regards to social support, Ali noted that Facebook had been a positive support, with people being inspired by Rosa's progress. Ali would post regularly about Rosa, as well as connect with other mothers on Facebook groups about CHARGE syndrome and hearing loss. Moreover, Ali spoke about changes in people's perceptions towards Rosa, notably her own dad who thought that Rosa would get teased constantly, but now thinks: "she is ... the most amazing thing in this whole entire world". She also spoke about how support from Ben's extended family would be helpful, and had played a role in their decision to possibly move to Queensland to be closer to them. Importantly, Ali discussed the difference between their ECIC service providers and other specialists in how they interacted with Rosa. She commented on how the other specialists were not as attuned to Rosa's needs and how this may have impacted Rosa's hearing test results.

***Feedback.*** Ali and Sarah provided positive feedback regarding the study. Sarah noted that the researcher in her role as an observer was "respectful... [and] incredibly sensitive". Moreover, Sarah described the researcher as "observing and, commenting on a process that's happening, but you've done it so without judgement. And so you've made me and Ali feel really safe".

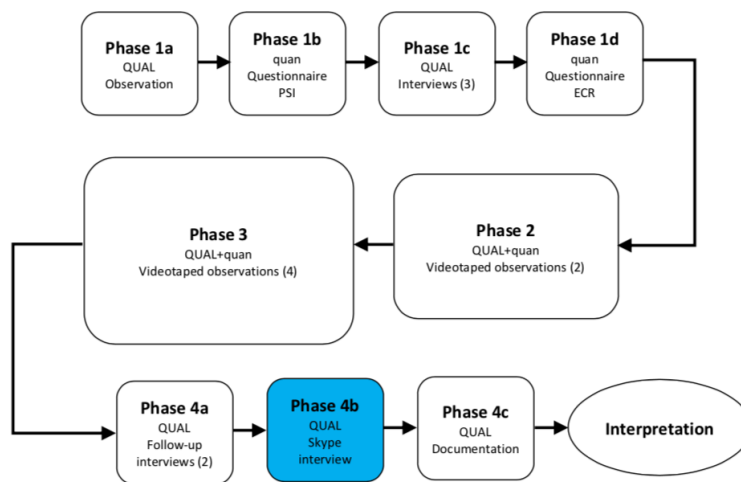
As discussed previously, both Ali and Sarah believed that improved understanding of attachment had a positive impact on Rosa's attachment relationships and development. Ali commented on this, saying:

definitely think attachment's got a huge deal with it. If she [Rosa] felt like you were pressuring her or pushing her, we know that she wouldn't do it. So she would not be achieving what she was if she didn't feel safe and happy and loved.

**Limitations.** No limitations were apparent.

**Implications.** During the analysis stage, key findings derived from the follow-up interviews were compared with findings from the Skype interview with Ben, Rosa's father, in order to corroborate results.

#### 4b - Interview with Secondary Caregiver.



**Collection.** Due to Ben's work schedule, the researcher arranged a Skype interview with him at a convenient time. The researcher ensured that Ben had signed the consent forms before conducting the interview. The researcher used a recording application on an iPhone 6 to make an audio recording of the Skype interview. The interview was approximately 30 minutes in duration. Topics covered were the same as those discussed in Ali's first interviews (see Phase 1).

**Analysis.** The audio recording of the Skype interview was transcribed verbatim by the researcher in a Word document. This document was then uploaded into Nvivo for analytical coding.

The same coding methods used in the Phase 1 interviews, and Phase 4 follow-up interviews were used to analyse the Skype interview transcript (see previous sections on Nvivo interview analysis in this chapter for detailed descriptions). Any new codes that emerged were added to the existing coding scheme, and organised under the appropriate parent nodes.

**Results.** From the Nvivo analysis, a number of key findings emerged, and will be discussed under the following topics: *Understanding attachment*, *Factors around attachment*, *Attachment relationships*, *Early Childhood Intervention*, *Caregivers' attitude towards pregnancy*, *Caregivers' experience of Child's diagnosis*, and *Caregivers' hopes and concerns for their Child*.

**Understanding attachment.** When asked what he understood about attachment, Ben replied: “[an] emotional connection there with the child”. He also commented on Ali and Rosa’s attachment relationship:

it’s a very special thing there. They’re very close. ... I think Ali understands Rosa so well ... she knows how to foster, or to let her grow and to develop. Obviously again this comes back to her teaching ... skills. ... She’s got a very strong relationship with her.

**Factors around attachment.** In terms of factors around attachment, Ben believed that it was due to Ali being attuned and sensitive to Rosa, and being so understanding of her that Rosa had been so successful in her development. He noted that Ali’s teaching skills also played a big role. Ben also described how he wasn’t able to provide Ali with as much emotional support as she probably needed, particularly during the more difficult times in those early months when Rosa was very sick: “but for me, yeah it was difficult because as much as I tried to listen I- being a male (laughs) I think it ... didn’t always make things better”. Ben also mentioned that he was very close to his friends, and drew on their support much more than his own family who lived some distance away. Like Ali, he noted

that both their families were not hugely supportive with Rosa during the early months, with the exception of Ali's sister who was a big emotional support for Ali. Ben also commented that due to work, he did not spend as much time with Rosa as Ali did.

***Attachment relationships.*** As mentioned, Ben believed that Ali and Rosa had a strong relationship. When asked to comment on his own relationship with Rosa he answered: "But as far as an attachment or an emotional sort of connection there, it's sort of hard to do sometimes. Um, being with her- it's only a few hours a day. I'd like to get closer to her." Interestingly, Ben did not mention Rosa's attachment relationships with anyone else, such as with Sarah or other relatives. This shows his limited understanding of attachment relationships and which people a child may develop an attachment relationship with.

***Early childhood intervention.*** When asked to comment on the ECIC and strategies, Ben replied: "you can see immediately the difference. She'll come home, and everyday she develops and ... learns something new, and it's amazing to watch... I think without actually experiencing it it's hard to understand what actually goes on". This reflects Sarah's earlier comment, describing how fathers found it more difficult to be involved in their child's therapy. Although admitting he did not know much about the early childhood intervention therapies, Ben did note that he had been involved in physiotherapy which he described as: "sort of common sense". He commented:

But when it comes to speech and teaching her ... all those sorts of things, Ali's good at that. I'm far from that. I don't always understand the best ways to communicate those to Rosa, compared to what Ali does. But I think that also comes down to her being a preschool teacher.

***Caregiver's experience of child's diagnosis.*** When asked to describe how he dealt with Ali's difficult pregnancy and Rosa's diagnosis, Ben commented:

I think I was just excited to have a baby. ... Yeah it was tough obviously at the beginning, being in hospital. Obviously that was not normal (laughs). ... And I think I probably had to be a bit stronger than usual, just to help Ali get through it.

This contrasts with Ali's constant worry, and reflects Sarah's comment that Ben and Ali were not on the same page in respect to parenting Rosa and coped with their situation in different ways.

*Caregiver's hopes and concerns for their child.* When asked if he had any concerns for Rosa, Ben replied:

No not really at all. I'm very excited about who she'll become as a person when she grows up. There's no concerns at all.... Only, excitement (laughs) and ... that's why it's probably been quite easy for me, even when she was younger, going through a lot of problems. Because ... I've always been positive and always been excited to see how she grows so. Obviously, you worry when she goes into a big heart operation but ... that's only a very short period, it's only a week here and there and, the rest of the time, ... you're, living a normal, happy life. I suppose you'd push things out of your mind, like I always forget that she was tube-fed and, those sorts of things were tough, but I always knew that she would get out of that and certainly a blip in time until she became self-sufficient as she has now, and I never had a doubt in my mind that it would happen. So always looking through the tunnels at the light there in the end.

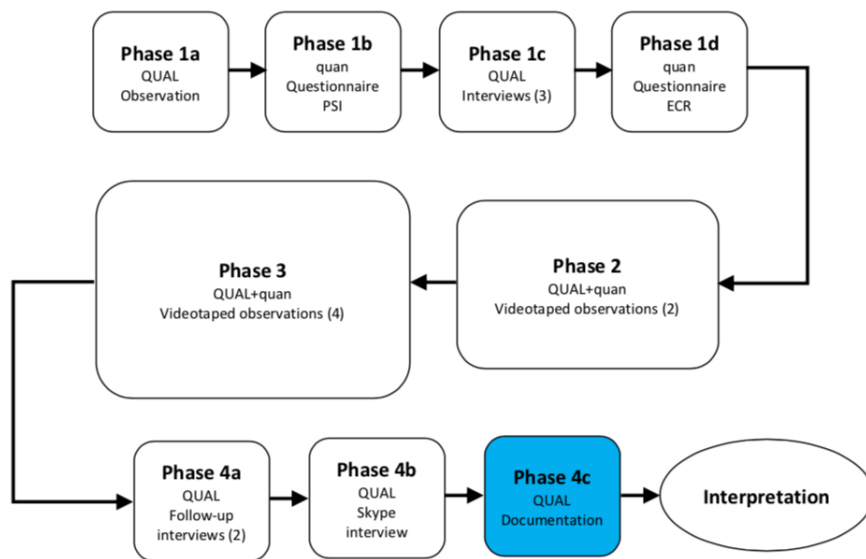
This response is interesting as it is in stark contrast to Ali's response when asked the same question. Clearly Ben and Ali have quite different personalities and attitudes towards their daughter. This may impact on how their individual attachment relationships form with Rosa, in light of what the literature says regarding parental coping mechanisms.



**Limitations.** Because the interview was conducted over Skype, it was less personal and the interviewer and interviewee were not able to establish a more personal rapport with each other. However, it can be argued that conducting a Skype interview allowed for a less intrusive mode of communication, enabling the interviewee Ben to feel more comfortable responding to the more personal questions (Janghorban et al., 2014).

**Implications.** Conducting the interview with Ben on Skype changed the CS1 protocol, adding another data collection technique. It also opened up the possibility to conduct later interviews via Skype, rather than in person.

#### 4c – Documentation.



**Collection.** In accordance with the university's ethics approval, the researcher examined Rosa's medical and audiological records from the ECIC. The researcher also scanned copies of the information leaflets on display at the ECIC. These scanned documents were uploaded onto Nvivo for analysis. Finally, the researcher gathered her logbook notes ready for analysis.

**Analysis.** The researcher analysed Rosa's medical and audiological records manually by taking detailed notes of relevant information in her logbook. Analysis of the scanned information leaflets was completed through using the 'select by region' tool of Nvivo. The researcher selected key words, phrases, paragraphs and images, and coded them using the existing codes from the interview transcripts. For example, any references to speech pathology or speech therapy were coded under 'speech pathology'. Any new codes were coded 'in vivo' (see Interview section for a detailed description of analysis using Nvivo). Documents were coded in order to compare these codes to the coded interview transcripts, during the triangulation analysis stage.

### **Results.**

**Medical and Audiological Documentation.** The primary codes from the document analysis were Rosa's diagnosis of CHARGE syndrome, her heart issues, her hearing loss, and feeding issues.

At 3 weeks old Rosa was diagnosed with CHARGE syndrome. The letters in CHARGE stand for features common to those with the syndrome: Coloboma of the eye, Heart defects, Atresia of the choanae, Retardation of growth and development, and Ear abnormalities and deafness (CHARGE Syndrome Foundation, 2020). She had an episode of hypoglycaemia while in hospital where she turned purple and stopped breathing. Rosa was diagnosed with field vision loss in her right eye.

Rosa had two open-heart surgeries, one when she was 18 hours old (repaired coarctation of the aorta), and the other when she was 6 months old (hole in heart repaired). Rosa was also diagnosed with severe-profound bilateral hearing loss. She underwent cochlear implantation at 9 months, with successful implantation on her left ear, despite reports of an abnormal auditory nerve.

Rosa was naso-gastrically tube fed from birth, with associated feeding issues such as vomiting and being over-fed. Ali decided to attend a new feeding clinic in a different state, one that would support her goal of taking Rosa off tube-feeding and focus on her oral feeding. For a detailed table of Rosa's medical and audiological data see Appendix C.

Analysis of Rosa's medical reports, audiological reports and audiograms, and external assessments, confirmed what was described in the interviews conducted with Ali, Sarah, and Ben, that is, the numerous, ongoing appointments, operations and tests that Rosa underwent (see section on Interviews). These documents also revealed the varied and many professionals involved in supporting and treating Rosa. The significance of these findings will be further discussed in the case study summary at the end of this chapter.

### **Logbook.**

**Collection.** Throughout the research study, the researcher kept hand-written notes of the research design, case study protocol, observations, the researcher's memos of therapy sessions, informal conversations with participants, concerns and ponderings in a logbook (Stake, 2010). These field notes were used to record any new data, or other data that supported conclusions from the existing databases, therefore providing another source for triangulation.

**Analysis.** The logbook was typed up and added to the researcher's Nvivo project file as a supplementary qualitative database that could be analysed and coded through Nvivo, for key themes. Towards the end of the data collection period, the researcher typed up her handwritten notes from her logbooks; three in total. This Word document version of the logbook was then imported into the researcher's Nvivo project. Thematic coding via Nvivo was then used to analyse the logbook, and key themes were matched with any key themes from the other CS1 databases, for example, interview transcripts (Edhlund & McDougall, 2012).

**Results.** Thematic findings that emerged from the logbook notes included: additional information on Rosa's characteristics and medical issues; Ali's emotions towards Rosa's physical appearance; the family's financial issues; Ali's perspective of her husband's support during and after

her pregnancy; Ben's occupational stressors; the impact on the family as a whole; insight into the thoughts and experiences of Sarah; and, empowerment through early childhood intervention, and understanding attachment.

Regarding Rosa's characteristics, during an informal chat before the first time the researcher met the family, Sarah described Rosa as having low muscle tone, vestibular issues (balance and eye movement), and gross and fine motor planning issues. Sarah noted that along with Rosa's hearing loss, visual impairment, heart issues and other issues related to her CHARGE syndrome, these characteristics also affected Rosa's ability to engage and interact with her caregivers and service providers.

Further evidence of Ali's concerns regarding Rosa's physical appearance emerged from the analysis. As described in the Phase 1 interview, Ali commented informally on how her child appeared physically, noting her fixation on her not looking like other children. This is important as it highlights Ali's sense of loss or grief, over the child she had imagined, as well as the impact of perceived negative community pressure.

The financial burden on families with children with HL-CN was spoken about extensively during informal chats. Both service provider and mother noted how difficult it was with only one parent looking after the child with HL-CN, and with the family living on one income. Ali spoke about the "expensive private doctors and clinics" they had visited with Rosa. Both service provider and mother also commented on how if one child was sick, how it impacted on their other children's experience and indeed the family's experience as a whole. Ali also noted that her husband experienced stressors at his workplace, and how long hours and the distance from their home meant they had to move closer to Ben's workplace, away from the suburb she grew up in, and away from the support of her family who lived nearby.

Finally, empowerment emerged as a key theme. Sarah spoke about how through the case study, she was able to learn more about the process of attachment and her role in facilitating those attachment

relationships. She also spoke to Ali about ‘mother’s guilt’, and how it would always stay with her, but that it was all part of developing that attachment relationship with one’s children.

During informal conversations between the researcher and Louise, Louise remarked on a key difference in the process of attachment development for children with HL-CN. Louise noted that children with HL-CN would be toddlers before they reached the second and third attachment phases, in comparison to typically-developing children who reach both phases within their first year. This suggests that for infants with HL-CN, the development of attachment relationships is slower, with infants reaching attachment phases at ages much later than their peers.

### **Summary of Case Study 1**

The results of Case Study 1 reveal several factors that likely impacted on the attachment relationships Rosa was developing. Belsky and colleagues have classified stressful or supportive factors, stating that it is an accumulation of these factors that often impact on the caregiver’s parenting (Belsky, 1984; Belsky & Fearon, 2002; Belsky & Jaffee, 2006; Fearon & Belsky, 2016). Table 4.3 shows the different variations under which such factors can affect the parent’s ability to function competently (Belsky, 1984). The factors have been divided into three categories: parent’s personality and psychological attributes, the parent’s social support, and the child’s characteristics.

Figure 4.37 displays a summary of the risk (stressful) and protective (supportive) factors contributing to Ali’s parenting, as informed by Belsky’s (1984) determinants of parenting model. Risk factors are coded orange, and protective factors, green. These factors affect the quality of Ali’s parenting, and therefore the sensitivity of her caregiving, a major determinant of attachment security. The subsequent section will discuss the risk and protective factors together in further detail using the five categories in Belsky’s (1984) determinants of parenting model, and comment on their impact on the developing attachment relationship, using the results from the data.

Table 4.3

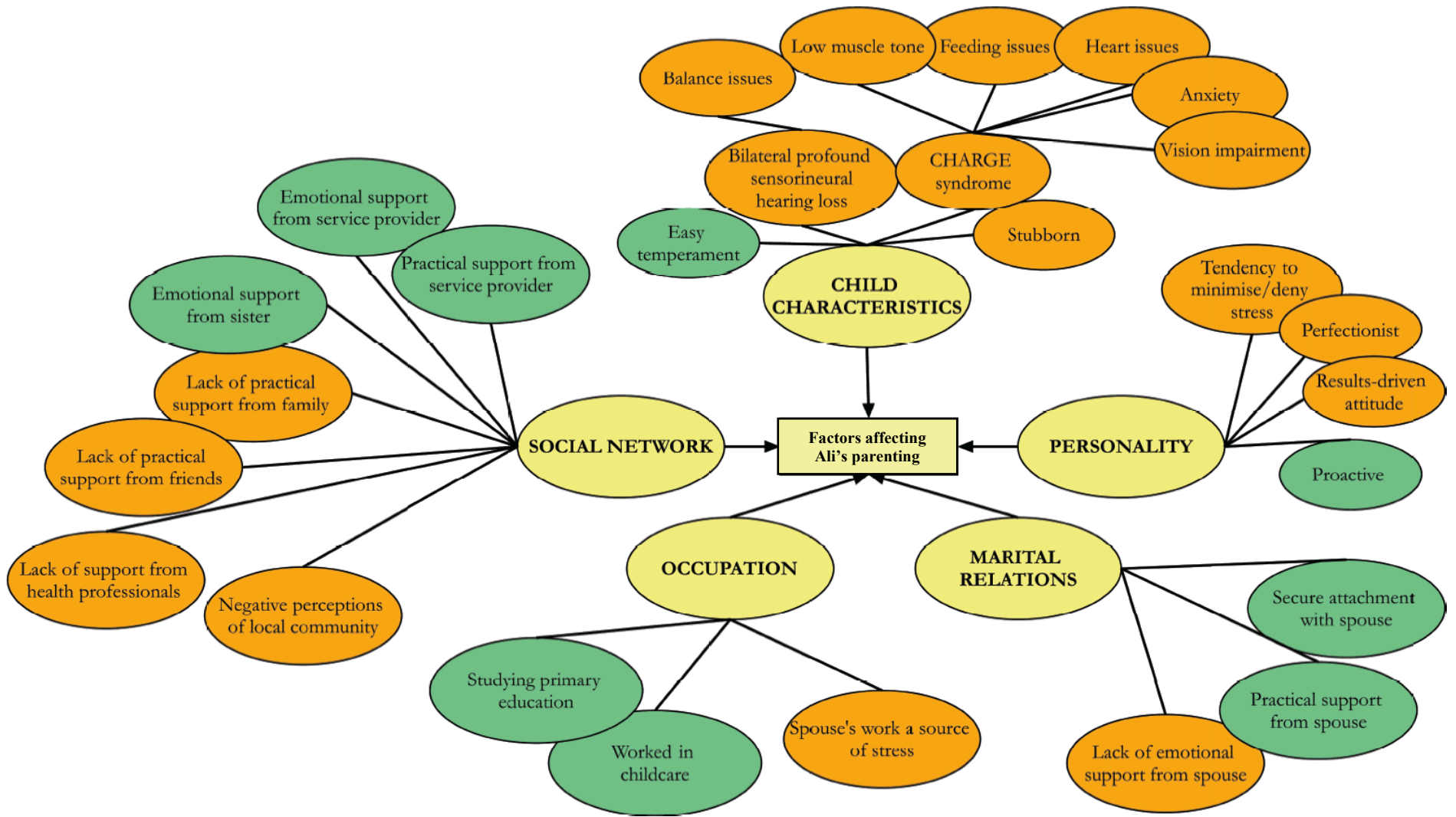
*Theoretical Model of the Relative Probability of Effective Parental Functioning in All Possible Conditions of Parenting Systems (Belsky, 1984, p. 92).*

Relative probability of parent functioning competently	Conditions of the parental subsystems		
	Parental personality and psychological well-being	Contextual subsystems of support	Child characteristics
Highest (8)	+	+	+
	+	+	-
	+	-	+
	-	+	+
	+	-	-
	-	+	-
	-	-	+
Lowest (1)	-	-	-

*Note.- Plus sign (+) stands for supportive mode; minus sign (-) stands for stressful mode.*

Figure 4.37

Factors Affecting Ali's Parenting.



### *Child Characteristics*

As seen in Figure 4.37, Rosa had various complex needs that impacted on Ali's caregiving. Taken from her audiological and medical data, there is evidence of a long list of complex needs: Rosa's profound, bilateral sensorineural hearing loss, and her diagnosis of CHARGE syndrome, which involved heart issues, feeding issues, balance issues, visual issues, low muscle tone and anxiety (see Appendix C for a detailed table). Interview responses from the service provider, and Rosa's mother and father described the impact these various medical complications have had on the family.

Firstly, Ali described her pregnancy with Rosa as difficult. Due to the diagnosis of Rosa possibly having Down syndrome, her husband and herself were of two minds whether to terminate the pregnancy or not. Ali insisted that they keep Rosa, regardless of the disability she may have. There was also some confusion about Rosa's actual diagnosis, with tests revealing she had congenital heart issues, and not Down syndrome. However, later in the pregnancy, doctors told Ali and Ben that their daughter would have Di George's syndrome. When Rosa was born, she was labelled and treated as a Di George's syndrome baby. However, further tests revealed a misdiagnosis. Rosa actually had CHARGE syndrome. Ali described the way medical professionals disclosed this diagnosis to her as insensitive, cold and intimidating as there were several doctors in one room with just her, her husband and their newborn. They left them with the news that Rosa would likely be deaf and blind, with nothing but some pamphlets to ease their shock. Just 18 hours after her birth, Rosa underwent open heart surgery, which was traumatic for both Ali and Ben. Rosa also had another heart operation at 6 months of age. Ali noted in particular how Rosa's feeding issues were quite traumatic for her. She felt that she was not being heard by the health professionals, and lost trust in them.

When Sarah was interviewed, she confirmed how these various medical complications impacted on Rosa's ability to interact with Ali. Sarah described in her interview how she worked on Rosa's visual attentiveness, and also used sensory integration to help Rosa be more present, regulated, and engaged. Only then was Sarah able to connect with Rosa and eventually help Ali better connect with Rosa. Sarah also noted Ali's distrust with some medical professionals, and so endeavoured to



gain her trust and build a relationship with Ali. Sarah confirmed that because of the ongoing hospitalisations, medical appointments, and assessments that are part and parcel of parenting a child with HL-CN, parents and their children often did not have the space and time to simply interact and bond with each other. Sarah highlighted the chronic anxiety, grief and fear that both child and parents often experienced as a result of complex needs. Unfortunately, this was the case with Ali and Rosa, thus Rosa's characteristics – namely her disabilities – affected her attachment development with her mother.

A protective factor that was identified was Rosa's easy temperament. Regarding the results of the PSI, Ali's Mood subscale score was very low, which revealed that Ali perceived Rosa to have a very happy and relaxed temperament. This finding was confirmed when corroborated with the interview data as both Ali and Ben described Rosa as a happy and easy-going baby.

### ***Parent's Personality***

The mother's own personality and psychological attributes appeared to have influenced her caregiver sensitivity. Results of Phase 1 showed that Ali's experience of parenting stress and coping mechanisms – both evidence of her personality and psychological attributes – were multidimensional. Ali scored within the normative range in the PSI, however a score of 25 that was very close to the defensive responding cut-off score of 24, as well as content from her interviews, and those of Sarah's, showed that Ali was indeed minimising her experience of parenting stress in order to cope (see Figure 4.2). More so, a sense of empowerment and drive came through from Ali's interview responses, showing that this part of her personality may have helped her to cope with the difficulties of parenting Rosa, a child with HL-CN.

Another aspect of Ali's personality was her results-driven and perfectionist attitude. In her interview, Sarah's comments on Ali's results-driven attitude as being detrimental to Ali and Rosa's developing attachment, and Ali's own admittance that she was focussed on Rosa's progress and therapies, provided further evidence of the effect of a parent's personality on their parenting. Phase

2 videos, as well as early Phase 3 videos lent further support to this conclusion, and showed how Ali was so concentrated on Rosa's ability to meet audiological and developmental milestones, she did not allow herself to enjoy interacting with her daughter. Indeed, the external CARE-Index coder noted how Ali was responding to the infant in her mind, rather than to the infant in front of her, showing Ali was not always attuned to Rosa's needs. The videos also showed Ali's anxiety with Rosa making progress, as seen in her biting her nails, and her negative comments such as "It took you a while but you got there in the end". Thus, while Ali was motivated to parent Rosa well, her perfectionism and desire for Rosa to achieve actually detracted from the quality of her caregiver sensitivity.

In his interview, Ben told of his experience with Rosa's diagnosis and various medical operations, assessments and complications. He described how he felt that he had to be strong for Ali, and kept positive, keeping his emotions inside. Though Ben naturally had an easy-going personality, his experience shows how fathers also need to express their emotions with such difficult situations.

### ***Occupation***

Ali's occupation influenced her parenting as it gave her more knowledge of child development than most parents, thus perhaps more stress and anxiety when interacting with Rosa. In her interviews, Ali revealed that working in a preschool as well as studying primary education, made her place a lot of pressure on herself to be a good mother, and to be able to teach her child and help her achieve developmental milestones. Again, this gives further evidence of Ali's results-driven personality, and the impact it had on her relationship with Rosa. Furthermore, her husband Ben became the sole breadwinner as Ali needed to look after Rosa full-time. This caused some strain on their finances, with Ben and Ali facing a decision to move to a different state due to better job prospects and to be closer to relatives who could help them with Rosa. Along with the ongoing costs of parenting an infant with HL-CN (e.g., cochlear implants, various early intervention therapies and services, a feeding clinic program in Adelaide, insufficient funding), the financial burden on parents with

children of multiple disabilities is clear, and can indeed add more stress to their lives, impacting their parenting capabilities.

### ***Marital Relations***

Ali scored as secure in her adult romantic attachment style with her husband (see Figure 4.3), though her interview responses revealed that she felt she needed more emotional support from Ben, as well as more support in parenting Rosa. In her interview responses, Ali described how she wanted Ben to be able to attend early intervention therapy sessions and other appointments with her, however, Ben insisted that it was more important for him to work. Ali also felt that Ben did not understand nor appreciate how much work went into Rosa's early intervention therapy. Yet in his interview responses, Ben described how great a mother Ali was, and how close he thought her relationship was with Rosa. Evidently, as Sarah pointed out in her interview response, Ben and Ali were on separate pages when it came to parenting.

### ***Social Network***

Ali's social network was considered both a risk factor and a protective factor. In her interviews, she spoke about her mother being an alcoholic and was therefore unreliable. Her father also was not capable of supporting her with Rosa, having described him as infantile. A close friend of hers did not offer any help or support. Also, Ali felt that the community largely were not helpful to her as a parent with a child with HL-CN. Ali did not appreciate the comments made by community members, or the pity they gave her. In terms of positive support, Ali relied on her husband who was great with practical help, though not so much with emotional support. Ali placed a lot of trust in Sarah, Rosa's speech pathologist. She would often share joyful news with Sarah, and spoke to her about Rosa's progress with tests and assessments. Their professional relationship and friendship were also evident in the videotaped therapy sessions. In both Phase 2 and Phase 3 videos, Ali and Sarah were seen working together to interact and teach Rosa. Ali also spoke to Sarah about her life, sharing the progress Rosa was making at home, e.g. when she told her how amazed they were at the number of animals Rosa

had memorised the name of. Sarah appeared always to actively listen to and empathise with Ali. Evidently, Sarah provided Ali with a lot of the emotional support she needed.

### *Attachment Relationships*

Finally, in terms of attachment and ECI, results of Phase 2 and Phase 3 videos showed improvement in Rosa's relationships with both Sarah and Ali. In the Phase 2 videos, Sarah took a more dominant role during therapy sessions. The researcher and Louise provided this feedback to Sarah, and suggested that she take a supportive role, to allow Ali and Rosa the space to engage with each other. After receiving this feedback, Sarah was seen taking a more supportive role in the Phase 3 videos. She would coach and model for Ali, and encouraged Ali in her playful interactions with Rosa. By the end of the Phase 3 videos, it was seen that Sarah and Ali were working in tandem during the therapy sessions.

Ali and Sarah's relationship also improved and together they were working on helping Rosa build resilience and on teaching her self-regulation, a great example of this was shown in the session on Humpty Dumpty. Results of the vocal interactions between the participants revealed that Rosa appeared to respond more to Sarah, who used acoustic highlighting, took the time to wait for Rosa, and was more emotionally attuned to her. In particular, across the videos, Sarah and Rosa completed more circles of communication than Rosa and Ali, and Sarah had fewer counts of misattunement to Rosa's behavioural cues, though Ali's improvement across the time of the videos cannot be discounted. Her use of acoustic highlighting increased, as well as the circles of communication she was able to complete with Rosa. One interesting observation was how often Rosa referenced Sarah – upon hearing her voice as Sarah used motherese and acoustic highlighting despite being in the middle of play interactions with her mother. These findings appear to support the importance of the quality of the caregiver's voice, and its likely impact on the attachment relationships of infants with HL-CN (see Chapter 2 Literature Review).

The follow-up interviews in CS1 were significant in regards to the developing attachment relationship between Ali and Rosa. In her interview, Sarah was given an opportunity to describe her relationship with both Ali and Rosa. She explained that at the beginning, she felt that she needed to provide that extra support for Ali, in order for Ali to believe that Rosa was capable. She agreed that the researcher's feedback regarding Sarah's more dominant role in the Phase 2 videos, was true to an extent, however maintained that at the time of the Phase 2 videos, it was necessary for her to play such a role. It seemed that what Sarah was describing was a balancing act, where the service provider had to support both child and parent, in order to facilitate their developing attachment relationship. Sarah spoke of being an emotional support for Ali, and how important it was for her as a service provider to be emotionally regulated.

In her follow-up interview, Ali spoke positively of Rosa's progress and development. She described how their attachment relationship had deepened and how Rosa's positive experiences with her attachment figures – including Sarah – were playing a role in her speech and language development. In his interview, Ben also expressed his views of the strong emotional bond between Rosa and Ali. He also expressed some regret at having to work a lot and therefore not being able to spend as much time with Rosa as he would have liked, thus he expressed that his relationship with his daughter was not as strong as Ali's.

Overall, Case Study 1 gave evidence that an infant with HL-CN did not develop attachment relationships in a predictable way. Factors such as the child's disabilities, parents' and infants' experience of anxiety, grief and misattunement may all hinder the formation of attachment. For those families that decide to attend ECI at this particular ECIC, service providers endeavour to help parents and child to connect. Service providers know the importance of attachment and seek to overcome and address potential barriers that parents and children may face in reaching the earlier phases of attachment. Often the service provider learns how they can best be attuned with the child first, in order to show the parent how to be more attuned with their child. To facilitate the developing attachment relationship between parent and child, service providers then model playful interactions

and ECI therapy techniques for the parent, and progress to coaching them and finally simply supporting them during therapy sessions as parents and children gain confidence. Service providers also support parents emotionally, helping them work through anxiety or grief they may have experienced. This was the case for Sarah, Ali and Rosa, and as she described in her follow-up interview, Sarah stated that this was frequently the norm for many of the families that attend their ECIC.

### **Impact on Methodology**

As detailed in Chapter 3 Methodology, CS1 was designed as the pilot study. The role of the pilot study was to test the feasibility of the research design and to test and trial its data collection and analysis methods. In response to the data collection and analysis procedures of the pilot study, the following changes to the research design, case study protocol, and data collection and analysis methods were made:

Table 4.4

*Changes in Methodology Following the Pilot Study.*

Outcome from Case Study 1	Implications	Changes to Case Study 2 methodology
Prolonged data collection	The lives of infants with HL-CN and their families are busy due to several factors (e.g., numerous appointments and therapy sessions)	Extending the time period for data collection accommodates for the needs of the families
Findings from Parenting Stress Index used to revise interview schedule	Allowed for triangulation of data (Yin, 2018) and a more focussed interview schedule	Revised interview schedule
During interview with mother, the interview schedule was loosely adhered to	Open-ended questions to encourage the parent's narrative	Less structured interview style
Not all questions in interview schedule were answered in one interview, thus a second interview was conducted	Gained more detailed and in-depth interview responses	Option of a second interview
Researcher recognised the value of an interview with the secondary caregiver	Gave perspective of the father	Interview with secondary caregiver (via Skype)
No value in collecting data in a certain order for Phase 4	Flexibility in scheduling interviews and gathering documentation	No need for instruments to be in the same order as Case Study 1
Testing and trialing of the video-coding scheme for Phase 2 was successful	Purpose of Phase 2 was to trial the video-coding scheme. No need for this to be repeated in Case Study 2	No second phase of videotaped observations for Case Study 2
CARE-Index chosen as a video analysis tool	A well-validated video coding tool used by an external coder added reliability to the study	Inclusion of the CARE-Index for video analysis
Participants asked to be given feedback regarding the progress of the study	Feedback given to the Case Study 1 participants seemed to have a positive impact on their interactions during therapy sessions	Provision of feedback to participants
High attrition rate	High attrition rate due to the complex nature of the participants. Parents cited lack of time and parenting stress as reasons for discontinuing with the research study	Two case studies instead of the intended three case studies

In conclusion, the various data gathered and analysed unveiled an in-depth and complex picture of CS1. The findings point to how the development of Rosa's attachment relationships with her key caregivers such as her mother, father and service provider was indirectly influenced by factors that impacted on Rosa's and her mother's ability to interact and engage with each other. Major factors included emotional support from Sarah, Ali's anxiety and results-driven attitude, Rosa's own anxiety and disengagement, and the many appointments, tests and trauma from the hospitalisations that Rosa and her family had undergone. This investigation resulted in changes to the methodology used in Case Study 2, the results of which are reported in the following chapter.



## Chapter 5 Case Study 2

The following chapter will present the findings of Case Study 2 (CS2). The chapter opens with a brief overview of the changes to the research design and the case study protocol as summarised in the previous chapter. The remainder of the chapter reports only the results of CS2, given the data collection and analysis methods used in this case study were the same as those described previously in Case Study 1 (CS1) (see Chapters 3 and 4 for a detailed discussion).

### **Modification of the Research Design**

During the course of the study, the initial research design was modified from a three-case study design, to a two-case study design. Five families initially agreed to take part in the study however, three of the families who began the study felt that they could not continue. Parents cited a lack of time and parenting stress as reasons for not continuing with the research study. Parents were attending early childhood intervention (ECI) sessions weekly with their children at the setting of the research study, as well as many other medical and hearing appointments and tests for their children's various needs. As such, they felt that they had no room for another commitment in their already busy lives. The flexibility of the research design gave evidence of its strength, which was able to adapt based on the nature of the participants (Creswell, 2018; Yin, 2018). The present study completed two case studies which followed Yin's (2018) replication logic, despite the unforeseen challenges resulting in a reduction in the number of intended case studies.

### **Modifications to Case Study 2 Protocol**

The case study protocol followed in CS2 saw some important changes including the elimination of the second phase of videotaped observations. These changes are explained below. Figure 5.1 shows the revised data collection steps with the instruments used shown within each phase.

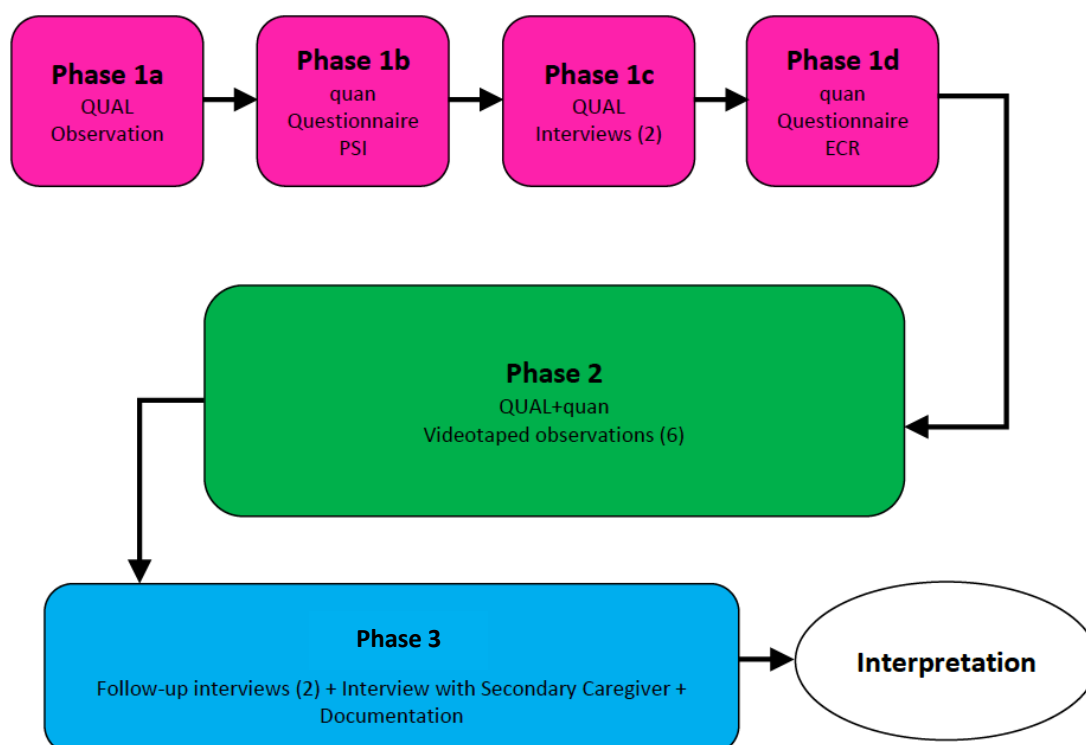
In Phase 1, one longer interview with the mother was conducted, replacing the two shorter interviews with the mother undertaken in CS1. In CS2, all interviews were conducted at the early childhood intervention centre (ECIC), whereas in CS1 interviews with the primary caregiver were conducted at her home.

In the pilot case study (CS1), the purpose of conducting two phases of videotaped observations was to use the first phase of videos to test the validity and reliability of the researcher's original coding scheme. This was successfully conducted in CS1's Phase 2 videotaped observations, thus the same coding scheme was used to analyse all the videos in CS2. As such, where CS1 had two phases for video observations – Phase 2 and Phase 3, CS2 only had one – Phase 2. Another change was that the setting for the videotaping was at the ECIC, different from CS1 where Phase 2 videos were taken at the participants' home.

In Phase 3, the order of follow-up interviews and the interview with the secondary caregiver varied. Interviews were all held at the ECIC. Finally, the interview conducted with the secondary caregiver was in person and not over Skype as used in CS1.

Figure 5.1

*Case Study 2 Protocol.*



## Case Study 2 Results

The results derived from data collection and analysis revealed that various factors affected the developing attachment relationships of the CS2 infant. Following a description of the CS2 participants, these factors are reported under the three phases and their instruments.

### *Case Study 2 Participants*

The participants of CS2 included an infant with HL-CN – Luca, his primary caregiver- Mikaela (mother), his secondary caregiver- Peter (father), as well as their service provider- Jasmine, who had been working with the family since Luca was 6 months old.

**Luca.** At the beginning of data collection, Luca was 17 months old. He was born prematurely at 33-weeks' gestation, with a teratoma (tumour) in his throat. Birthing complications resulted in his staying in hospital for three and a half months (see Appendix O for a summary table). The tumour in

Luca's throat was misdiagnosed as a neuroblastoma and, as a result, he was given incorrect treatment, in the form of chemotherapy, which caused the tumour to grow (see Appendix O for a summary table). The correctly diagnosed teratoma was eventually surgically removed when he was about a month old. When he was a few weeks old, Luca was also diagnosed with a bilateral hearing loss when tested under the State Wide Infant Hearing Screening (SWISH) Program. Luca's hearing was assessed again at 4 months old, where he was confirmed to have a bilateral, permanent, sensorineural hearing loss of 40dBHL or greater. He was fitted with hearing aids a couple of weeks after. Hearing aid compliance was inconsistent in the months that followed (see Appendix O for a summary table).

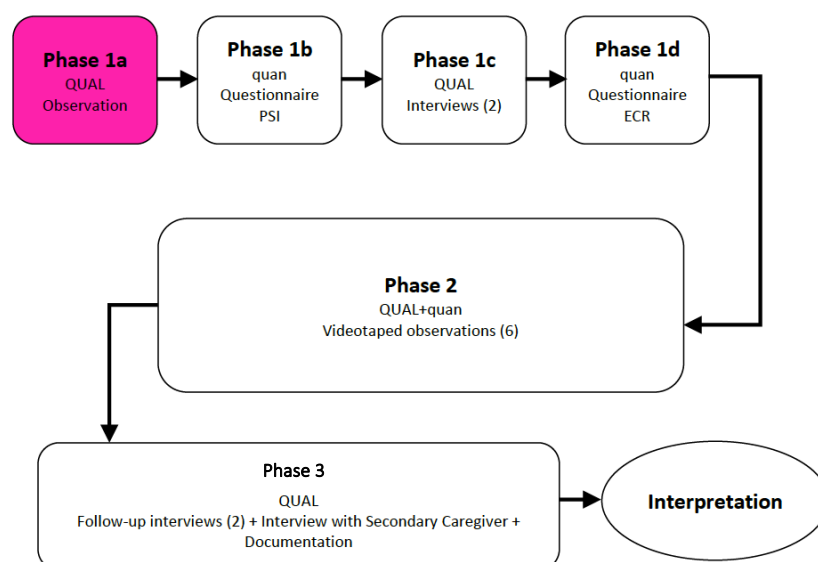
**Mikaela and Peter.** Luca's mother Mikaela and father Peter were an older couple when they conceived, being in their late thirties and early forties. Both had immigrated to Australia in their twenties. Mikaela was originally from the Czech Republic, while Peter was from Slovakia. They completed their tertiary education in those countries, Mikaela in the field of architecture, and Peter in education. At the time of the study, Peter was working fulltime as a handyman at a school, while Mikaela worked part time as a drafter at a landscaping business. Luca attended childcare on the days that Mikaela worked. At home the couple spoke predominantly in Czech and Slovak, though they wanted Luca to learn how to speak in English as he would be attending English-speaking schools.

**Jasmine.** Jasmine was the service provider working with Luca and his parents. She was a special educator and had a tertiary degree in special education, specialising in deafness and communication disorders. Jasmine had worked at this ECIC for 8 years, and before then, had been working in the field of hearing loss for several years. During the case study, Jasmine had a back injury and took several weeks off work, which resulted in her not being able to provide therapy sessions for Luca and his family. During her time off, no service provider was assigned to Luca and his family. Jasmine's injury impacted the study in a number of ways which are discussed in the following paragraph.

Data collection for CS2 took 1 year. This length, when compared to the shorter data collection period for CS1 (7 months), was the result of several unanticipated factors. These factors included Jasmine having a back injury that prevented her from working for several weeks, the infant Luca being sick and missing therapy sessions, as well as Mikaela, his mother, also being sick, being prone to migraines. The researcher therefore worked around the participants' schedules, with a number of therapy sessions that were scheduled to be video-recorded having to be postponed. There was also a 3-month hiatus on video-recording due to Jasmine's back injury.

## *Phase 1*

### **1a - Live Observation.**

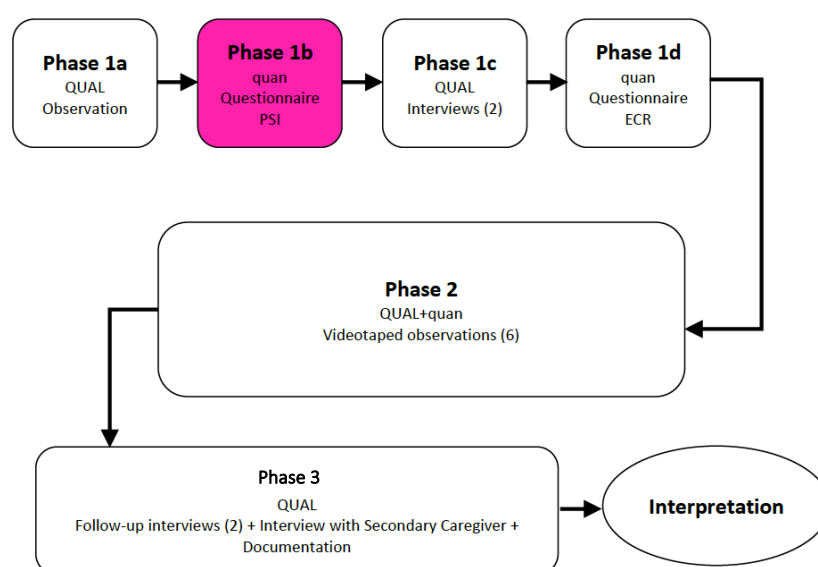


The live observation of the first therapy session was conducted in one of the therapy rooms at the ECIC. Present were Luca, Mikaela, Jasmine, a physiotherapist, and the researcher. It had been decided beforehand by Jasmine and Mikaela that the session would be a joint session on speech therapy and physiotherapy. Mikaela appeared friendly and quite talkative and spoke to Jasmine and the researcher at length about what had happened to her in the past week. She spoke about her baby shoe business and showed Jasmine and the researcher a sample of the special shoes she made. While Mikaela continued talking, Jasmine began her therapy session with Luca. Luca interacted with

Jasmine and the physiotherapist. He became upset at times (e.g. crying), in particular when the physiotherapist encouraged him to do more difficult tasks, such as attempt to walk unaided. Jasmine and the physiotherapist verbally praised and clapped Luca for his efforts, and encouraged Mikaela to do the same. However, Mikaela seemed reluctant and commented, “I will be happy when he takes a number of steps on his own”. Jasmine tried to coach Mikaela on how to play and interact with Luca. Mikaela made some attempts to connect with Luca although she appeared unsure and almost embarrassed when Luca did not interact with her in the way he interacted with Jasmine. At the end of the session, Mikaela expressed her concern that Luca had not yet begun to walk. The physiotherapist and Jasmine assured Mikaela that in the new year he would definitely be walking, and reminded her that Luca had spent an extended time in hospital and that could be a reason for some of his gross motor delays.

Regarding his attachment development, Luca was observed to be in the first phase of attachment, that is, Orientation and Signals with Limited Discrimination of Figure (shortly after birth to first few months of life) (Bowlby, 1969).

### 1b - Parenting Stress Index.



The results from the PSI reflect Mikaela's perception of parenting stress she experienced at the time of the study. As with CS1, a table was drawn up to display Mikaela's scores (see Appendix P), and used to create her Percentile Profile (see Figure 5.2). Figure 5.2 displays Mikaela's scores from all Child and Parent subdomains, her total Child Stress score, her total Parent Stress score, her Total Stress score, and her Life Stress score. Results show that more than half of her scores fell in the upper ranges, that is, the clinically significant range, 90<sup>th</sup> percentile or higher (red segment), the high range, 85<sup>th</sup> to 89<sup>th</sup> percentile (red segment), ranges just outside the normative range, 80<sup>th</sup> to 84<sup>th</sup> percentile, or 15<sup>th</sup> percentile and below (orange segments), and the upper normative range (yellow segment). Seven of Mikaela's subdomain scores fell within the normative range, 16<sup>th</sup> to 84<sup>th</sup> percentiles (white segment), though most fell toward the upper normative range. She scored a Defensive Responding score of 55, which indicates she was not responding in a defensive manner; therefore, her scores could be interpreted without caution (Abidin, 2012). Mikaela's Attachment score of 14 is marked in green due to its importance to the study.

In regards to Total Stress, Mikaela's score fell in the 87<sup>th</sup> percentile, which is in the high range. According to the PSI manual, a result such as this suggests a referral to a clinician, such as a psychologist, should be discussed (Abidin, 2012). When the researcher broached the subject with the key informant, Louise informed the researcher that Mikaela was seeing a psychologist for her clinical depression. Her life stress score, however, was in the normative range, 59<sup>th</sup> percentile, meaning that at the time of administration, Mikaela was not experiencing any major stress outside of her control.

### ***Child Domain***

Mikaela scored a total Child Domain score that fell in the 77<sup>th</sup> percentile, which is in the upper normative range. Upon closer examination, Mikaela's profile showed that her Distractibility/Hyperactivity (DI) and Demandingness (DE) subdomain scores fell in the clinically significant range, scoring in the 94<sup>th</sup> percentile and 95<sup>th</sup> percentile, respectively. A high DI score is often associated with a child who shows behaviours characteristic of attention-deficit/hyperactivity

disorder (ADHD), including restlessness, short attention span, failure to listen and failure to finish tasks (Abidin, 2012). Other reasons behind a high DI score could include: “(a) the parent lacks the energy necessary to keep up with a ... child; (b) older parents with a formerly stable life pattern are experiencing difficulty adjusting to the child; or (c) unreasonable parental expectations for mature, adult-like behaviour are present” (Abidin, 2012, p. 17).

High scores in DE may be a result of the parent experiencing the child as placing too many demands on him or her (Abidin, 2012). Such demands may include: “crying, physically hanging on the parents, frequently requesting for help, or exhibiting a high frequency of minor problem behaviours” (Abidin, 2012, p. 17). Again, further evidence needed to be gathered to affirm that Luca was a demanding child. Mikaela’s scores in the Adaptability (AD), Mood (MO), and Acceptability (AC), were within the normative range, though in the upper segment. Her Reinforces Parent (RE) score was well within the normative range. These scores do not impact the study.

### ***Parent Domain***

Mikaela’s total Parent Domain score fell higher than her Child Domain score, being in the 95<sup>th</sup> percentile. This is significant because characteristically, the Child Domain score is higher than the Parent Domain score in parents of a child with a disability, such as the case with Mikaela and Luca. Mikaela’s high Parent Domain score suggests that the sources of stress in the parent-child system may be related to the parent’s functioning, more so than the child’s disability (Abidin, 2012). According to Abidin (2012), parents who are highly educated but obtain a high score in the Competence (CO) subdomain may possess limited knowledge about child development or child management skills, or find that parenting their child is more than they can handle. Mikaela – who scored in the 97<sup>th</sup> percentile of the CO subdomain, appears to fall in these categories, being an older, educated, first-time mother.

Mikaela also scored high (94<sup>th</sup> percentile) in the Isolation (IS) subdomain. This suggests that she felt isolated in her parenting role, feeling unsupported by friends and family and possibly that her

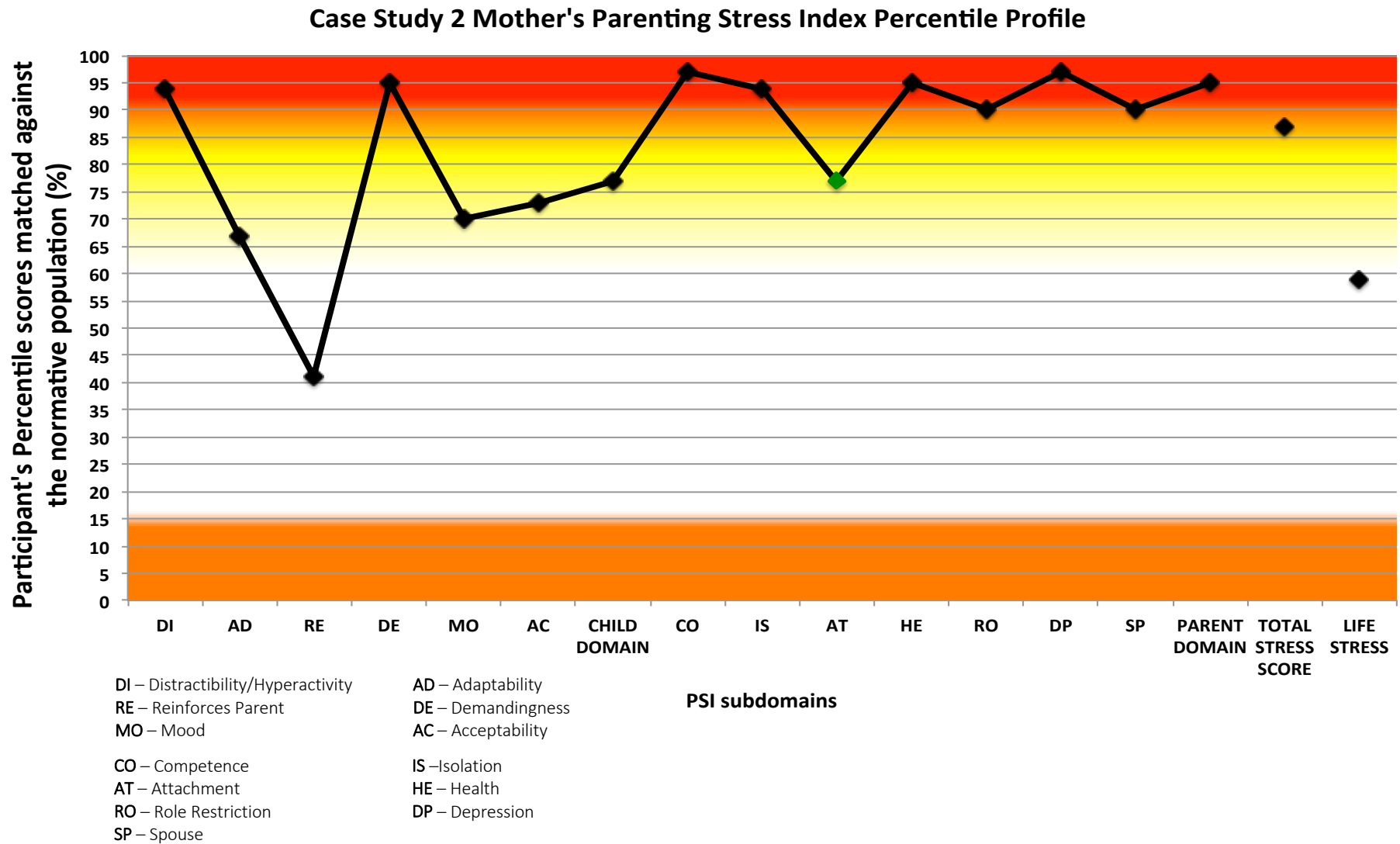


husband is not overly supportive of her in parenting their child (Abidin, 2012). Mikaela's Health (HE) score (95<sup>th</sup> percentile) indicated her belief that her health, physically or psychologically, was deteriorating (Abidin, 2012). This could be physically or psychologically. Her Role Restriction (RO) score fell in the 90<sup>th</sup> percentile, which suggested she felt "controlled and dominated by [her] child's demands and needs" (Abidin, 2012, p. 20). Mikaela's Depression (DP) score was also high being in the 97<sup>th</sup> percentile, signifying that she "finds it difficult to mobilise the psychic and physical energy needed to fulfil parenting responsibilities" (Abidin, 2012, p. 20). According to the PSI manual, a parent who scores in this range as Mikaela did, should be provided with "parental therapy or counselling aimed at enhancing self-esteem and assessing the significance of the depressive symptoms" (Abidin, 2012, p. 20).

Finally, Mikaela also had an elevated Spouse/Parenting Partner Relationship (SP) score, which fell in the 90<sup>th</sup> percentile. This suggests that she did not have the "emotional and active support of the other parent in the area of child management and emotional support" (Abidin, 2012, p. 21). Before any conclusions could be made, however, Mikaela's elevated Parent Domain scores needed to be triangulated with the results from the researcher's interviews with Mikaela, her husband Peter and their service provider Jasmine.

Figure 5.2

Case Study 2 Mother's Parenting Stress Index Percentile Profile.



It is interesting to note that although Mikaela scored in the clinically significant range for all her Parent subdomains, for the Attachment (AT) subdomain, her score was in the 77<sup>th</sup> percentile, which is within the normative range, albeit in the upper range. This result indicated that Mikaela felt close to Luca, despite her other elevated Parent subdomain scores. However, as her score fell toward the upper normative range, Mikaela may still have had difficulty accurately observing and understanding her child's feelings and needs (Abidin, 2012). Similar to the other Parent subdomains, this hypothesis needed to be corroborated with data observed in the subsequent phases, before drawing any definitive conclusions.

### ***PSI Profile Comparison***

Mikaela's PSI profile was compared to the mean profiles from clinical groups that reflect the same family dynamic as Mikaela and Luca. Table 5.1 displays the raw scores of Mikaela and of the associated parents of children with disabilities.

Table 5.1

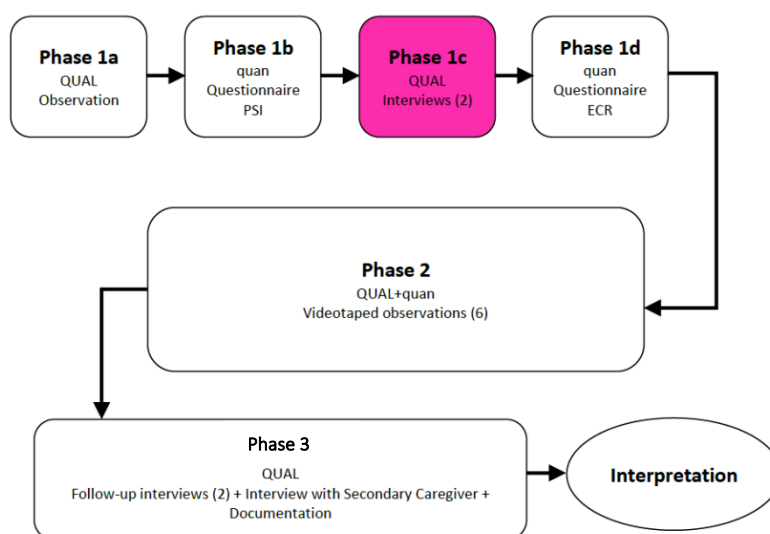
*Case Study 2 Mother's PSI Profile Compared to the Mean Profiles of Other Clinical Groups (Abidin, 2012).*

	Mikaela and Luca	Parents with children with hearing impairment	Parents with children with multi-handicaps*	Parents with children with developmental delay
Child domain score	128	113	120	121
Parent domain score	181	128	123	133
Attachment subdomain score	14	13	12	14
Total stress score	309	241	243	254

\*Note: Language usage is reflective of the language used in the PSI manual (Abidin, 2012, p. 147).

Based on the Total stress scores, Mikaela's PSI profile fell within two standard deviations from the other PSI profiles, with a standard deviation of 32 and a mean score of 261.75. This is of statistical significance since in statistics, 65% of all data fall within one standard deviation, while 95% of data fall within two standard deviations. As the other three PSI profiles only fell within one standard deviation from the mean, Mikaela's score was an outlier. Indeed, her Child domain and Total stress scores were notably higher when compared to these other profiles. Overall, Mikaela's PSI profile was concerning given the majority of her scores fell in the high or clinically significant range. Thus, according to the PSI manual, Mikaela was a caregiver that required a lot of emotional support as well as education in parenting (Abidin, 2012). How these findings may have affected Mikaela's attachment relationship with her son Luca will be discussed in the summary section of this chapter.

### 1c – Interviews.



The interviews with Jasmine and Mikaela were analysed using Nvivo, and followed the same procedure as that detailed previously for CS1, using Nvivo (see Chapter 4; interview data analysis; p. 126). Seven themes emerged from analysis of the CS2 interview responses. These themes were: *Understanding attachment, Factors around attachment, Attachment relationships, Early Childhood Intervention, Caregivers' experience of pregnancy, Caregivers' experience of Child's diagnosis, and Caregivers' hopes and concerns for their Child.*

***Understanding attachment.*** When asked what she knew about attachment, Jasmine replied that a child must first be self-regulated before they can form a connection. She noted that one way to facilitate attachment was to engage the child in circles of communication. When asked what she thought parents understood about attachment, she commented that she found it tricky to tell parents about attachment because she did not want to make parents feel guilty by suggesting that they could be better attached to their child: “You don’t want to bring guilt, and you don’t want to put them in a position where they aren’t ready to do something, and they just feel worse.”

Mikaela was not asked about her understanding of attachment. Although, when asked if she felt close to Luca when he was first born, Mikaela responded with: “First 2-3 weeks I was still thinking should we just give him back and ask for something else?” suggesting the difficulties she had bonding with her son.

***Factors around attachment.*** Mikaela’s own story about her parenting experience of Luca also gave some indication of factors that may have affected their developing attachment relationship. Mikaela described how for the first three and a half months of his life, Luca was hospitalised, diagnosed with a tumour in his throat. He stopped breathing once, had numerous tests done, and underwent surgery to remove the tumour. Luca spent some time in an incubator because he was premature, and in the first few weeks, Mikaela only held him a handful of times. Mikaela also expressed her regret that the antibiotics that were part of Luca’s chemotherapy treatment were the likely reason for Luca’s hearing loss: “I still sometimes think, it’s such a bloody shame that we, still have something left from it. After we went through all this. ... it’s not cosmetic, of course it’s not just little cosmetic thing, and we have to work on it.”

Jasmine noted various factors that could affect an attachment relationship, including the child’s characteristics, such as a disability, and the caregiver’s abilities and emotions. She described how in most of the families at the ECIC, their experiences of parenting a child with significant disabilities

was difficult. Jasmine spoke about a mother who once told her: “our lives get more chaotic, because they are chaotic”. Jasmine noted that things such as organising appointments and attending regular therapy sessions were hard for some parents. When speaking about factors that impacted on Mikaela and Luca’s attachment, Jasmine stressed that she felt it was Luca’s traumatic start to life that contributed to him being disengaged: “I think because he was so, poked and prodded and, traumatised in hospital that he just ... turned off, that would be my guess, to everything around [him]”. Jasmine also commented that in Mikaela’s case, fear was a major factor: “I don’t think she has that deep ... attachment. I don’t think she’ll allow herself ... to form that attachment for the fear, in case she loses him.”

In their interviews, both Jasmine and Mikaela also spoke about how the family received a scare a couple of months ago when Luca was diagnosed with another tumour which they had surgically removed. Jasmine again commented on the fear that Mikaela had of losing Luca, which she believed prevented her from attaching to him.

Mikaela expressed how her husband Peter could have been more supportive of her:

Mikaela: Oh, yeah he is supportive. He just doesn’t do it exactly the way I would like it, but you know.

Researcher: You take what you can get?

Mikaela: Yeah but still you know, sometimes I want to \*makes sounds and gestures as if to strangle someone \*

This supports Mikaela’s high PSI scores regarding the lack of support from her spouse, suggesting that Mikaela did indeed feel that Peter needed to support her more.

***Attachment relationships.*** When asked to describe her early relationship with Luca, Mikaela reported:

when I left hospital, we had so many appointments and everything. And ... I really was just a wreck, and I did not want to do anything. Yeah, and I started kind of enjoying him. It took me 3 months to start barely enjoying him. Yes, I grew closer with him in hospital, then at home. But enjoying, that did not happen until start of [the following year]. No kidding ... because it was all too hard. Everything was too hard ... and then another maybe 3, 4, 6 months before I started having fun! Like enjoying and having fun was another stage.

This excerpt illustrates how challenging it was for Mikaela to bond with Luca in those first few difficult months. This would also have impacted on their developing attachment relationship, since meeting all of Luca's medical and audiological needs likely left little time and space for Mikaela and Luca to bond.

Jasmine noted that her relationship with Luca was still developing, and admitted that when she first started working with him, it was very hard to engage him and elicit responses from him. These comments gave weight to the suggestion that Luca's traumatic start to life in the hospital hindered his attachment to his caregivers.

***Early childhood intervention.*** Jasmine described the ECI therapy strategies that they used at their ECIC, including: adapted auditory-verbal therapy, DIR/Floortime, occupational therapy, sensory integration and physiotherapy. She linked attachment to the therapies by explaining that the child first had to be self-regulated – often by using the aforementioned therapy strategies – before they could work on the child's relationships. When asked what strategies Jasmine used that were helpful, Mikaela was not able to name any, and noted how often she did not do follow-up therapy at home – due to all the other responsibilities around the home. Mikaela did comment that Jasmine and the whole ECIC were “lifesavers”.

*Caregivers' experience of pregnancy.* Mikaela spoke about how she conceived when she was 39 years old and gave birth to Luca at 40. She explained that at 7-months gestation they had a scare where she almost gave birth to Luca. Some complications they experienced at Luca's birth involved the pressure from the breaking of her waters, which resulted in an emergency caesarean section.

*Caregivers' experience of child's diagnosis.* Both Jasmine and Mikaela spoke of Mikaela and Peter's traumatic experience with Luca's birth and diagnosis. Mikaela spent most of the hour-long interview detailing her experience, often not in sequential order, which the researcher interpreted as Mikaela still being emotionally affected by this experience. Mikaela described how Luca was born prematurely and was incubated immediately. He had trouble breathing and so the doctors attempted to intubate him. However, they had difficulty inserting the breathing tube down his throat, and a scan revealed that a mass was blocking the tube. Mikaela explained how the doctors misdiagnosed the nature of Luca's tumour: "Yeah they got it wrong and gave him chemotherapy and that made this particular type of tumour grow, so it grew 50 percent the size in 1 week". She also spoke of how they were told about Luca's situation, and how insensitive the doctors seemed:

When there was this mass thing, and before they started doing chemo, when they were even finding even what's happening, there was a meeting of ten doctors and us. Yeah. Literally when I'd just gone home, and maybe 2 days later, like from the hospital. Um, we've had this massive meeting, and every man who was on board was there. You know because they had to say what's going to happen.

Mikaela appreciated the help of nurses during their stay in hospital, and was grateful that the ENT specialist who performed the surgery on Luca was the best there was.

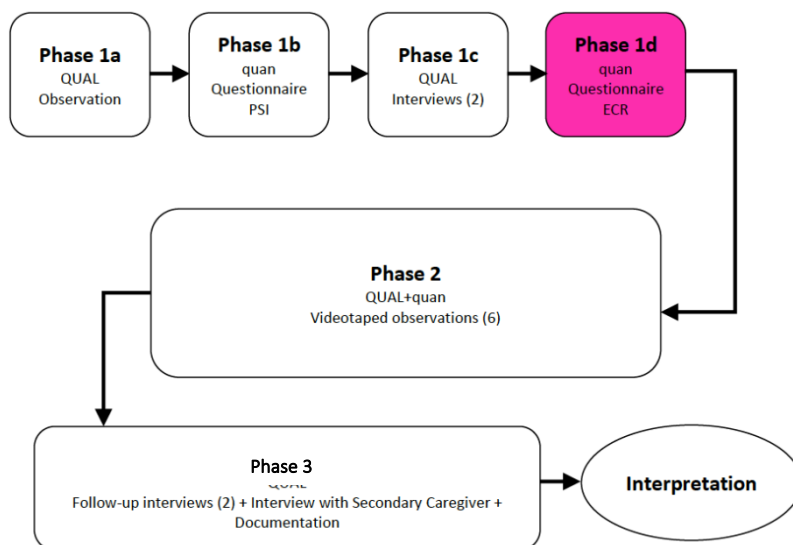


**Caregivers' hopes and concerns for their child.** Mikaela thought that Luca was “a smart kid” and did not express any concerns for him. This is in contrast to Jasmine, who was worried that Mikaela and Luca were not progressing as much as she hoped:

I think, my problem is that she'll be okay when he's okay. ... But he needs her, to be okay. Like it would help, he would get there quicker, if she could do it now. But she almost can't until he talks and walks. But if she was tuned in he would do that quicker.

In sum, findings from the interviews suggest that Mikaela and Luca possessed a number of factors that may have hindered the development of their attachment relationship. These include: Luca's 3-month hospitalisation and associated complications, resulting in his disengagement with others and the world, and Mikaela's fear that she may still lose Luca. While Mikaela seemed unconcerned about Luca's ability to listen and learn how to speak, Jasmine highlighted that Mikaela needed to be more attuned to help Luca develop.

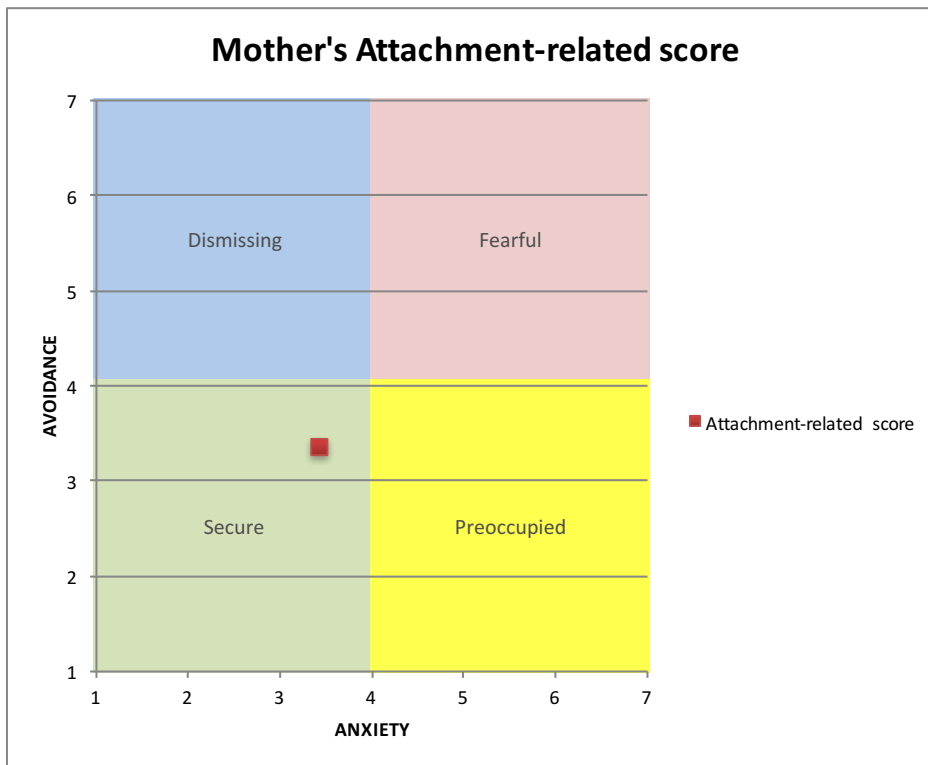
### 1d - Experiences in Close Relationships Scale.



Mikaela scored 3.3 on the attachment-related avoidance dimension, and 3.4 in the attachment-related anxiety dimension. In other words, Mikaela scored relatively low on both dimensions, which indicated that her adult romantic attachment style was relatively secure (the secure quadrant is marked green in Figure 5.3). Figure 5.3 displays Mikaela's secure romantic attachment-related score, in relation to the three other quadrants. Her secure score suggested that Mikaela was confident and secure in her romantic relationships in general, and in her relationship with her husband (Fraley, 2002). Typical of a secure individual, Mikaela should hold a positive image of herself "as worthy and lovable", and a positive image of others, "viewing them as responsive and attentive" to her (Fraley & Shaver, 2000, p. 142). Furthermore, her secure adult romantic attachment style pointed to a relationship where both adults can use each other as a 'secure base' and as a 'safe haven' during times of distress (Fraley & Shaver, 2000). However, as shown in Figure 5.3, Mikaela's score was leaning towards the Dismissing (blue) and Preoccupied (yellow) quadrants. A person whose attachment related score falls in the Dismissing quadrant has an avoidance score that is high, meaning that they tend to avoid closeness in their adult romantic relationships (Fraley & Shaver, 2000). A person whose attachment related score falls in the Preoccupied quadrant has an anxiety score that is high, meaning that they tend to be anxious about their romantic relationships, feeling that their partner may not be as emotionally available as they need them to be (Fraley & Shaver, 2000). These descriptors were considered when analysing Mikaela's interview responses and behaviours in the videotaped therapy sessions, as they may help in interpreting the findings.

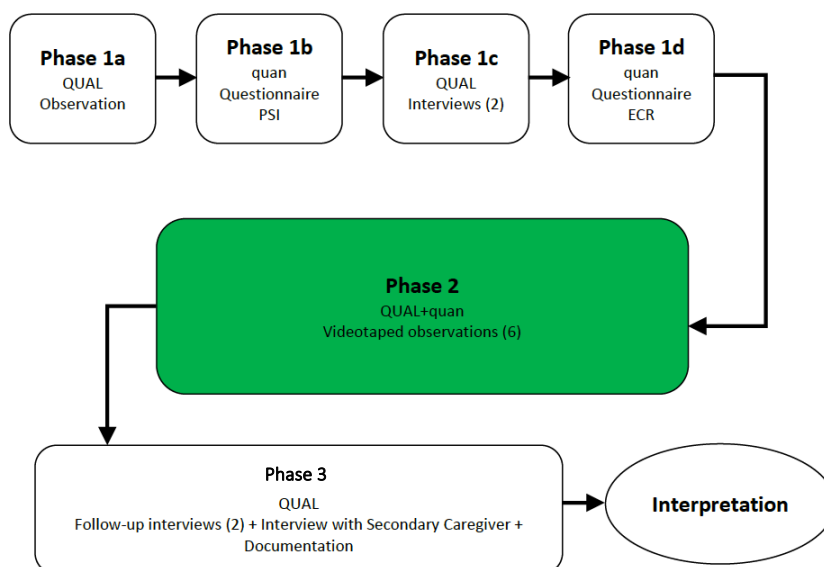
Figure 5.3

*Case Study 2 Mother's Experiences in Close Relationships Score.*



Interestingly, Mikaela's ECR score did not reflect her high PSI score in the Spouse/Parenting Partner Relationship (SP) subdomain, which fell in the 90<sup>th</sup> percentile. This discrepancy was supported by the interview responses noted in the previous section, which suggested that Mikaela felt that Peter could have better supported her emotionally and with parenting Luca.

## Phase 2



**Videotaped Observations.** The results of the Phase 2 video data analysis will be presented chronologically. The results for the CARE-Index analysis of video 1 – the 10-minute mother-infant play interaction – will be presented first. Findings for videos 1 to 6 will be presented with the qualitative description first, followed by the quantitative video codes.

**CARE-Index.** This section discusses the results from the external coder’s analysis of a short, videotaped play interaction between Mikaela and Luca, using the CARE-Index framework. CS2 used the same external coder as was used in CS1. Overall, the coder rated the dyad’s synchrony as 10 out of 14, which placed them at the top of the adequate range and not considered at-risk. Mikaela was coded as ‘sensitive’ and at times, ‘unresponsive sensitive’. Luca was coded ‘cooperative’, and scored some difficult and passive ‘non-cooperative’ points.

The coder described the dyad as showing “mastery of reciprocal communication around an object of joint attention” (B. Adams, personal communication, 8<sup>th</sup> August, 2016). The coder explained that Mikaela was able to introduce language into their play interaction, which was developmentally relevant and age-appropriate. The coder described Mikaela’s behaviours: “The mother uses situations such as the child’s interest in pushing the toy to repeat ‘push’ in context, providing an opportunity

for the child to connect the word and action. She also uses a name for the object the child retrieves, again helping the child make meaningful connections” (B. Adams, personal communication, 8<sup>th</sup> August, 2016). In describing Mikaela’s vocalisations and facial expressions, the coder remarked:

The mother copies the child’s vocalisation when he is excited about the toy, and validates his interest by smiling broadly. She uses positive face, voice and affect when encouraging the child to go and pick up the object off camera and he follows her suggestion apparently very willing to do this.” (B. Adams, personal communication, 8<sup>th</sup> August, 2016)

These positive comments supported the coding results of videos 1 to 6, as detailed in the following sections.

One specific example that the coder highlights is Mikaela’s ability to regulate Luca’s high arousal when he becomes over-excited over the toy. She details: “The mother uses language and gesture to intervene when the child almost tips the toy over. ... This slows down the play and he is able to engage positively again.” (B. Adams, personal communication, 8<sup>th</sup> August, 2016). Finally, the coder explained why the dyad was not rated as highly sensitive on the synchrony scale. She noted that because the mother had a cold, the connection between mother and child was disrupted several times, with Mikaela stopping to blow her nose, cough or take a sip of her drink. During these times, Luca was left to play on his own, though he did not show signs of distress.

Importantly, the coder noted that because the dyad scored 10 out of 14 in the dyadic synchrony scale and were thus not at risk, there was no need for intervention. In fact, the coder remarked: “Indeed the CARE-Index framework would suggest that intervention should be avoided in an adequate dyad because of the risk that intervention does not necessarily enhance dyadic functioning and can in fact impair it, so intervention poses risks in situations where the relationship is functional.” (B. Adams, personal communication, 8<sup>th</sup> August, 2016). The implications of these results for the overall case study will be discussed at the end of the chapter, in the summary of results for CS2.

***Qualitative Descriptions and Video Codes.*** The analysis method used for this phase was the same as that used for the Phase 3 videos in CS1. Six videos of Luca's therapy sessions were taken and then uploaded to a computer for qualitative and quantitative analysis. Videos were analysed chronologically. First, the researcher watched the video to gain an overall sense of the structure and atmosphere of the therapy session. Notes were taken down into the researcher's logbook. Secondly, the researcher watched the video several more times for key constructs that emerged. The researcher then wrote up qualitative descriptions of the main constructs. Thirdly, the researcher used Vcode to code the videos using the same coding scheme as used in the Case Study 1 Phase 3 videos (see Appendix M). The researcher watched the videos until a point of saturation was reached. Vdata was used to extrapolate the raw data from Vcode, which was then exported to Microsoft Excel. The researcher used Excel to create charts from the data and track trends across the six videos. The following sections describe the results of the qualitative and quantitative video analysis.



At the ECIC, most therapy sessions were conducted on the floor, following the DIR/Floortime model (Wieder & Greenspan, 2003). However, due to Jasmine's back problems, for most videos, Luca was seated at a table in a chair with straps that could be adjusted to suit his height. Jasmine and Mikaela were also seated at the table. According to the COMBINES Methodology, 'following the child's lead' is an important part of their ECI philosophy, thus Luca's position at the table restricted his movement around the room as well as the natural 'flow' of the therapy session (see Chapter 3 Methodology, Figure 3.4). Before the therapy session began, Mikaela spoke to both Jasmine and the

researcher about things that were going on in her life, for example, how Luca recently got a haircut. This discussion continued for some time after Jasmine had commenced with the therapy session. While Jasmine listened to Mikaela, it did not seem that she was actively listening and was more focussed on beginning therapy with Luca. Another example of Jasmine not practising active listening was when Mikaela tried to tell Jasmine about her sushi train lunch with Luca. Mikaela tried to interest Jasmine in this story, returning to it three times. Jasmine did not respond the first two times, but during the third time that Mikaela mentioned it, Jasmine responded: “That’s so good”, in reference to Luca playing with the sushi plates for half an hour, allowing Mikaela to have her lunch in peace, which Mikaela described as a rare occasion.

Regarding the constructs of ‘modelling’ and ‘coaching’, Jasmine would prompt Mikaela to play with Luca. She would model for Mikaela how to play with a toy, then hand it over to her to try with Luca. Mikaela seemed unsure of what to do when playing with Luca. Her play interactions with Luca were brief, and averaged 13 seconds. She would then look towards Jasmine for reassurance or to cue her on what to do next. Interestingly, often Jasmine would interject not long after prompting Mikaela, leaving child and mother little opportunity to play and interact on their own. One example of this was when Mikaela and Luca were playing with the toy train, and made one exchange of turn-taking. Instead of letting them continue on their own, Jasmine commented “whee!” and “round and round” in reference to the train’s wheels.

Jasmine appeared to exhibit anxiety when she perceived that Luca was not responding or playing enough with his mother. For example, Jasmine would change the activity or toy frequently and, in this 40-minute session, Jasmine changed the activity nine times. Mikaela also displayed some anxiety behaviours, such as nervous giggling, often after Luca had not successfully completed a task he was given. In one instance, when Jasmine asked Luca to take the rings off their base, yet Luca proceeded to put the rings on and Mikaela laughed. Another example was when Luca put the wrong-sized cup in the stack of cups, and again Mikaela laughed nervously.

'Misattunement' was a significant construct, with both Mikaela and Jasmine missing opportunities to interact with Luca. For example, during an activity where Jasmine was trying to get Luca to feed the cow, Luca initiated by flipping the bowl over. However, instead of following Luca's lead, Jasmine flipped the bowl back the right way up. She did this twice, and the second time stopped Luca from trying to flip the bowl. Further, Jasmine would scaffold Luca's play by holding his hands to place shapes where they belong, rather than allowing him to problem-solve on his own. In this example, Luca showed his determination and independence by taking his hand away from Jasmine's and then trying to place the shape in the corresponding hole. Similarly, when playing with Luca, Mikaela tried to direct him too much. Luca was putting the rings on in the wrong order, and so Mikaela insisted on trying to get him to put them on according to size. She would remark "Uh oh!" whenever Luca tried to place the 'wrong' ring. Both Jasmine and Mikaela seemed more interested in what they were trying to accomplish with Luca, rather than with what he was actually showing them he was able to do and was interested in.

'Emotion regulation' emerged as an important construct, with Luca often left to regulate his emotions on his own. For example, Jasmine began the activity using soft, quiet, low vocal tones as she put the cow to sleep. Suddenly, she woke the cow up, with a loud and bright expression. Luca put his thumb in his mouth, perhaps distressed by this change in Jasmine's vocal tone and facial expression. Neither Jasmine or Mikaela acknowledged Luca's discomfort, or helped him to regulate his emotions, thus Luca self-soothed by sucking his thumb. Another instance was when Jasmine took the train away from Luca, who showed that he was upset by crying out and gesturing for the train. Jasmine proceeded to introduce a new toy, and did not stop to comfort him. Interestingly, neither did Mikaela, who merely remarked that Luca wanted the train. These are examples of both 'misattunement' and caregivers not attempting to help regulate the child's negative emotions.

Another construct that emerged was 'preoccupation'. Often, Mikaela appeared more concerned with Luca's physical state, for example, would often wipe his nose or wipe his hands during a messy activity such as bubbles. In these instances, she seemed distracted and did not completely follow the



activities Jasmine and Luca were engaged in. Another example of Mikaela's preoccupation was when Jasmine and Luca were playing with bubbles. Jasmine used acoustic highlighting to stress the word "pop!" and then popped the bubbles, and soon after, Luca said "pop!". Jasmine noted to Mikaela that she heard Luca say "pop", however Mikaela said that she did not hear it and had a look of disbelief on her face.

At the end of the session, Mikaela was quick to leave the room to go to the bathroom, and Jasmine suggested that she first take Luca out of the chair and let him play on the floor. Mikaela spoke to Luca in Czech, assumingly to let him know that she was leaving and would be back soon. Luca appeared to show no indication that he understood that his mother was leaving the room. Jasmine and Luca played with blocks on the floor and this play interaction seemed more natural than the previous activities. On the floor, Jasmine followed Luca's lead a lot more and allowed him to play with the shapes at his own pace. Upon returning, Luca did not go to his mother or acknowledge that she had returned and simply continued to play. This behaviour showed a lack of preference towards his mother – his primary caregiver. Therefore, according to the phases of attachment formation, Luca had not reached Phase II: Orientation and Signals Directed towards One (or More) Discriminated Figure(s). For typically-developing children, this phase would be consolidated around 6 months of age. Aged a year and a half, it appeared that Luca and Mikaela's attachment relationship was developing at a considerably slower pace when compared to typically-developing infants. Mikaela commented that Luca was at a stage where he loved to put things in boxes, though did not join in Jasmine and Luca's play, and only towards the end did she imitate Luca's vocalisation of "ah".

In sum, the key themes that emerged from video 1 reveal that the quality of Luca's play interactions with his mother and service provider had room for improvement, with both caregivers missing a number of opportunities to follow his lead and connect with him emotionally.

## Video codes

Results from the first early intervention therapy session video, overall, showed that Jasmine appeared to spend more time with Luca, was able to pause and wait for him during appropriate times, and shared social moments with him, unlike Mikaela, who shared no moments of social connection with Luca. Mikaela was recorded as having the least counts of sensitive and appropriate facial expressions and/or body language. Both Mikaela and Jasmine had a few instances of touching or comforting Luca.

Key findings are shown in Figures 5.4 and 5.5. The results show that both Mikaela and Jasmine were missing a considerable amount of Luca's bids for attention, often not following his lead. Compared to the number of times they interacted with him, the ratio of completed circles of communication was quite low. Moreover, there were several occurrences of misattunement, where Mikaela or Jasmine misinterpreted or even ignored Luca's signals. It is also interesting to note that Luca turned away from Jasmine more times than from his mother, indicating at times a need for gaze aversion to regulate himself, or protest towards the activity. Jasmine used 'acoustic highlighting' much more than Mikaela (see Figure 5.5). Mikaela did not sing at all. In response to their vocalisations, Luca vocalised more towards Jasmine. He did not sign, as this was not a chosen mode of communication for the family. Luca gestured towards his mother less than he did towards Jasmine.

There was a clear discrepancy between Mikaela and Jasmine’s vocal interaction, with Mikaela coded as having only five counts of ‘acoustic highlighting’ compared to Jasmine’s 284 counts.

Figure 5.4

*Case Study 2 Phase 2 Video 1: Circles of Communication.*

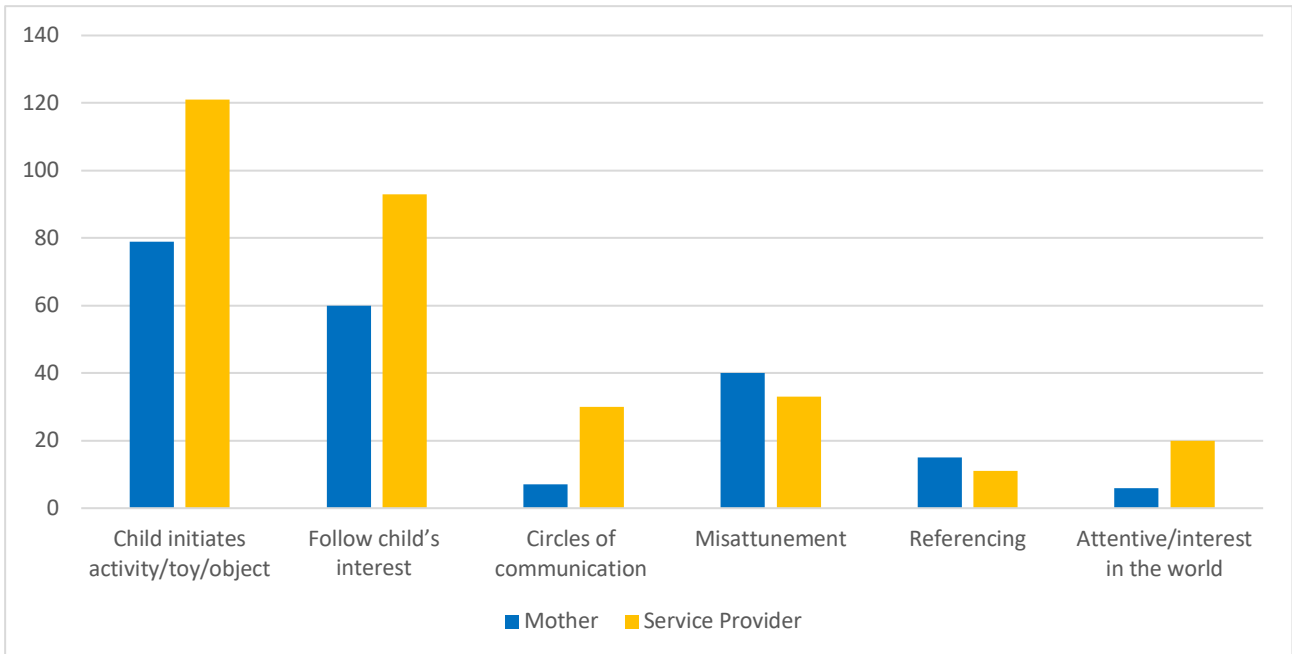
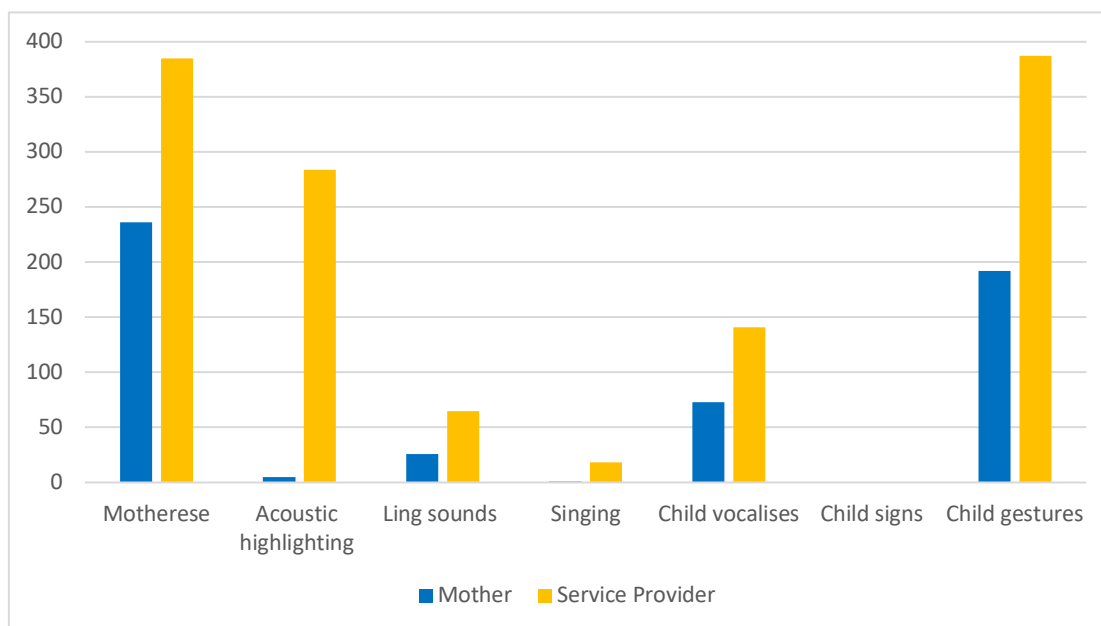


Figure 5.5

*Case Study 2 Phase 2 Video 1: Vocal Interaction.*





The key constructs that emerged from analysing video 2 were: ‘relationship between mother and child’, ‘emotion regulation’, ‘misattunement’, ‘relationship between service provider and mother’, ‘coaching’, ‘modelling’, and ‘anxiety’. These are discussed below.

Regarding Mikaela and Luca’s relationship, the researcher observed some interesting behaviours. Luca referenced his mother a number of times, though these gazes were very fleeting. In typically-developing infants of Luca’s age, frequent, long eye gaze with caregivers is developmentally-appropriate and consistent with reaching the third attachment phase (Bowlby, 1969). Luca’s inability to do this was indicative of his slower pace in progressing through the attachment phases. In regards to Mikaela’s behaviours, she appeared surprised and amused whenever Luca did something funny, vocalised clearly, or completed a task. She was also concerned about Luca’s safety and comfort, adjusting his chair when it appeared that he was falling over – though he was safely strapped in, and wiping Luca and the table whenever there was mess from bubble play. A few times she laughed nervously, or made self-critical remarks, showing embarrassment when she felt that she did not say or do the right thing. On the other hand, Mikaela was able to notice and point out to Jasmine Luca’s interests, showing attunement and knowledge of her child. Lastly, the researcher found it interesting that Mikaela’s voice changed dramatically depending on whether she chose to speak in English or Czech. In English her tone was quite deep and monotoned, whereas when she spoke to Luca in Czech, her tone became much softer and rhythmic, characteristic of motherese.

There were a number of times where Luca appeared to be uncomfortable or distressed, and resorted to self-soothing, as neither his mother or service provider responded to his affective state and behavioural cues. One example was at the beginning of the session. Jasmine had taken away a toy

from Luca and he became upset, crying and throwing his arms in the air. However, neither she nor Mikaela tried to pacify him. Both seem preoccupied; Jasmine looking for another toy, and Mikaela adjusting her chair. In another example, Luca took his comfort cloth, sucked his thumb, and looked at his mother. Mikaela did not respond to Luca's bid for attention, and simply looked at him briefly. Similarly, Luca displayed the same behaviour during play with Jasmine, who also had not noticed his discomfort and continued to brush the toy cow. This pattern of behaviour occurred another two times during the therapy session, and each time it resulted in Luca self-soothing as neither of his caregivers responded to his discomfort or distress. In the above examples, neither Mikaela nor Jasmine showed signs of being able to read Luca's affective cues, and respond to them appropriately. Thus, they did not help in his learning of emotion regulation, a key aspect of the developing attachment relationship.

'Misattunement', that is, misinterpreting, missing, or ignoring the child's behavioural cues, was another significant construct that emerged in this video. Several times, it seemed that Jasmine had her own agenda during play interactions with Luca. She appeared too focussed on developing his language skills and prompting and directing him to complete certain tasks. Naturally, Mikaela often followed Jasmine's suggestions. One example showed Jasmine trying to build the cups up, even though Luca was content with stacking the cups inside of each other. She continued to try to engage him in building the cups up by singing, and taking the cups away from him. She also tried to put the cup on top of Luca's head, to which he protested against quite loudly, and shook his head vigorously. Mikaela told Jasmine that Luca wanted to stack the cups, not build them up. Jasmine eventually relented and allowed mother and child to play with the cups on their own. Yet soon after, Jasmine interrupted, even though Mikaela and Luca were interacting well completing circles of communication and in joint attention as they stacked the cups.

Toward the end of the session, Jasmine tried to show Luca how to place the shapes into the correct holes, rather than simply letting him play. She took the shapes from him, to which Luca responded by shouting loudly. Jasmine then asked him "What?" repeatedly, with a slight exasperated tone in her voice. During the 40-minute therapy session, Jasmine changed activities 14 times. This

would serve as an example of her anxiety, namely restlessness. Ironically, at the start of the therapy session, Jasmine explained to Mikaela that she was following Luca's lead, copying whatever game he was playing. She then proceeded for most of the session to do the opposite – not following Luca's interest, and instead challenging him too much, both in his fine motor skills and language development, and moving on to a different activity when she perceived there to be little progress.

The behaviour described above also points to an interesting construct, 'anxiety', in the service provider. Jasmine displayed some anxiety behaviours during the therapy session – restlessness, tense facial expressions, and at times an exasperated tone in her voice, as she tried to balance doing therapy with Luca, and coaching Mikaela. Jasmine's anxiety behaviours were quite evident when she continuously interrupted Mikaela and Luca, interjecting with her own use of acoustic highlighting, or taking over the activity. Jasmine's restlessness was also evident through the number of times she decided to change the play activity. Finally, Jasmine was often not tuned in to Luca's wants, directing him to do tasks he was not interested in. This need for control was another anxiety behaviour that Jasmine displayed. In sum, 'anxiety' emerged as a significant construct, having effects on the quality of Jasmine and Luca's interactions, Mikaela and Luca's interactions, as well as Jasmine and Mikaela's relationship.

With regards to Jasmine's relationship with Mikaela and her coaching, her interactions were mixed. Whenever Mikaela made a comment or shared a story, Jasmine was focussed on Luca, and responded to Mikaela minimally. She did not demonstrate active listening skills, and gave no response when Mikaela made a joke. However, Jasmine did coach and explain therapy techniques to Mikaela, and also praised Mikaela during her interactions with Luca. Jasmine reassured Mikaela whenever Mikaela made self-critical comments. While Jasmine modelled for Mikaela well, she also made a lot of suggestions as to what Mikaela should be saying or doing, during play, perhaps indicating some doubt in Mikaela's abilities.

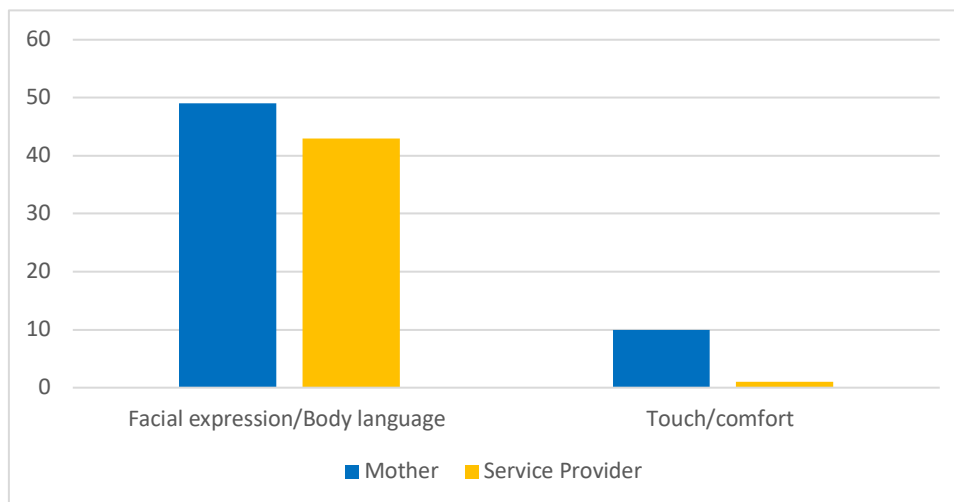
## Video codes

The following graphs display the results of the video analysis for video 2. In sum, the results indicate that the quality of playful interaction between Mikaela and her son Luca had greatly improved. Notably, Jasmine had a greater number of moments of ‘misattunement’, less completed ‘circles of communication’, followed the child’s interest less, and spent less time in ‘joint attention’ with Luca, in comparison to Mikaela.

Figure 5.6 shows the data of Mikaela and Jasmine’s use of ‘Facial expression’, ‘Body language’, and ‘Touch/comfort’. Interestingly, when compared with the results from the previous video (see Appendix R), these results reveal that Mikaela was coded using these behaviours a greater number of times than the service provider.

Figure 5.6

*Case Study 2 Phase 2 Video 2: Facial Expression and Body Language.*

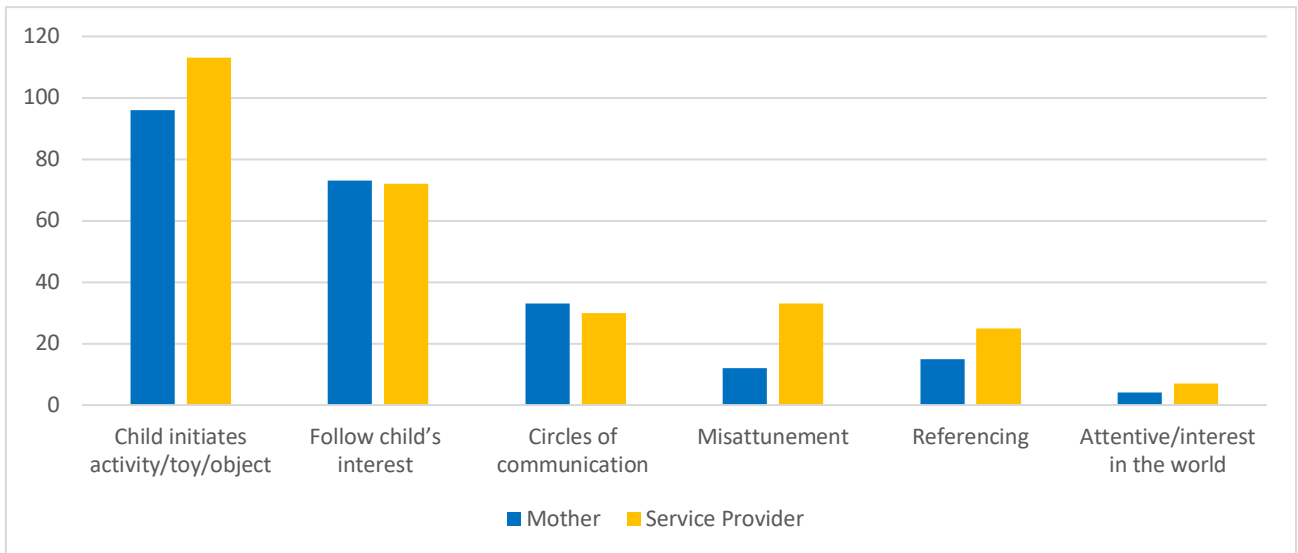


In Figure 5.7, we see that Luca initiated more with Jasmine than with his mother, yet, Mikaela had significantly fewer counts of ‘Misattunement’ in comparison to Jasmine, showing improvement from video 1. It appears that for this therapy session, Mikaela and Luca were more attuned to each

other during their playful interactions, having completed a greater number of circles of communication.

Figure 5.7

*Case Study 2 Phase 2 Video 2: Circles of Communication.*

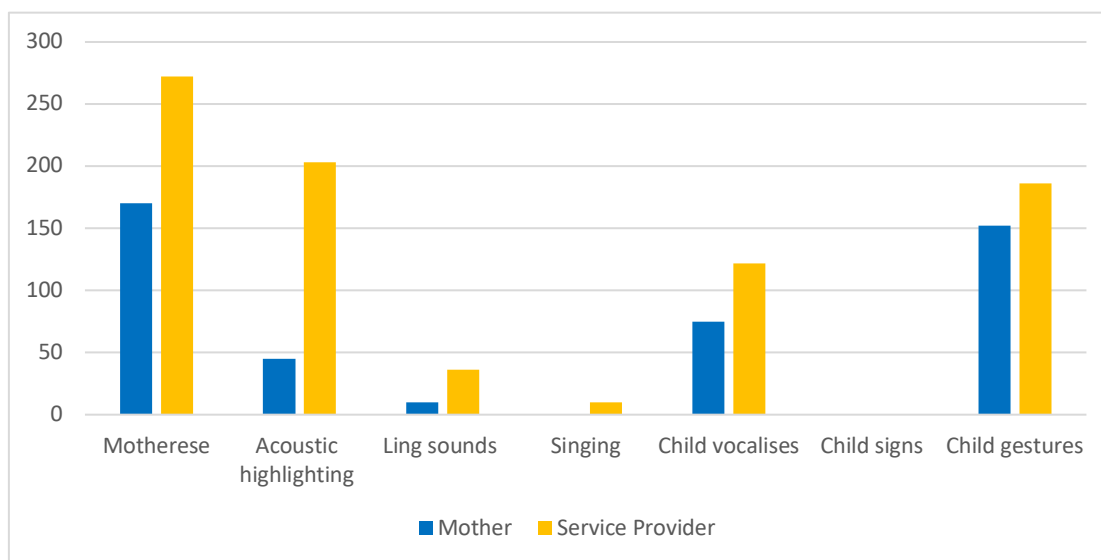


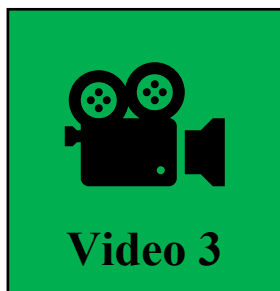


Similar to video 1, Jasmine was shown vocalising more times towards Luca (Figure 5.8). However, the ratio of the amount Luca responded to Jasmine's vocalisations, and the ratio of the amount Luca responded to Mikaela's vocalisations strongly suggests that while Jasmine used her voice more than Mikaela, Luca responded more times to his mother's voice. In summary, video 2 shows improvement in Mikaela's behaviours and interaction with Luca.

Figure 5.8

*Case Study 2 Phase 2 Video 2: Vocal Interaction.*





In video 3, significant constructs that emerged from analysis were: ‘coaching’, ‘modelling’, ‘misattunement’, ‘anxiety’, ‘relationship of mother and service provider, and ‘active listening’.

In this video, Mikaela and Jasmine appeared better at working together, and showed a sense of rapport. One example was when Luca vocalised and gestured for the train, and Mikaela and Jasmine shared a look of joy with each other. Another was when Mikaela jokingly remarked that Jasmine was teaching Luca unfavourable behaviours, after she encouraged Luca to push the tower of blocks down all over the floor. In times that Mikaela appeared uncertain, Jasmine simply said “Do whatever you like”. Jasmine praised Mikaela often and affirmed her with encouraging looks. Several times Mikaela and Jasmine modelled for Luca how to partner play with a toy, for instance, with the toy car, how to ask for it so that the other person would push it towards him. Jasmine also demonstrated active listening, taking the time to listen to Mikaela’s suggestions and observations about Luca, as well as her stories and jokes. Compared to earlier videos, there appeared to have been growth in Jasmine and Mikaela’s relationship, as well development in Jasmine’s modelling and coaching of Mikaela.

Mikaela displayed anxious behaviours, including nervous laughter and self-critical comments. On one occasion, Mikaela was surprised that Luca was able to bang on the toy with the hammer, and remarked “Much better than Mummy!”, laughed nervously, and buried her face in her hands, appearing embarrassed. Another example was when Jasmine said “lights”, while Mikaela said “eyes”, to which she corrected herself “Oh, lights”, her face looking embarrassed. Similar to the previous videos, Jasmine also showed her anxiety. For example, in the 32-minute therapy session, Jasmine changed activities 12 times, indicative of her restlessness and a need for control.

Misattunement was another important construct to emerge from this video. Similar to the previous videos, both Mikaela and Jasmine did not overtly respond to Luca's distressed behaviours. Twice he placed either his thumb or comfort cloth in his mouth, on both occasions, neither Mikaela nor Jasmine comforted Luca, or even showed recognition that he was uncomfortable. Jasmine misread Luca's signals 13 times. For example, when Luca gestured and vocalised for the toy car, Jasmine ignored this and passed the car to his mother. Another time, Luca communicated that he wanted that same car, but Jasmine was ready to move on to a new activity and took the car away. This recurring trend of misattunement may likely impact on Luca's developing attachment relationship with Jasmine, as his cues and signals are not being responded to sensitively. At Jasmine's request, at the end of the therapy session and video recording, the researcher spoke to Mikaela and Jasmine about the results of Case Study 1, and made some suggestions about their behaviours and interactions during therapy sessions, based on these results (see Appendix O for the suggestions sheet).

## Video codes

Results of video 3 data analysis are displayed in Figures 5.9 to 5.14. Overall, the data indicates that Mikaela and Luca appeared better attuned to each other, with less counts of 'Misattunement', and Mikaela more able to follow Luca's lead during play interactions. They also spent more time in joint attention than did Jasmine and Luca. However, Mikaela and Luca completed fewer 'Circles of communication', and Jasmine used her voice more than Mikaela to interact with Luca. Notably, there were no recorded instances of 'Social connection' between either dyad.

In Figure 5.9, we see that Mikaela, showed more counts of appropriate and sensitive facial expression/body language than Jasmine. Likewise, she touched or comforted Luca more than Jasmine.

Figure 5.9

Case Study 2 Phase 2 Video 3: Facial Expression and Body Language.

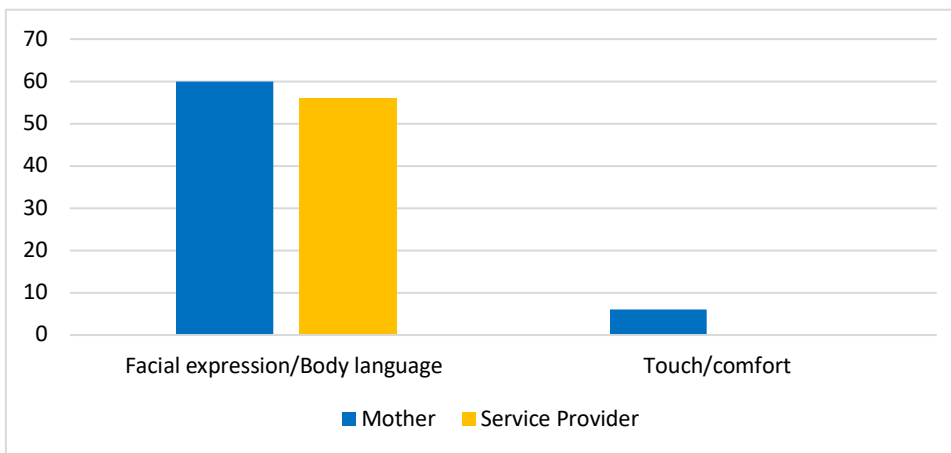
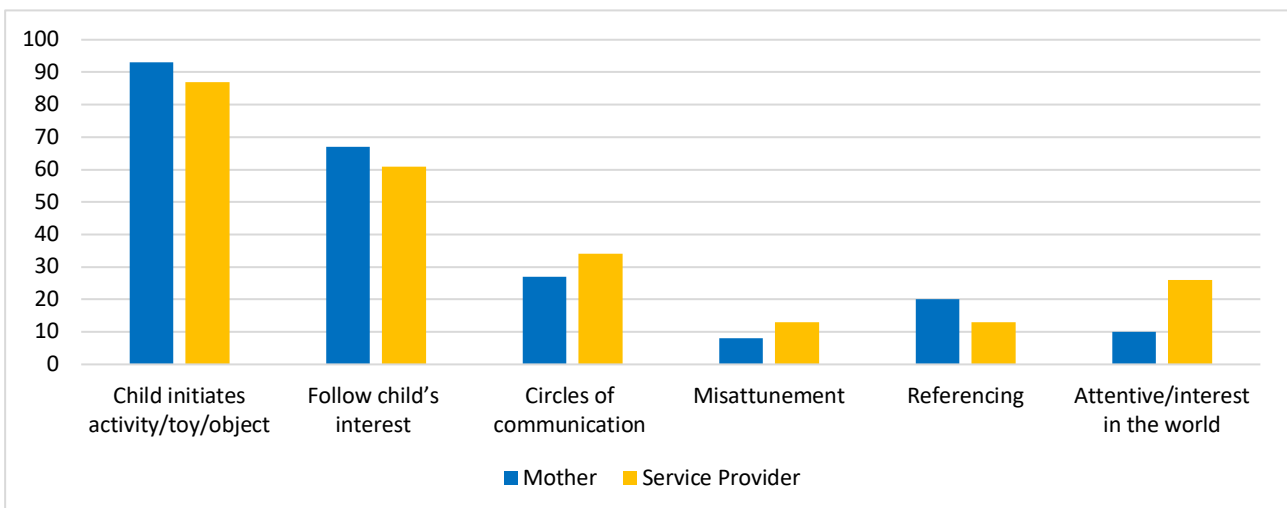


Figure 5.10 shows that Mikaela and Luca were more attuned in their interactions, with the exception of 'circles of communication'. Importantly, these findings continue the trends that emerged in video 2.

Figure 5.10

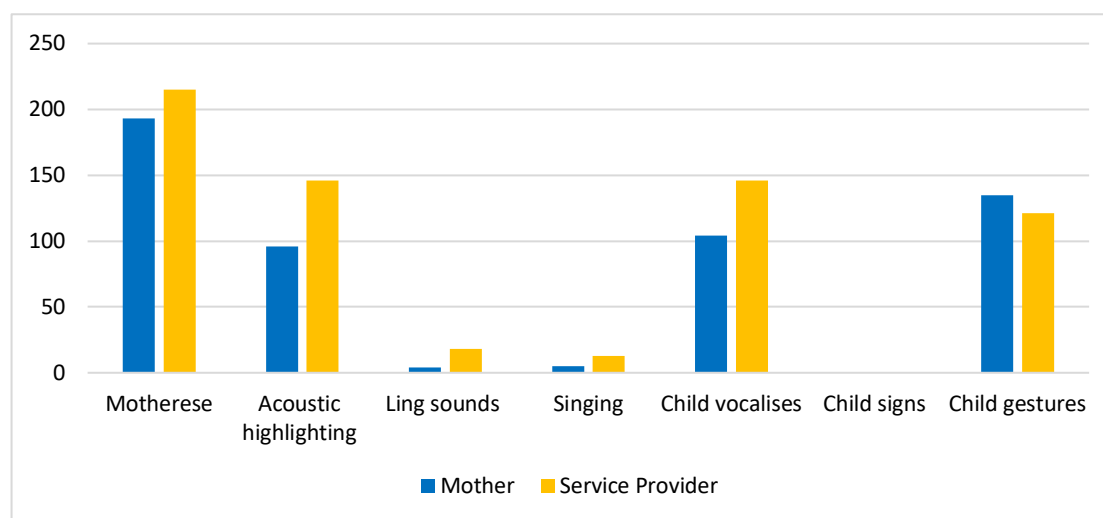
Case Study 2 Phase 2 Video 3: Circles of Communication.



In Figure 5.11, vocal interaction codes are presented. In sum, Jasmine used her voice more times when interacting and responding with Luca. This was the case for all codes, except the child's response. Interestingly, Luca gestured towards his mother a greater number of times than he did to Jasmine.

Figure 5.11

Case Study 2 Phase 2 Video 3: Vocal Interaction.



In video 4, key constructs that emerged through analysis were: ‘relationship of mother and service provider’, ‘coaching’, ‘modelling’, ‘misattunement’, ‘emotion regulation’ and ‘anxiety’.

In this video, Jasmine and Mikaela appeared more at ease with each other – listening to each other’s suggestions and laughing. They worked together during the session, with Jasmine prompting Mikaela to interact with Luca, and Mikaela easily following Jasmine’s prompts. Their interactions showed a greater sense of rapport, with Mikaela teasing and making jokes with Jasmine. An example was when Jasmine brought out the water and tray for the duck; Mikaela disliked mess and getting wet, but humoured Jasmine’s choice in activity, seeing as Luca enjoyed it as well. Mikaela remarked “Oh the dreaded tray comes”, and Jasmine laughed in response. Another example was when Mikaela told Jasmine, “You’re every parent’s worst nightmare”, as she watched

Luca splash about and spread water all over the table and himself. Jasmine simply laughed and handed Mikaela a towel.

Jasmine also valued Mikaela's opinions and ideas more when compared to previous sessions. In one instance, Jasmine asked Luca "Should we say bye bye?", to which Mikaela firmly responded, "No not yet". Jasmine immediately dropped the toy, stepped back, and watched mother and child continue playing together. Jasmine also asked Mikaela if she knew any songs about ducks, rather than singing her own song. Mikaela asked Jasmine more questions and for advice whenever she felt uncertain, for example, "What sound do frogs make?". Jasmine was able to coach and prompt Mikaela more subtly, often simply handing her a toy, and Mikaela would know what to do. Jasmine praised Mikaela often, which seemed to encourage her to keep playing. Mikaela also referenced Jasmine whenever Luca did something well. They often shared moments of joy and smiled and laughed, proud of Luca's achievement.

Regarding 'modelling', one example was when Jasmine showed Mikaela how to open the back door of the bus, while highlighting the word "open" for Luca. She then closed the door once Luca placed the passenger inside the bus, and again highlighted the word "close", elongating the vowel sound. Mikaela observed and followed the example. In summary, in this video, Jasmine played more of a support role, guiding Mikaela and Luca as they played together.

Another construct was 'misattunement'. In this session, Mikaela had the same counts of 'misattunement' as the previous session. Most instances revolved around not comforting Luca when he was upset. One example was when Luca cried out as the tray and water were taken away. Mikaela did not comment or respond to his negative vocalisations, instead continued drying the duck with the towel. In a second example, Luca placed his thumb in his mouth and sucked it; neither Mikaela nor Jasmine responded. Later in the session, Luca again became upset and started crying and kicking his legs under the table. This received no response from his mother. Finally, towards the end of the therapy session, Luca became upset again. Jasmine responded, but Mikaela simply remarked, "What does he want?", with flat affect and a genuine tone of confusion in her voice. She was also quite

concerned with his physical needs, such as adjusting his chair (“Hope he doesn’t fall out”), wiping him dry, and making him drink water (“I want him to drink too, he never does”). Clearly, Mikaela still had some trouble reading Luca’s affective and behavioural cues, choosing instead to focus on physical concerns.

‘Emotion regulation’ was another construct observed in this video. In two examples, Jasmine was seen acknowledging and responding to Luca when he was upset. In the first example, Luca started protesting because they had taken away the tray and water. Jasmine responded to him, remarking, “I know! You wanted to keep playing with the water!” while throwing her hands onto the table – copying Luca and therefore communicating that she knew he was upset. In the second example, Jasmine said “Alright. One more” and brought out one last toy for Luca to play with. In other examples, instead of giving Luca what he wanted, Jasmine challenged him. During one instance, Jasmine took the duck away from Luca, quacking away as she played with it. Luca protested, but Jasmine continued playing to challenge him. Shortly after she returned the duck to him. In another instance, Luca would not let his mum or Jasmine have a turn with the bus, and so Jasmine teasingly tried to take the bus away from him. She tried this a few times with no luck, and so let Luca play with the bus. In both examples, Jasmine only let Luca cry for a while, knowing not to leave him in his distress for long periods of time. Jasmine also expressed empathy, with comments such as “No I want my duck”, and “No give me back my duck!”. In this way she helped him experience negative emotions, rather than always giving in to what he wanted, yet empathised with him by acknowledging he was upset and naming what she believed he was upset about.

Lastly, ‘anxiety’ was another construct that emerged. Mikaela laughed nervously a few times, usually if Luca did not complete a task, or did something she perceived as ‘naughty’ behaviour. Mikaela also made a few self-critical comments: “...but I’m slowly getting there”, commenting on her ability to teach Luca words and meanings; “He’s going to be a perfectionist like Mummy”, the tone in her voice suggesting negative connotations surrounding “perfectionist”, and “bad behavior

because of Mummy”, when Luca did something strange with the toy dog. Yet when compared to previous videos, the number of ‘anxiety behaviours’ Mikaela displayed had reduced.

In summary, major trends in video 4 showed improvements in Jasmine and Mikaela’s relationship, as well as Jasmine’s ability to help Luca regulate his emotions. The following section will provide quantitative data to supplement these qualitative results.

## Video codes

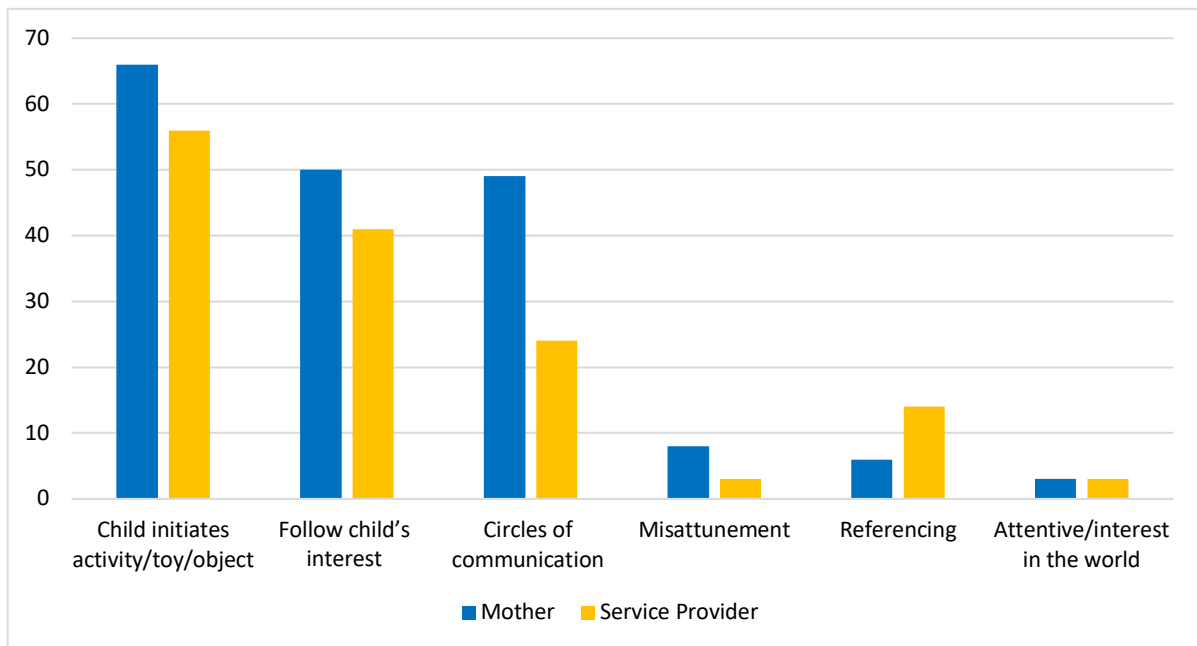
Figures 5.12 to 5.17 present the quantitative video coding results of video 4. Generally, the results indicate that Luca and his mother Mikaela had improved quality in their interactions. This is evidenced by having spent the longest time in ‘Joint attention’ together, and having completed the greater number of ‘Circles of communication’. Moreover, Luca vocalised or gestured towards his mother, in response to her uses of ‘Motherese’, and ‘Acoustic highlighting’ more times than he did toward Jasmine. When compared to the previous three videos, these results show an increase in Mikaela’s engagement with and attunement to Luca.

Figure 5.12 clearly shows a greater amount of completed circles of communication between Mikaela and Luca, when compared to Jasmine and Luca. It also shows how Mikaela followed Luca’s interest more times than Jasmine, specifically when Luca initiated an activity. However, Mikaela misinterpreted or ignored Luca’s affective and behavioural cues more times than Jasmine.



Figure 5.12

*Case Study 2 Phase 2 Video 4: Circles of Communication.*



In terms of the quality of vocal interaction between the dyads, Figure 5.13 shows that Mikaela used her voice more than Jasmine in video 4. These results show a vast improvement from the results of previous videos. The stark difference in these counts could be due to the greater amount of time that Luca and Mikaela spent in joint attention during this session (see Figures 5.14 and 5.15).

Figure 5.13

Case Study 2 Phase 2 Video 4: Vocal Interaction.

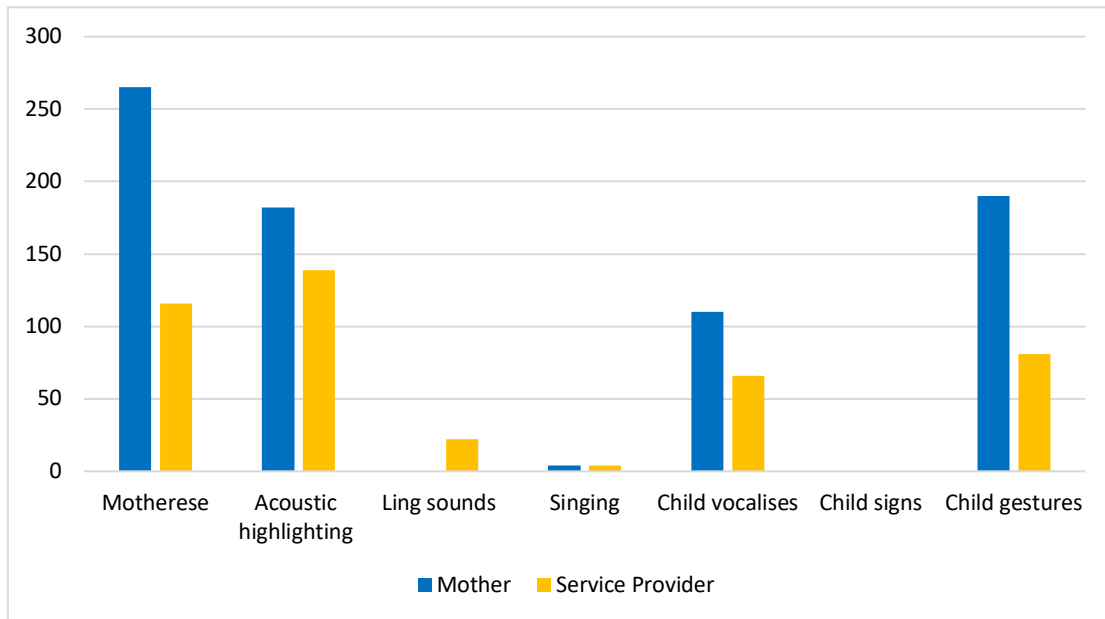


Figure 5.14

Case Study 2 Phase 2 Video 4: Joint Attention between Service Provider and Child.

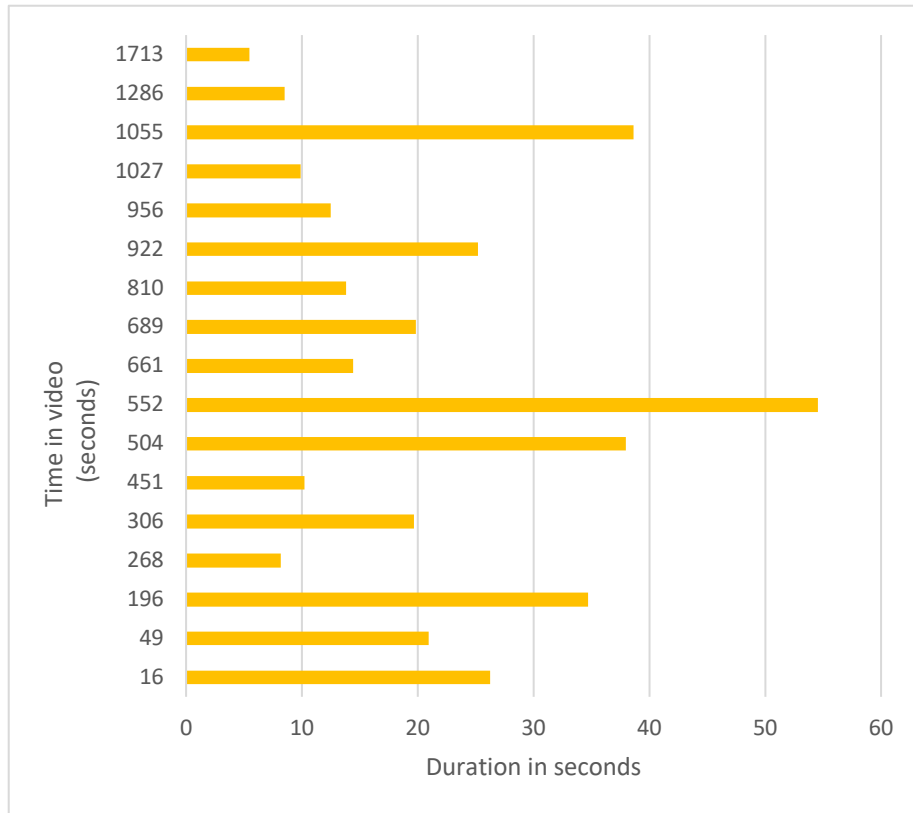
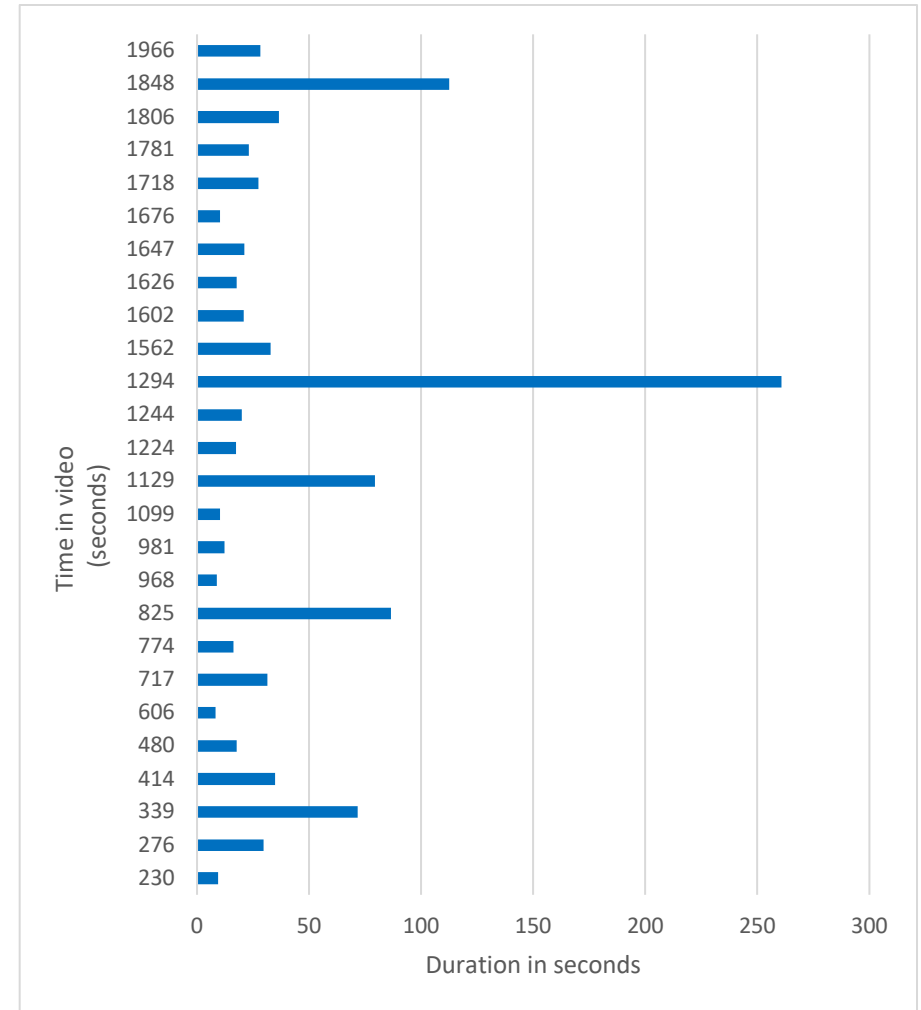


Figure 5.15

Case Study 2 Phase 2 Video 4: Joint Attention between Mother and Child.



Finally, Figures 5.16 and 5.17 show the results of the code 'Social connection'. Mikaela and Luca spent 5.6 seconds in 'Social connection'. In comparison, Jasmine and Luca spent almost 12 seconds in 'Social connection', over two instances. It seemed that Luca and Jasmine enjoyed more moments of shared joy than Luca and his mother.

Figure 5.16

*Case Study 2 Phase 2 Video 4: Social Connection between Mother and Child.*

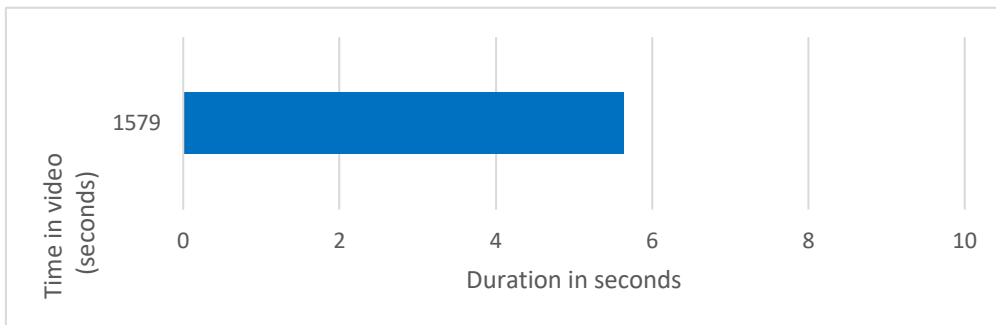
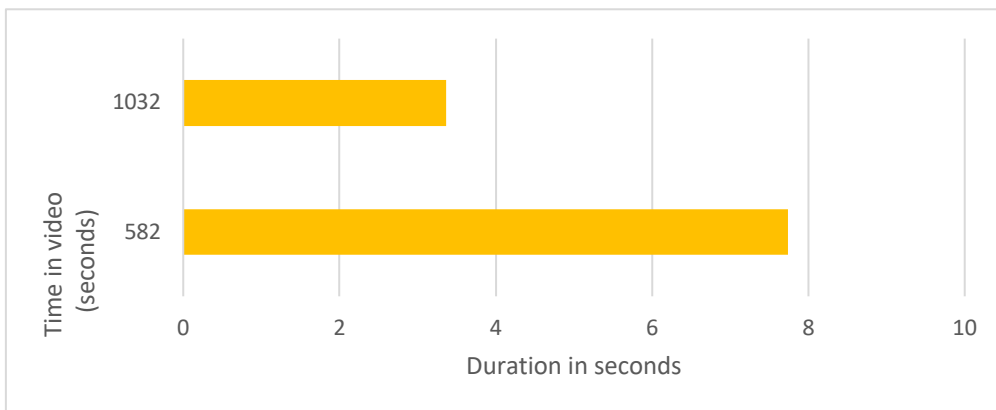


Figure 5.17

*Case Study 2 Phase 2 Video 4: Social Connection between Service Provider and Child.*





The key constructs that emerged from the qualitative analysis of video 5, included: ‘coaching’, ‘modelling’, ‘misattunement’, ‘service provider-led therapy’, ‘relationship of mother and service provider’, and ‘anxiety’. In terms of ‘coaching’ and ‘modelling’, the service provider, Jasmine, coached Mikaela throughout the therapy session, and often modelled play interactions for her. For example, during play with the toy train, Jasmine told Mikaela: “What I want you to do is hold on to these [train] tracks and don’t give them to him until he [Luca] asks for it”. In another similar example, Jasmine told Mikaela to hold back the bee toy until Luca called out for the bee. Interestingly, in both cases, Luca became upset as neither Jasmine nor Mikaela would give him the toy, even though he had asked for it. However, he had not asked for it using the words specified by Jasmine, “more track” or “bee”, therefore he was not given the toys. Indeed, in the first interaction with the toy train, Jasmine would not comfort Luca, though he became increasingly upset. Both instances were thus coded as moments of ‘misattunement’ as both mother and service provider appeared more concerned with Luca’s language than his emotional needs.

Another instance of ‘misattunement’ occurred when Luca had vocalised and gestured for a toy from the toy box, however Jasmine would not let him have the toy he was interested in. Instead Jasmine insisted they continue with the train activity. Luca tried to communicate his want four more times through vocalising and gesturing for the toy, each time becoming more upset, yet Jasmine firmly refused each time. From this occurrence emerged the construct ‘service provider-led therapy’, wherein instead of following the child’s lead, the service provider maintained their own agenda for the therapy session. In another example, Jasmine brought out toys to test Luca’s hearing using the Ling sounds. Immediately, Luca’s eye caught the toy train and he asked for

it using the Czech word for train. Jasmine told him to wait and refused to give him the train. Luca eventually became quite upset and Jasmine allowed him to hold the train, though continued to test his hearing despite Luca's disinterest. Again, the service provider's focus on improving Lucas's language ability, seemed to be at the cost of Luca's emotional needs and perhaps, by extension, their developing attachment relationship. Since caregiver sensitivity is crucial to attachment security, repeated instances of this kind may indeed lead towards problems in the attachment relationship between Jasmine and Luca.

Jasmine also displayed a sense of misattunement to Mikaela and Luca's relationship and play interactions. In one instance, she interrupted and stopped their play with the duck, though they were interacting well and completing circles of communication. Jasmine stopped Mikaela from pouring the water for Luca – after he had asked for “more” water in Czech – and prompted her to ask Luca to “pour” the water instead. Shortly after, Jasmine broke the flow of Mikaela and Luca's play interaction again, by prompting Mikaela to tell Luca that the toy duck was wet. Jasmine did this though Luca and Mikaela were contently playing with the mother duck and baby duck in the water.

Regarding the construct ‘relationship of service provider and mother’, interactions between Jasmine and Mikaela appeared quite smooth. Mikaela was familiar with Jasmine's coaching style, and anticipated when Jasmine would instruct her to on how to use a toy when playing with Luca. However, most activities were led by Jasmine and few, if any, of Mikaela or Luca's play initiatives were followed.

Finally, ‘anxiety’ was observed, similar to that shown in previous videos. Mikaela would laugh or giggle nervously if she felt that she had not said the ‘correct’ word or phrases when playing with Luca, or when Luca did not follow an instruction from herself or Jasmine. Mikaela would also ask Jasmine if she was saying or doing the ‘right’ things as she played with Luca. Jasmine also displayed some anxiety, in that she seemed to want to rush play activities when she perceived that they were

not successful. In one example, Jasmine moved on to a new activity quite quickly because Luca was not able to successfully push, pull or pop the toys, nor say the words.

The following section details the quantitative video data that supplements these qualitative findings.

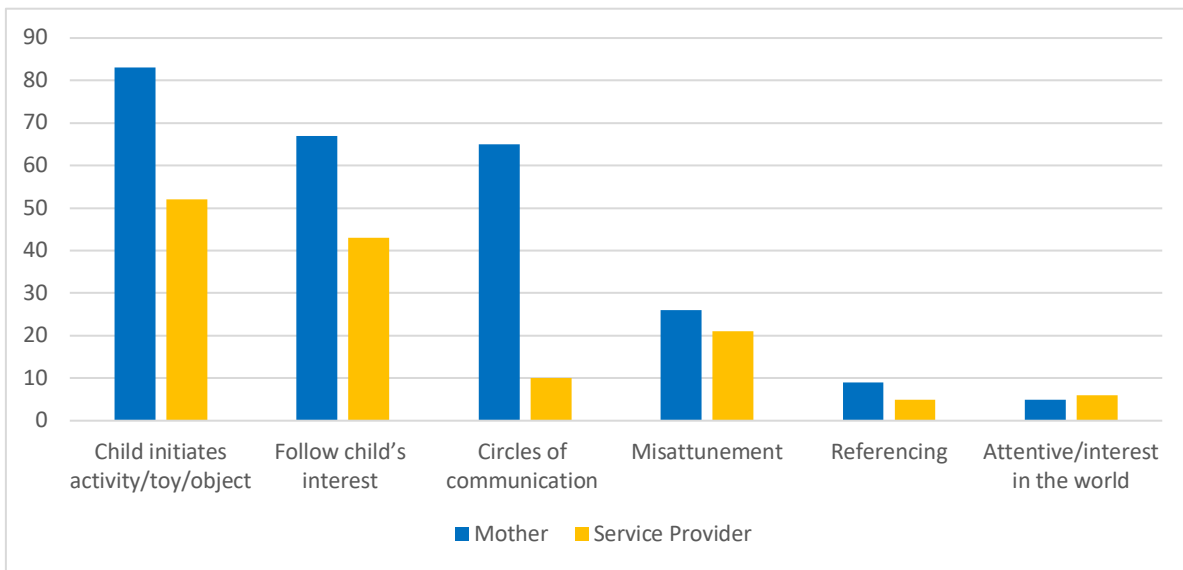
## Video codes

Figures 5.18 to 5.21 display the results of the video coding analysis of video 5. Key findings include Mikaela coded as having a greater amount of ‘Facial expression and body language’ and ‘Circles of communication’ than Jasmine. Mikaela also showed more counts of following Luca’s interest than Jasmine. Further, Mikaela shared more time in ‘Joint attention’ and ‘Social connection’ with her son, in comparison to Jasmine. Thus, the data appear to suggest that Mikaela was more attuned to Luca in this therapy session when compared to Jasmine.

Figure 5.18 below shows that Luca initiated an activity, toy or object with his mother more than he did with Jasmine. Regarding the code ‘Circles of communication’, a key finding was that Mikaela and Luca completed 65 circles, whereas Jasmine and Luca only completed 10 circles of communication. This result maintains the trend from the previous video that Mikaela and Luca completed more circles of communication than Jasmine and Luca. Both Mikaela and Jasmine showed about the same amount of misattunement to Luca’s needs or wants.

Figure 5.18

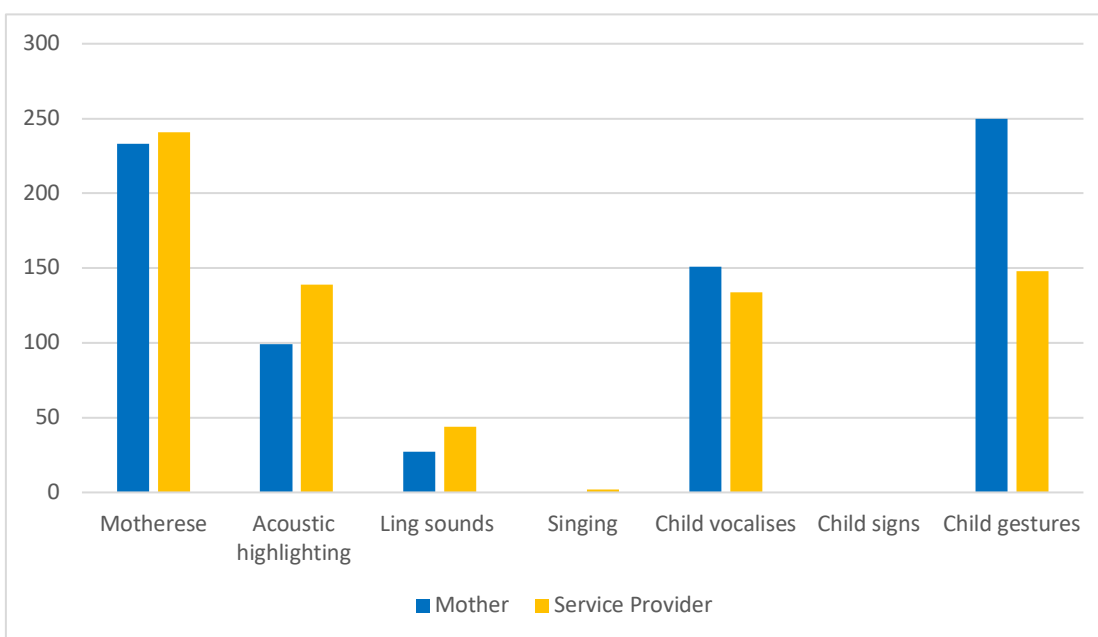
Case Study 2 Phase 2 Video 5: Circles of Communication.



Jasmine is shown vocalising a greater number of times than Mikaela (see Figure 5.19 below). However, it appears that Luca responded more to his mother than Jasmine. Similarly, Luca gestured 250 times towards his mother, though only 148 times towards Jasmine.

Figure 5.19

Case Study 2 Phase 2 Video 5: Vocal Interaction.





The code 'Joint attention' is displayed in Figures 5.20 and 5.21 below. In sum, the data shows that Luca and Mikaela spent more time together with their attention on a shared activity or toy than Luca and Jasmine, in fact, double the amount of time spent by the latter.

Figure 5.20

Case Study 2 Phase 2 Video 5: Joint Attention between Mother and Child.

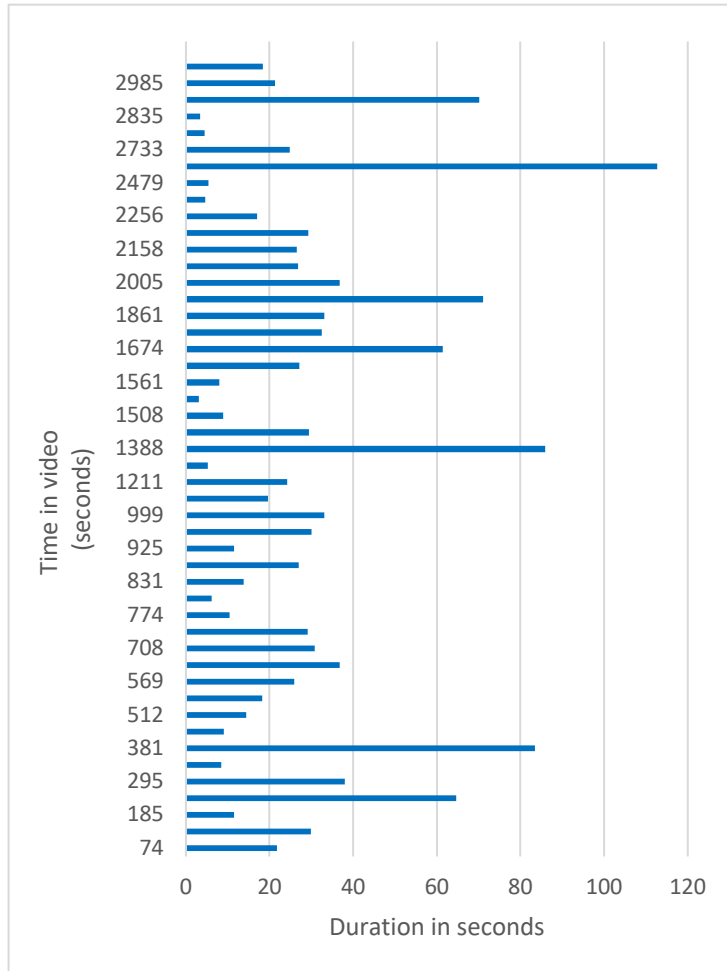
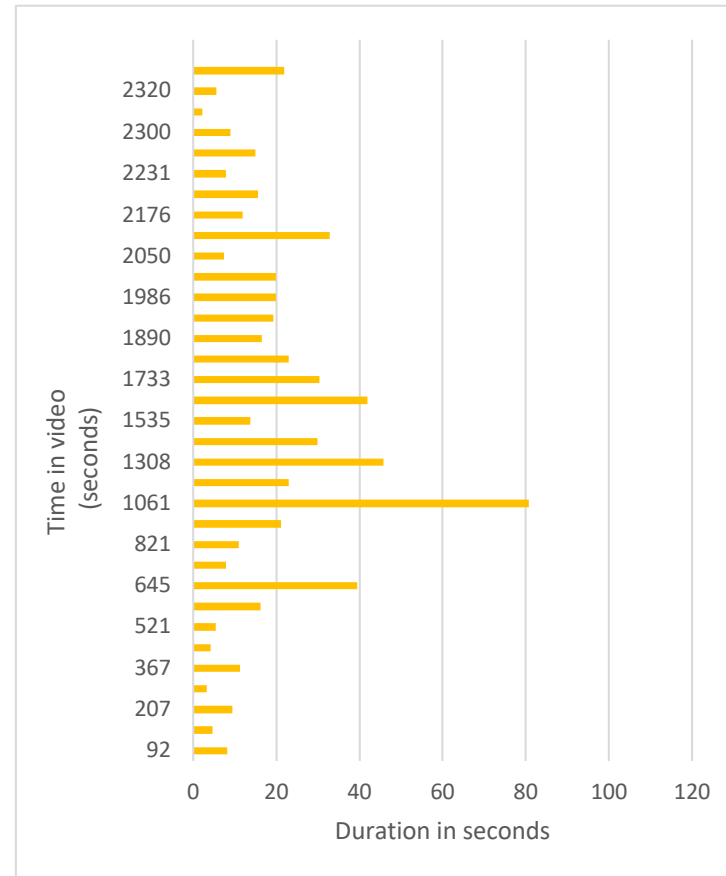


Figure 5.21

Case Study 2 Phase 2 Video 5: Joint Attention between Service Provider and Child.





In video 6, key constructs that emerged were: ‘relationship of mother and service provider’, ‘coaching’, ‘modelling’, ‘misattunement’, ‘emotion regulation’, ‘service provider-led therapy’, and ‘anxiety’.

In the beginning of the video, Jasmine followed Luca’s interest and began to sing ‘The Wheels on the Bus’, as he was playing with a toy bus. Mikaela joined in the singing and they took turns singing parts of the song, showing good partnership during the therapy. In another instance, Mikaela and Jasmine were seen playing and working together as they played with the toy kitchen. They took turns pretending to drink from the toy cup. Here they were also modelling play for Luca.

There were several examples of Jasmine coaching Mikaela or modelling how to play with Luca. For example, while playing with puzzles, Jasmine would slide the next puzzle piece in front of Mikaela, cueing her in on what to do next with Luca. During the activity with the toy kitchen, Jasmine told Mikaela to hold out two types of fruit and ask Luca to make a choice between the two. Jasmine also modelled for Luca how to play with the toy kitchen. She showed Luca a toy oven and asked him if he wanted to cook the fruit. Luca became frustrated as he could not open the oven door. Jasmine demonstrated what to do, and in doing so was able to de-escalate his frustration, therefore helping him to regulate his emotions. Jasmine said to Mikaela

So you can see I’m not just doing it for him. I show him, and then he does it. ... whether it’s taking it out, or closing the door. Because sometimes he just seems to get frustrated and he doesn’t think he can do it, and he can.

However, there were some instances during the therapy session where Jasmine did not appear to help Luca regulate his emotions as she pushed Luca past his comfort zone, resulting in him whining, throwing tantrums or refusing to cooperate. In one example, Jasmine asked Luca three times if she or his mother could have a turn playing with the toy train. Each time Luca protested, began to cry and physically turned away from Jasmine. Neither Jasmine nor Mikaela attempted to comfort Luca in his distress. In another example, Jasmine transitioned to the next activity too quickly for Luca. Jasmine asked Luca if he would like to do a puzzle. Luca replied with yes, and so Jasmine took the bus away. However, Luca became upset after the bus was taken away. Jasmine responded flippantly with “Yeah, yeah it’s alright” then tried to distract Luca with the puzzle, however he continued to cry and gestured for the bus. Luca put his face down on the table and had a tantrum, to which Jasmine responded “You want the bus”. Luca continued to cry and Jasmine comforted him by patting his arm and saying “That’s okay. You ask Jasmine, bus please?”, yet Luca continued crying. In this instance, Luca was unable to do as Jasmine requested because his emotions were too heightened. Jasmine chose not to give Luca the bus and continued with the puzzle activity. She showed misattunement to both Luca’s emotional needs and his interest in the bus. Eventually Mikaela wiped Luca’s tears with a tissue and tried to soothe him by talking to him in Czech. Luca began to calm down yet was still upset, and Jasmine moved on with the new activity.

Another example of misattunement was during the book and boat activity, where Luca wanted to play in one way and Jasmine another way. Luca took the lion out of the boat. Jasmine asked Luca, pretending to be the lion “Excuse me boy, can I go in?” she did not wait for a reply and put the lion in the boat – “in!”. Immediately Luca took the lion out, to which Jasmine responded “Out! I want to go in!”. Luca then pushed the boat towards the lion, hoping to crash into it, but Jasmine took the lion and asked again “Can I go in?”, disrupting Luca’s play. Luca proceeded to grab the lion out of his service provider’s hand and protested by crying out for the lion. However, Jasmine took the lion out of the boat’s path a second time, though it was clear what Luca intended to do. Jasmine put the lion back in the boat again, and Luca took the lion out again. Jasmine then took the lion straight out of

Luca's hands, and Luca tried to take it back but Jasmine roared, pretending to be the lion. She put the lion back in the boat, and Luca took the lion out again. In this instance, Jasmine used obstructive play, and intentionally ignored Luca's cues and interests to try and push him out of his comfort zone and extend his play. Yet it did not seem to be effective as Luca continued to insist on how he liked to play, and indeed was more adamant the more Jasmine obstructed his play.

As in previous videos, the previous example shows Jasmine doing service provider-led therapy as opposed to following the child's lead. Similarly, there were times during the session where Jasmine failed to follow Mikaela's lead – her own suggestions on how to play with Luca, or interrupted interactions between Mikaela and Luca. In one example, Mikaela took the initiative to play with Luca, and pretended her hand was a buzzing bee. Rather than allow Mikaela to continue exploring this play interaction with Luca, Jasmine introduced a toy bee and disrupted Mikaela's attempt. Another example of the construct service provider-led therapy showed Jasmine being too hasty, and gave Mikaela mixed messages. Mikaela commented that Luca was not interested in the animals and simply wanted to play with the boat. Jasmine responded with "That's fine" and told Mikaela to play with him and the boat. However, just 14 seconds later, Jasmine took the boat from Mikaela and started playing with Luca. Jasmine's hastiness revealed anxious behaviours, where perhaps she could not see Mikaela 'doing enough' with Luca and therefore took control of the play interaction. Indeed, throughout the therapy session, Jasmine tended to be more focussed on getting Luca to do things, as opposed to facilitating interactions between Mikaela and her son. This is problematic in light of what the ECIC proposed it did, that is, facilitate the attachment relationships between caregiver and child, to ensure that the child's socioemotional development becomes the foundation to further growth and development, listening and communication.

The section that follows will present the supplementary quantitative data from the same therapy session, to provide a more comprehensive picture of the sixth video.

## Video codes

The following figures (Figures 5.22 to 5.27) show the quantitative results of the sixth video recorded therapy session, the final early childhood intervention therapy session recorded in case study 2. In summation, the data revealed that Jasmine and Mikaela spent an equal amount of time in joint attention with Luca. During these times, the data show that Mikaela and Luca were able to complete more 'Circles of communication', in comparison to Jasmine and Luca. Mikaela was also shown as being able to follow Luca's lead more than Jasmine. Furthermore, Jasmine was coded with more counts of 'Misattunement' than Mikaela. In light of the qualitative analysis, this could have been due to Jasmine using obstructive play with Luca. These findings are similar to those of the previous two videos.

The code category of Circles of communication is displayed in Figure 5.22. Luca initiated an interaction with Mikaela and Jasmine about the same amount of times, 59 and 56 times, respectively. In response to this initiating, Mikaela appeared to have followed Luca's lead more times than Jasmine. Luca and Mikaela completed slightly more 'Circles of communication' than Luca and Jasmine. Moreover, Jasmine was coded as having misinterpreted Luca 29 times, while Mikaela did so fewer times at 19.

Figure 5.22

Case Study 2 Phase 2 Video 6: *Circles of Communication.*

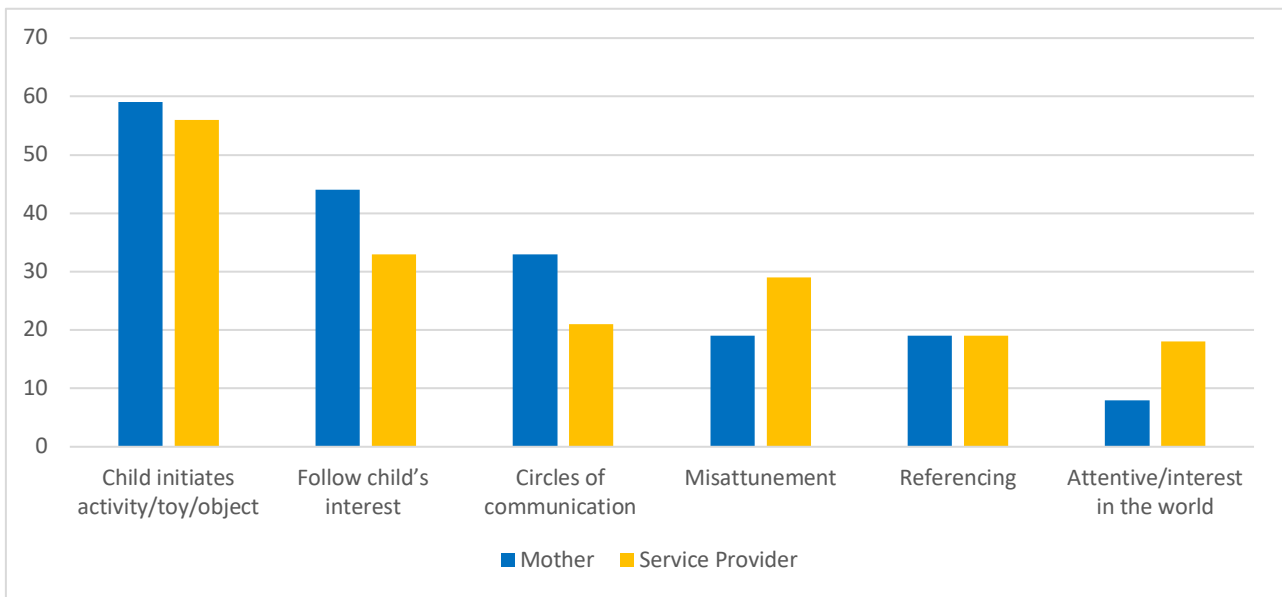
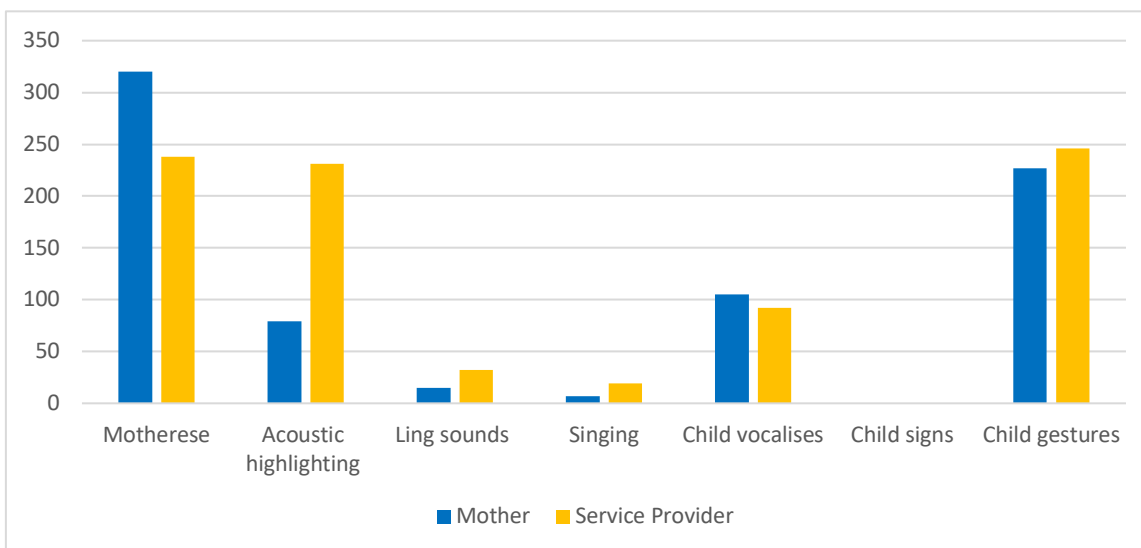


Figure 5.23 reveals that although Jasmine vocalised towards Luca more than Mikaela, Luca vocalised towards his Mother more than he did to Jasmine, with 105 counts and 92 counts respectively. However, Luca gestured towards Jasmine more – 246 times, and gestured towards his Mother 227 times

Figure 5.23

Case Study 2 Phase 2 Video 6: *Vocal interaction.*



Figures 5.24 and 5.25 present the results of the video data for the category ‘Social connection’.

These are moments of shared joy between child and caregiver. Luca and Jasmine shared more of these moments together, though were quite brief in duration.

Figure 5.24

*Case Study 2 Phase 2 Video 6: Social Connection between Mother and Child.*

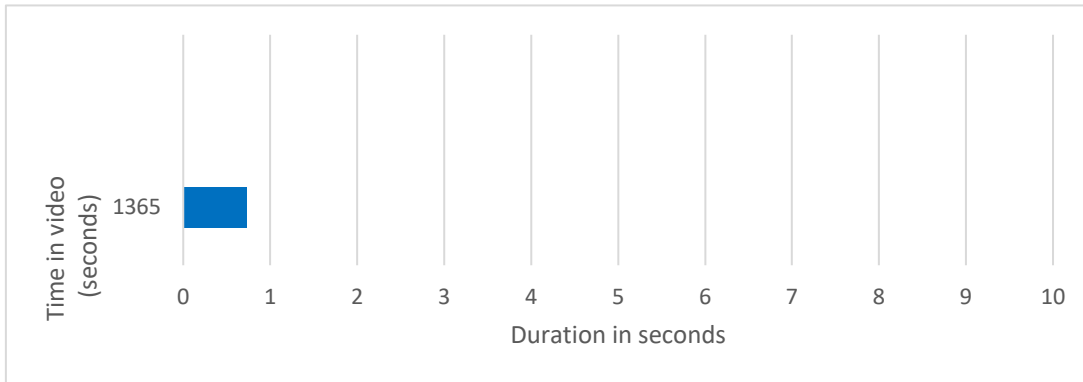
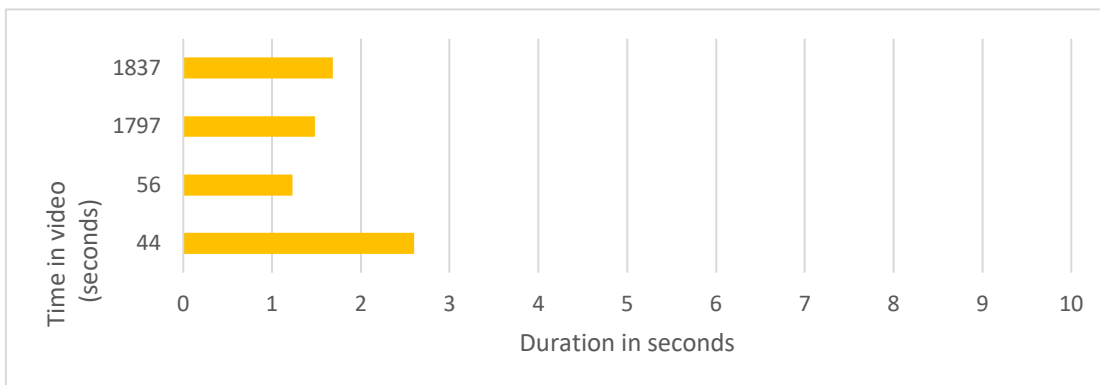


Figure 5.25

*Case Study 2 Phase 2 Video 6: Social Connection between Service Provider and Child.*



Finally, Figures 5.26 and 5.27 present the video data results of the category ‘pausing and waiting’. Mikaela paused and waited for her son on three separate occasions, the longest duration almost 8 seconds long. Jasmine waited for Luca four times, though the longest duration was shy of 3 seconds. This may suggest impatience on Jasmine’s part for Luca to respond to her, and more timely responses from Mikaela.



Figure 5.26

*Case Study 2 Phase 2 Video 6: Pausing and Waiting of Mother.*

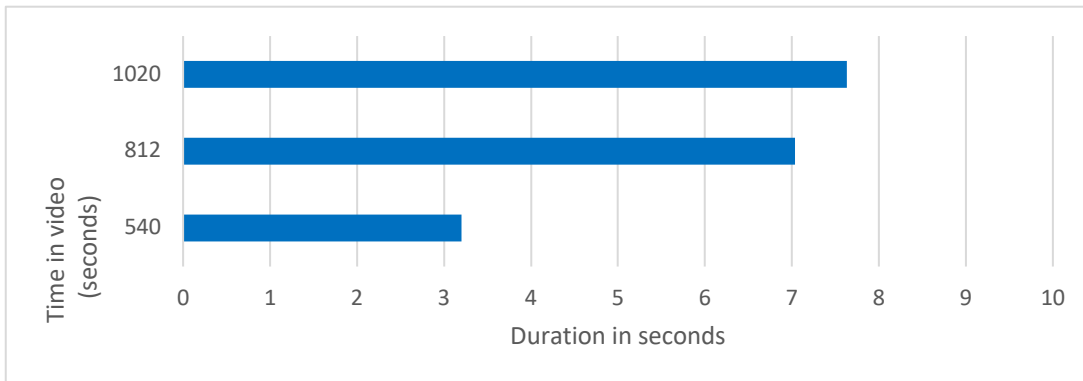
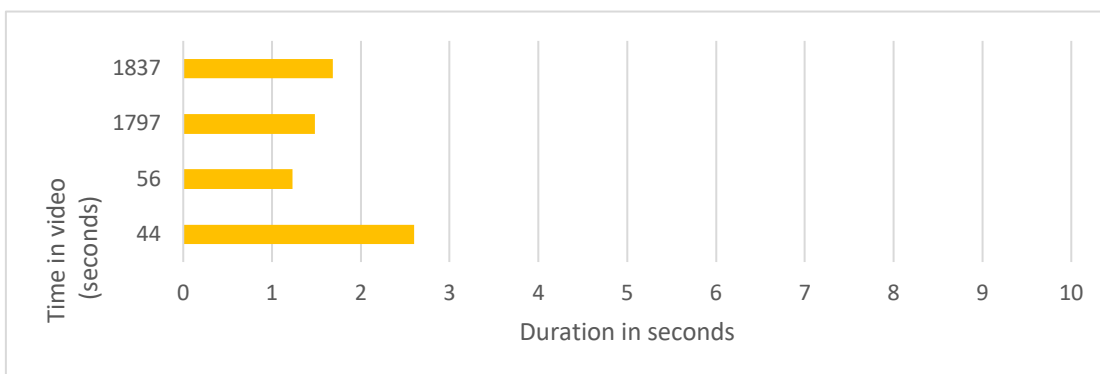
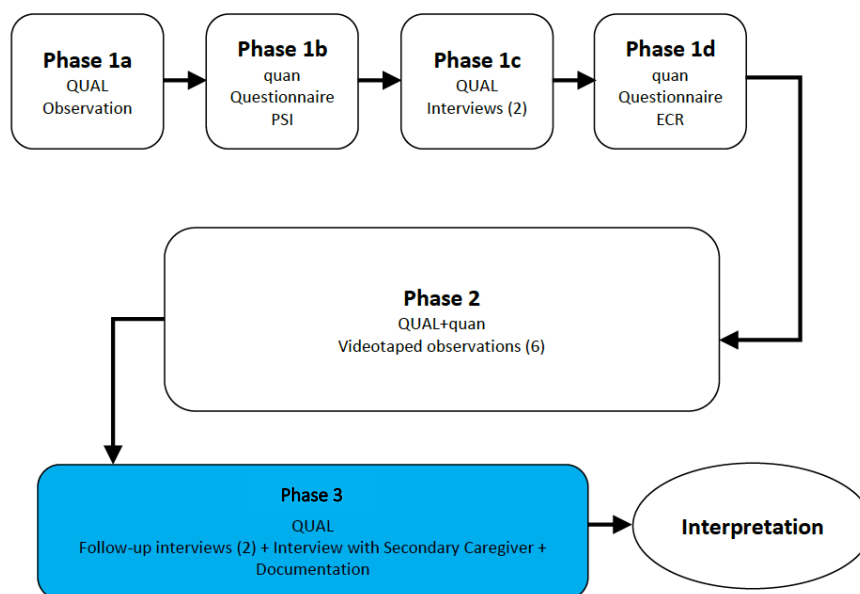


Figure 5.27

*Case Study 2 Phase 2 Video 6: Pausing and Waiting of Service Provider.*



### Phase 3



#### Follow-up Interviews.

Nvivo analysis of the follow-up interviews with Jasmine and Mikaela, will be discussed under the following topics: *Attachment relationships; Understanding attachment; Child's growth and development; Attachment in early intervention; Social support; and, Feedback regarding the research study.*

**Attachment relationships.** When asked if she felt that at present, her relationship with her son had become closer, Mikaela replied: "I think we were closer in the time after we got home from hospital." She went on to describe what happened one time when Luca was sick: "Actually coincidentally he was sick one day, which never happens, and he was throwing up all day. And that was the only time when he was hanging onto me like a koala otherwise, he is daddy's boy". These responses suggest that Mikaela felt some distance between her and Luca, and was reminiscent of the past when Luca would seek proximity and physical comfort from her. It may also suggest that Mikaela believed that Luca has a closer relationship with his father.

When asked about Mikaela and Luca's attachment relationship, Jasmine replied:

... from what I see, unfortunately, there are still issues for Mikaela. ... I think she still had the fear, of him, of losing him, a little while ago when they found another um, lesion on the back of his throat. They had that surgery, which was a few months ago. Um, and I think she will have to see him doing well to allow herself, that ability to sort of. Not have that fear and engage with him and connect with him at that level. That's my gut feeling.

Jasmine implied that this fear of losing Luca prevented Mikaela from tuning into Luca's socioemotional needs, which was delaying them from having a back-and-forth, playful relationship, necessary for speech and language development, indeed for overall growth and development.

***Understanding attachment.*** Mikaela was not asked about her understanding of attachment, though her overall responses such as the one below, appeared to suggest that she held the view that attachment did not involve her son but rather was about herself:

Parents are the ones who probably need support and would maybe feel rather criticised by being given more feedback. ... being told what else they can do better or more or what they are doing wrong. So, it's kind of sensitive, I guess it's even difficult maybe for the therapist to you know address this part, how to do it. And I'm sure they are trying to support you as much as the child.

Regarding understanding what attachment is, Jasmine was knowledgeable of what both the parent and child needed to do to develop their attachment relationship. She commented on the importance of a back-and-forth relationship, of the need for the child to reference his caregivers when playing, and of the role of memories and fun, silly experiences. When asked if she had learnt more about attachment from the research study, Jasmine replied: "I have learnt, I have learnt. I always knew that attachment was important. I think working with Mikaela and Luca highlighted how

important it really is, and what happens when you don't have that unfortunately." Jasmine noted how Mikaela probably did not learn much from the study, and likely saw the study as another burden, however she did comment: "But in the same vein I think it helped her because it made me more aware. And in that way hopefully even once the study is over, I can guide her more."

***Child's growth and development.*** Interestingly, Mikaela seemed to think that it was Jasmine's responsibility to keep Luca's speech and language development on track, as the following exchange demonstrates:

You would still feel like oh that's so hard I'm just not going to do this, forget it it's too hard.

But um, I guess everyone will feel often, like, I don't want to do anymore, I've had enough now I need a break

Researcher: yeah yeah

Mikaela: but that's, I don't know maybe other people don't see it like that, maybe it's just me being resistant to doing more. M-mm

Researcher: As long as you've got Jasmine, he'll do well won't he?

Mikaela: Yeah. That's actually kind of good because she manages this part. And I kind of leave it up to her you know?

This is in stark contrast to how Jasmine viewed the situation. Jasmine also noted that Luca not using words to ask for what he wants was also leading to some behavioural issues that was making life harder for himself and his parents, such as his frequent tantrums. Indeed, Mikaela spoke about occupational therapy and her hope that starting this soon would help improve things with Luca, and make his tantrums more manageable.

Jasmine noted that Luca's development in terms of his fine and gross motor skills was age-appropriate. However, Jasmine emphasised that Luca was behind in his speech and language development, most likely due to the emotional connection and attunement that is missing:

I think she [Mikaela] thinks that he'll just get it and he'll be okay. As long as he's healthy and doesn't have this tumour coming back and... She said to me a few months ago oh it's because he's learning two languages and because he had such a rough start to life that he's so far behind. Because he is so far behind. He's definitely nowhere near age level. But I also think that she doesn't realise that she could make such a huge difference. And because of that she isn't doing it. I think if she realised she could, maybe she'd try. Or maybe she just can't, maybe she's just not capable of doing that now.

Here Jasmine alludes to that fear and worry that she believed prevented Mikaela from truly connecting with Luca and being more attuned with his needs.

*Attachment in early intervention.* Jasmine spoke about how Mikaela was ignorant of her importance and role as Luca's primary caregiver, at least on the social and emotional side:

I think also that if she could enjoy him more, she would get so much from that, and then it would be easier and it would build their relationship so that when she did say no or made him wait a moment, he would realise that she'll still give it to him, but that he can just say the word. But because they don't have that back-and-forth relationship. Even yesterday when I was playing with him on the floor in the room, and she wasn't there. We were just being silly, and then he was putting the coins in the piggy...like a piggy bank. And before we had turns with the ball but he wanted all the coins. So, I did obstructive play and I put my hand over the top and I said "One for me, ta!" and then he went "Uh-hh!" and he grabbed them all, and then

I said “One for me pleaaaase! Please can I have one?” and then he gave me one. So, he will and he’s very sweet, but he has to have that back-and-forth and feel secure to do that

In contrast, Jasmine described how Mikaela interacted with Luca: “I think it’s been so much about don’t do this and don’t do that, and cleaning him and just making sure he’s okay. As opposed to- there definitely hasn’t been any silliness or fun.” She described how Mikaela did not let Luca cry or become upset, and gave into what he wanted immediately because it was easier in the short term, and because she was so energy depleted. Jasmine’s use of obstructive play and silliness with Luca, showed that Jasmine was aware of the need to encourage self-regulation in Luca, allowing him to experience discomfort and to learn how to tolerate it, as well as the importance of the caregiver in co-regulating the child’s emotions.

In the same vein, Mikaela was unable to interact and play with Luca in that same way, as her fear and anxiety about his health and physical needs, as well as her lack of energy, made it difficult for her to be more in tune with Luca. In fact, Mikaela admitted herself how much Luca’s birth and complications had affected her, and how long it had taken her to move on: “Um only this year, in the first half of this year I was dealing with it. Literally only then. Um, which is like almost 2 years after it happened or 18 months. Two years after it happened. Now that’s a bit more behind me, I guess”. This excerpt shows how difficult it had been for Mikaela to cope with the birth trauma she experienced with Luca, and that it is therefore understandable that she had not been able to completely open up and let herself bond with Luca for fear of losing him.

***Social support.*** Mikaela spoke at length about how she thought parents like herself needed to be better supported. She emphasised the importance of self-care and the fact that she hardly ever had the time to take care of her needs: “I think parents need support as much as children, often...Because they are the ones who actually need to support children, but no one supports them” When asked what other support she thinks parents need, Mikaela responded with:

help like almost regular time that you could drop your child off somewhere in business hours and actually go to the dentist, you know. Or do things. Even if it was say, 3-4 hours every fortnight. And it would be in a safe place, almost like a childcare or whatever. Or extra day you could get in your own childcare if that's what you choose, every month. And then you would book everything on the day that you could possibly fit in, I would do my chiro, I would do dentist, and I would do um, I don't know, I could even have a haircut maybe one day. Um, just so you would not feel like you can't do it. Because I can't do it.

It appears that Mikaela felt overwhelmed by all the responsibilities and tasks that were part of her day-to-day life, and would have benefitted from some extra support and help.

**Feedback.** As stated, Jasmine felt that Mikaela did not gain much from the study: "I think for her she was too overwhelmed... it was just another burden to be honest." She continued to describe how being made aware of Mikaela and Luca's lack of a connection, helped her learn more about the process of attachment:

So from that point of view, I really did learn. But, \*sighs\* I hope then also when she's in a better place, that she may be more open to what we did originally, which is sit down and discuss with her what she could do. Which she was open to but she couldn't take it in. So, that's what I'm saying, maybe, in a little bit of time when other things settle down medically. Maybe she'll be able to try and take it in again. Because she certainly wants the best for him.

Here we see Jasmine referencing a feedback sheet (based from the initial results of the pilot case study) that she and the researcher presented to Mikaela, with the hope that it would help with their attachment relationship.

Yet at the time, Mikaela was not able to process the information, as described in the excerpt below:

Researcher: Um, do you think it's helped in some way?

Mikaela: If it helped to me? Luca has nothing to do with it I think so \*both laugh \*No. I would say Luca doesn't care \*both laugh \* Or his outcome is not going to change. Um, if anything I did read those points from the first stage you gave us, you know. From the first family or whatever. And it kind of makes sense and yes, I understand it. But on the other hand, it makes you feel like oh god another thing which parent has to do, better or more or doesn't do good enough. So, you kind of feel um, and I'm working very hard on not feel like I have to do what other mothers do. I definitely don't want to compare myself to anyone. ... I guess if it was just research you couldn't then justify it because you couldn't say that there is going to be some outcome even for those parents involved. On the other hand, when you do give them some feedback, they might feel oh for god's sake I have to do more and I'm hardly coping now \*both laugh \* So that's why I look at it. I am very brutal now I'm sorry.

It seems clear from this response that Mikaela – already overwhelmed with daily life – felt at the time of the interview that the research study gave no benefit to herself or to her son. Indeed, Jasmine acknowledged that the study with its video recording may have placed added pressure on Mikaela: “I also hope that for her, and I don't know, but maybe without the camera and without the pressure that it may make a difference for her, I don't know. But we'll see. Hopefully.” Jasmine also gave some insight on other factors that affect how the caregiver interacts with their child: “But I also think that it's not- it's also where the parent's at. It is the personality of the parent, how they were possibly raised, all of those things.” This comment showed Jasmine's understanding of the intergenerational transmission of attachment, and the different aspects surrounding developing



attachment relationships. As discussed in the Literature Review, the intergenerational transmission of attachment proposes that the psychological and environmental factors surrounding a person's attachment experiences throughout their life, influence the subsequent development of their attachment relationships with their children (Verhage et al., 2016).

**Interview with Secondary Caregiver.** An interview with the secondary caregiver, Peter, was conducted before Luca's regular therapy session at the ECIC on a Tuesday morning. It ran for 20 minutes and Luca was present in the room.

A number of key themes emerged from the Nvivo analysis of the interview transcript and will be discussed under the following topics: *Understanding attachment*, *Factors around attachment*, *Attachment relationships*, *Early Childhood Intervention*, *Caregivers' experience of pregnancy*, *Caregivers' experience of Child's diagnosis*, and *Caregivers' hopes and concerns for their Child*.

***Understanding attachment.*** Peter did not have an understanding of attachment and attachment relationships: "That's uh, when a child tends to be more clingy to one parent than to the other. Is that what you mean?" When asked what he thought of Mikaela and Luca's relationship, he responded with:

It's perfect. You know, when I observe them, they're spending a couple of days at home when I'm not there. And of course, everyone has bad days and good days, and they have too. So sometimes he's nagging, but it happens with me and same as Mikaela. ... But I think they're joking a lot and they're having fun so, yeah yeah. ... they're singing songs and they're playing nicely so yeah, no, I have no concerns whatsoever about his relationship between him and Mikaela, so.

Peter described his own relationship with Luca as: “like 100% being, loving each other. Gosh. He’s totally hanging onto me like a koala and he loves me and we are just being silly”. Though Peter was unable to describe attachment in terms of being a reciprocal, two-way emotional relationship between a child and caregiver, he did speak quite positively about Luca’s relationship with him and his wife, perhaps almost ignorant of some of the issues that were occurring, such as delays in Luca’s speech and language development, his play, such as his lack of referencing, and behavioural issues such as self-regulation.

***Factors around attachment.*** When asked to describe Luca, Peter described him as a “naughty and noisy little boy”, and “a cheeky little bugger”, descriptions which he attributed to Luca being a typical little boy. Peter also described Luca as: “sometimes he gets nagging and gets too clingy but most of the time he is just nice and he can play and be independent.” Peter also spoke about how far Luca had come despite “all the anxiety from the beginning”, referencing the tumour and other complications at Luca’s birth, and his subsequent 3-month stay in hospital. These responses support previous descriptions made by Jasmine and Mikaela of Luca’s abilities and character.

In regards to Mikaela’s physical health, Peter briefly spoke about Mikaela being prone to migraines, and how there were times where she had been incapacitated and so he would be Luca’s primary caregiver for the entire weekend:

You know she’s suffering sometimes from migraines, so I know that’s a thing that’s sometimes unexpected. It just takes a weekend away when she’s in bed and I have to change up my plans and so I’m in daddy day care two and a half days, straight up, so.

This provides some insight into their supportive spousal relationship, as does this response:

Yes so, as I say sometimes you know you listen you have the selective hearing \*Researcher laughs \* because you know ladies like to speak...But doing the necessary thing doing everything out of love, and you know keeping it all running smoothly, I mean that's the priority. Support each other, we shopping for each other, we share the time with him.

In terms of other factors that may have affected Luca's growing attachment relationships, the following excerpt details the little social support the family had available to them:

Peter: friends every now and then, but no family. My mum was here in February but it's like a short-term visit, three weeks, it comes and goes. It wasn't like, she was helping with Luca. We were sightseeing, and going to Taronga Zoo and things like that. So, no we don't have much support besides the ECIC and sometimes friends every now and then.

Researcher: Yeah, so really, it's just you three.

Peter: It's just the three of us yeah. Fighting on you know? \*laughs \* Mikaela is working part-time, I'm working full-time.

The excerpt also alluded to the family's occupational and financial situation, with both parents having to work, which left Luca to spend 3 days a week in childcare.

***Attachment relationships.*** When asked to comment on Luca's relationship with Jasmine, Peter replied again, in a very positive way: "From what I've observed, perfect. I mean as much as can go between you know, a therapist and a kid, absolutely. Jasmine is good, very good".

***Early Childhood Intervention.*** When asked if Mikaela spoke to him about the therapy strategies they did with Jasmine and Luca, Peter replied:

Yes. Not like totally strategies, look she gets me involved but sometimes you know being a man, I'm just, one side in the other side out. Sorry, it's just some things men just leave to the women. For the wives. So yeah, I just know –and I've been to a few sessions- that he's progressing really well. Of course, she tells me like okay what's the next thing, like the music therapy and everything. And now I get to experience it a couple of times and he gets involved really nicely so. So, it's playing a part, yeah a big part.

Therefore, while Peter had been to a couple of speech therapy and music therapy sessions, it was clear he had limited involvement in doing therapy with Luca. In fact, his comment that Luca was progressing really well showed some ignorance on his part, on how behind Luca was in terms of his speech and language development, and social and emotional development. More so, Peter's perspective that therapy was 'women's work', showed his lack of involvement and responsibility in these matters.

*Caregivers' experience of pregnancy.* Peter spoke about how Mikaela and himself started a family quite late: "We were in our forties let's say. So, we started a little bit late and you know being excited about our first baby, we just simply are anxious that everything is going to be alright".

*Caregivers' experience of child's diagnosis.* Peter then described what it was like for him during Luca's birth:

he'd been born prematurely and then you know soon afterwards we find out that there is something obstructing his breathing and you know then it was just, pretty much bad news, bad news. And then you know, hopeful news and just simply listening to doctors, medics, you know, anaesthetists, all kinds of people while he was in a crib, in an incubator in the hospital. You know pretty much we were just on a regular basis, stuck there, like yeah. All this

apparatus connected to him and things like that. So, it was quite a tense, a tense period of time.

When asked if he ever feared that they might lose Luca, Peter replied:

Oh yeah. On a regular basis. Yeah. It was there on that back of your mind. I mean come on he was born with a tumour so now what kind of tumour? And the first diagnosis was wrong with the tumour. So, so, we were just like wow really? Is it malignant is it benign? Does it ever come back? How's he going to you know grow up and go in the future? If he was born already and was blasted with chemotherapy, you know, prior to his due date, so... yeah scary stuff. So, the thing that if he actually will make it was, you know, it always there.

Clearly that period in their life was a very tense and difficult time, with that fear of losing their only child constantly at the back of Peter's mind.

*Caregivers' hopes and concerns for their Child.* In terms of hopes and concerns for Luca, Peter expressed "no major worries" and that he was:

just hoping for the best and see how he's talented and what's his interest later on. ... Of course, we soon will have to decide where to sign him up for school. ...And yeah, with him, it depends, he's still such a baby so, you know. When he starts talking, when he starts more understanding and everything and. Then we can maybe communicate with him better and like see where he shapes up which way. For now, he's being a total boy he loves the trains and the cars and his little bike.

His comments show some evidence that Peter was again, unaware of some of the developmental issues that Luca was facing. Furthermore, Peter's comment: "I think sometimes he's lazy to say things. Like he knows the response" perhaps also revealed some ignorance of Luca's speech and language delay, and what he might have been able to do to help him progress in that area.

The following sections details results from an examination of Luca's documentation from the ECIC.

### **Documentation.**

Analysis of the medical and audiological documents associated with this case study highlighted some major factors that likely affected the formation of Luca's attachment relationships with key caregivers. Luca was born prematurely at 33-weeks gestation via an emergency caesarean section. His birth was complicated by premature labour at 25-weeks gestation, as well as polyhydramnios (excess of amniotic fluid in the amniotic sac). At birth he weighed just 2.085 kilograms and experienced respiratory distress. Doctors had trouble intubating him, with bleeding in his pharynx. A biopsy revealed a suspected neuroblastoma and Luca underwent chemotherapy for 3 days at just 12 days old. This was a misdiagnosis that resulted in the mass increasing in size. Luca experienced other infections and symptoms as a result of the chemotherapy, such as a fever and irritation of the digestive tract.

After a reexamination and an MRI, a revised diagnosis was that the mass was a teratoma, with a plan of removing the mass and inserting a tracheostomy. This surgery was conducted when Luca was just 1 month old. A small amount of the teratoma was left and was monitored. Luca stayed in the ICU until he was 2 months of age. He had a central line and was mostly tube-fed. He was then moved to the ward and was continually cared for, with a focus on increasing his oral feeds. Twelve days later, Luca was re-admitted to the ICU following a code blue (most likely a respiratory arrest), and an emergency tracheostomy change was performed. He continued to improve and was finally

discharged from hospital at three and a half months of age. In Luca's second year of life, the family had a scare as another tumor was found. This was treated. Since then, subsequent results were negative for cancer.

Luca failed the Newborn Hearing Screen at birth. He was subsequently tested and referred to Australian Hearing, with a diagnosis of a permanent, mild to moderate, bilateral, sensorineural hearing loss. His parents chose to receive early childhood intervention services from the same ECIC that the current study was conducted at. He was fitted with hearing aids at around 4 months old, with hearing aid compliance proving difficult. Fluid in his middle ear also affected Luca's hearing and listening, with grommets in place in both ears for several months. For both his medical and audiological needs, Luca attended several appointments, tests and check-ups, most ongoing. This description of Luca's medical and audiological history supports data from the interviews concluding that his medical needs have had a large impact on his development and on his family. The following section presents findings derived from other form of documentation, the researcher's logbook.

### **Logbook.**

A number of key findings surfaced from an analysis of the logbook, including: context for the PSI, interviews and follow-up interviews; informal conversations between Jasmine and the researcher, including watching the videos together for advice and feedback; context surrounding the chat that the researcher had with the service provider and mother regarding the feedback and results from CS1; input from Louise and other staff members on the participants in CS2; and, grief.

*Parenting Stress Index.* When given the PSI, Mikaela had an almost dismissive attitude towards it, wanting to get it over and done with. Following analysis of her PSI scores, the researcher spoke to Louise as Mikaela had reported very high stress levels with most domains being in the 90<sup>th</sup>-95<sup>th</sup> percentile. Louise assured the researcher that Mikaela was seeing a professional psychologist or counsellor for her depression.

**Interviews.** Context surrounding the interviews and follow-up interviews supported the conclusions that Mikaela was at times overly concerned about Luca's physical well-being, and unable to cope with him being upset. During her interview, Mikaela was distracted by her son's crying as she was able to hear him outside the interview room. She was quite bothered by his crying and stopped the interview to listen if he had stopped crying, which disrupted the flow of the interview. For most of the duration of the interview, the topic stayed the same, with Mikaela describing in great detail her experience of Luca's birth and the complications surrounding the tumour. This further supports the conclusions drawn that Mikaela was preoccupied and greatly affected by the events surrounding Luca's birth and diagnosis. When the researcher asked Mikaela to proof-read their interview transcript her email response was that she would read it soon as it was "full on right now".

In contrast, when her husband Peter was interviewed, he seemed able to focus on the interview questions, though Luca was inside the room during the interview. Luca was playing with a noisy firetruck that made a siren noise, and would cry out whenever he needed help with the truck. Peter addressed Luca each time he communicated that he needed his dad. Peter was able to answer the interview questions, despite Luca's interruptions. It was interesting that Peter described Luca as still being a baby, with few words, though at the time of the interview, Luca was two and a half years old.

**Informal conversations.** Jasmine and the researcher often had informal discussions about Mikaela and Luca, as well as other families who attended the ECIC. One discussion was on how feeding was an issue for some of these children, and how it added to the complex issues of the child. Another discussion was a reflection by the researcher after observing Mikaela and Luca during an excursion. The researcher told Jasmine how she observed Mikaela as being dismissive of Luca's emotional needs, not addressing his crankiness and tantrums. Jasmine reminded the researcher that Mikaela was a "gorgeous mother", adores her child and was doing her best. Jasmine suggested that



they have a talk with Mikaela regarding her attunement and attachment with Luca, in order to help both Luca and Mikaela progress.

***Feedback for mother.*** This talk with Mikaela was held after the third video-recorded therapy session. The researcher had made an information leaflet based on the feedback and results from CS1. It was difficult to start the discussion as it took a while to settle Luca and have him playing and sitting on the floor. Mikaela did not appear to be completely attentive to the points being discussed. She kept interrupting and speaking over the researcher, and while she said she wanted to listen, her behaviour showed otherwise. Mikaela took the leaflet home to read. Mid-way through this discussion, Mikaela told us about their last oncology visit, describing how they no longer have to visit the oncologist as Luca was cancer-free. She then noted how she cried for 3 days upon hearing that news. She was looking at the service provider during this exchange, and noted for Jasmine not to continue looking at her because she would begin to cry. Jasmine averted her gaze, though the researcher noticed Mikaela was teary and Jasmine was empathetic. Jasmine tried to point out that Mikaela's 3-day crying was perhaps due to relief and all the emotions from their ordeal. The researcher then tried to continue speaking about the leaflet, but observed that Mikaela was not in the right state to be receptive, and therefore ended the talk.

After Mikaela and Luca had left, Jasmine and the researcher spoke about the discussion that had just occurred and both agreed that it was emotionally intense. It was concerning that Mikaela had described crying about the oncology-related news for three days, in an almost flippant way. Both Jasmine and the researcher agreed that perhaps Mikaela was still holding onto a lot of anxiety, fear, and grief about the imagined child she had lost, and therefore was perhaps in denial of some of Luca's needs, as the researcher had pointed out in the leaflet. Jasmine also suggested that they go through each of the points on the information leaflet week-by-week and should model them and work on them, as this may be a better way to teach Mikaela how best help Luca.

**Case conferences.** The researcher noted how the service providers held case conferences, where they came together to discuss children and their families. The case of Luca and his parents Mikaela and Peter was often discussed during staff meetings. Regarding Luca's behaviour, Louise (key informant) suggested that Mikaela could be very anxious and not able to believe that in some ways, her child is still very much like a baby. Luca was exhibiting these challenging behaviours that are akin to how a baby who is learning how to communicate and self-regulate would behave. The researcher also agreed with Sarah (CS1 service provider) when Sarah commented that if the mother was not ready then we could not force that attunement and attachment. The researcher also agreed with Louise that if Jasmine followed Luca's lead and tried being even more attuned, Mikaela would eventually see and be engaged with her child. The researcher expressed how she observed that the mother and service provider were feeding off each other's anxieties and expectations.

**Key informant.** As the key informant, Louise also watched videos of CS2 with the researcher to provide some feedback and insight. She noted that there were some beautiful key moments between Mikaela and Luca, spinning around, tickling, feeding sheep, and Luca imitating Mikaela's words in Czech. Louise also observed how Mikaela was anxious, evidenced from her talking a lot and embarrassed or nervous laughter. Louise noted that the mother was trying so hard. She also wondered if Mikaela and Luca needed to do rough and tumble play and more tickling, because it seemed that they missed out on the important 'bodily play' early on in their relationship, due to Luca's extended hospitalisation and time spent in an incubator.

**Advice given to service provider.** The service provider also asked the researcher for advice on how to improve her practice, and if they could watch some of the videos of her therapy sessions with Luca and Mikaela, with the hope that she might learn from them. When asked for advice, the researcher was honest with Jasmine and made suggestions such as slowing down her pace, not having so many toys, and following Luca's lead more. Jasmine received this advice well and said that she

would try to practice it during their therapy sessions. Jasmine and the researcher both agreed that Mikaela – given her depression, grief and fear – was not yet ready to help Luca listen and speak. It was also suggested that perhaps Jasmine needed to listen more to what was happening with Mikaela and maybe set or re-direct the goals Mikaela has for Luca. A month after Jasmine and the researcher watched and reviewed the videos, Jasmine showed the researcher some video of her session with Mikaela and Luca. Jasmine was really excited and proud that she “stepped back and zipped it” and let Mikaela do most of the session, with some modelling. The researcher then suggested that they have a couple of sessions on their own before commencing video-recording.

**Grief.** Grief was a significant finding that surfaced in the logbook analysis. When planning when the last videos and follow-up sessions would take place, the service provider and the researcher also spoke about impact of grief on attachment. It was clear that Mikaela was mourning the loss of the healthy, typically-developing child she and her husband had imagined they would have. Her preoccupation with this loss, and fear that Luca may become sick again, seemed to prevent her from completely being attuned to Luca’s emotional and communicative needs. The reaction she shared of crying for 3 days after hearing the good news of Luca no longer being at risk of cancer was telltale of her inner turmoil.

The service provider also reflected on the fact that she could not change Mikaela’s situation for her, and that Mikaela had to overcome the grief on her own. Jasmine expressed the sadness she felt towards this realisation. With Mikaela and her grief, it seemed that her progress was very much one step forward and two steps back. For the fourth video-recorded session, the researcher noted the improvement Mikaela had made in comparison to earlier videos. However, during the fifth video-recorded session – just a month later – Mikaela seemed highly anxious and stressed, as well as sad. She felt that she was being judged by everyone. The service provider and researcher also appeared to feed off her anxiety. In contrast to Mikaela’s experience, her husband Peter appeared more able to be attuned to Luca. During a therapy session in between the fifth and sixth videotaped sessions, the

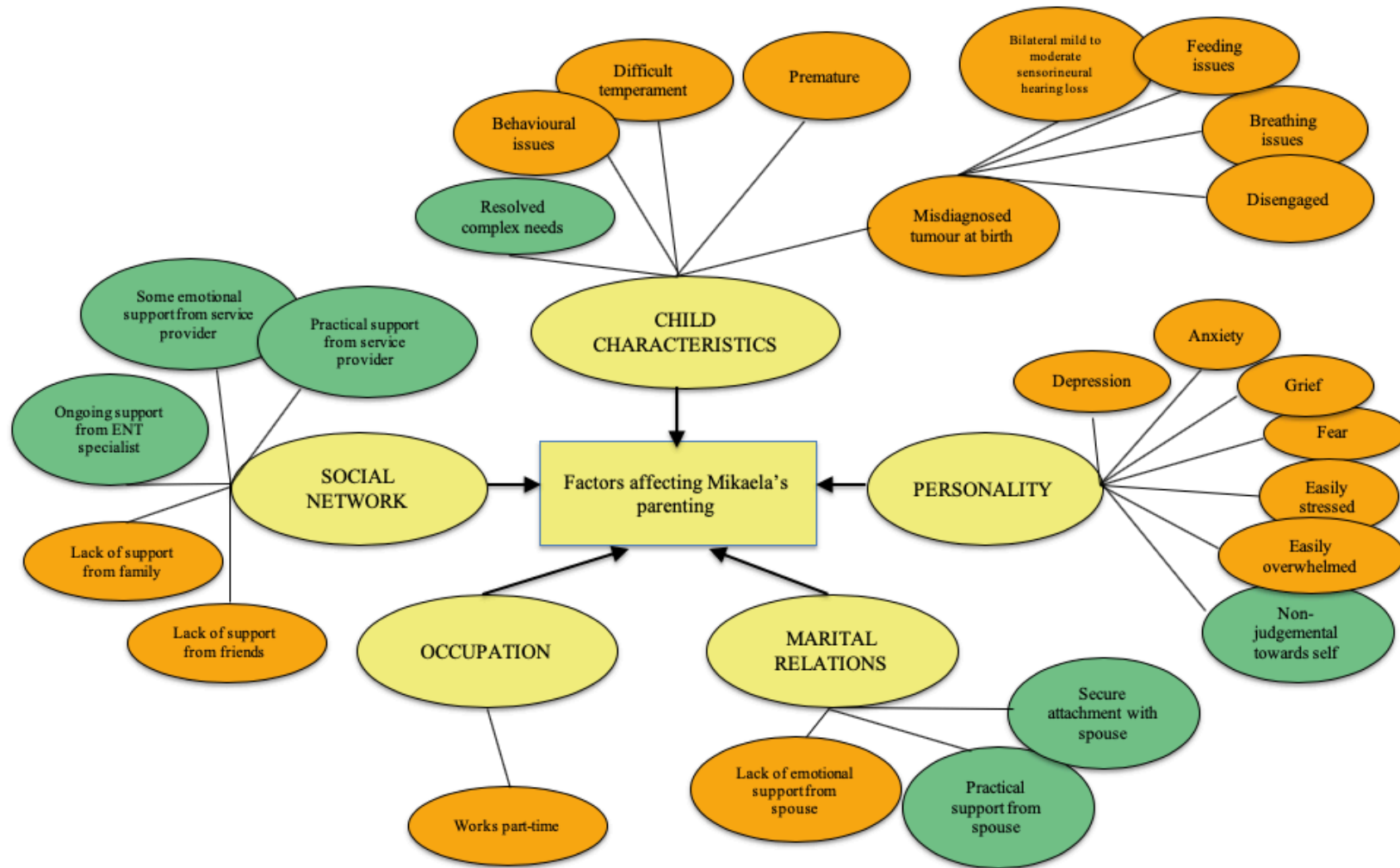
researcher and Jasmine observed Peter to be more relaxed and willing to play and be silly. It seemed like Peter really wanted his child to say the words that Jasmine was prompting him to say e.g. “more” or “quack quack”. In comparison to Mikaela, Peter was more natural at play with Luca; willing to be silly and did not mind Luca or himself getting wet with the toy duck. Peter followed Jasmine’s coaching and did not talk over Luca or Jasmine. Though it was his first time attending a therapy session with Luca, Peter was able to separate any concerns or anxiety he had about their situation, and focus on being with Luca and providing the play, interaction and connection he needed.

### **Summary of Case Study 2**

Informed by Belsky’s (1984) determinants of parenting model, Figure 5.28 below displays a summary of the risk (stressful) and protective (supportive) factors contributing to Mikaela’s parenting. Risk factors are coded orange, and protective factors, green. These factors affected the quality of Mikaela’s parenting, and therefore the sensitivity of her caregiving and ability for reflective functioning, major determinants of attachment security. To summarise the accumulation of factors, in Mikaela’s case, her personality, her child’s characteristics, her occupation, and most of her systems of support were risk factors. Her marital relations were mostly a protective factor, as well as some of her other systems of support. From the overall data, it seems that Mikaela’s personality and psychological attributes, and her child’s characteristics, overwhelmed the support she received from her spouse and social networks.

Figure 5.28

Factors Affecting Mikaela's Parenting.



### *Child Characteristics*

Figure 5.28 above shows Luca's many needs, most stemming from his birth. He was born premature, and had difficulty breathing. Scans revealed a tumor which increased in size due to a misdiagnosis. When Luca was 1 month old, the tumour was surgically removed. Luca was hospitalised for three and a half months. Peter described this period in their lives as quite tense, with the fear of losing Luca always on his mind. When asked to describe this experience, Mikaela spoke lengthily, and often relayed the events not in the correct order. As she retold her story, the researcher observed Mikaela to be emotionally affected by this experience. When asked to comment on Luca's hospitalisation and how it may have affected him, Jasmine said that it had traumatised him and likely the reason why when they first began therapy, Luca was very disengaged. Moreover, Jasmine, throughout the study – during interviews and informal conversations – commented repeatedly on Mikaela's fear. That is, Jasmine felt that the ordeal this family went through left Mikaela fearful of losing Luca, and therefore would not allow herself to become deeply attached to her son. Significantly, Jasmine described how when she played with Luca, Luca did not reference her. Jasmine noted how it was strange that unlike other children his age, Luca did not want to seek approval or a shared connection with a familiar caregiver.

Fortunately, Luca's hearing loss – though permanent- was classified as mild to moderate, and when hearing aid compliance is optimal, can be managed well. Furthermore, towards the end of the study, tests revealed that Luca was no longer in any danger of the cancer returning, a huge relief for the family as they had received a second scare where a mass had had to be removed. Therefore, most of Luca's complex needs as a result of his traumatic and complicated birth had been addressed.

In Mikaela's follow-up interview and Peter's interview, concerns with regard to Luca were his difficult temperament and some behavioural issues to be combatted with occupational therapy. Mikaela's Parenting Stress Index scores revealed that she felt Luca was demanding

and easily distracted and/or too hyperactive. It was likely that because Mikaela was an older parent, she lacked the energy necessary to keep up with Luca and was experiencing difficulty adjusting to her child (Abidin, 2012). She may also have been experiencing the child as placing too many demands on her including, “crying, physically hanging on the parents, frequently requesting for help, or exhibiting a high frequency of minor problem behaviours” (Abidin, 2012, p. 17). Video data also showed Luca often becoming upset and throwing tantrums when he was not given what he wanted straightaway.

Though Luca did not seem to face any major complex needs, his traumatic start to life had clearly affected the development of his attachment relationships, and was also likely a factor in his communication and language delays, and behavioural issues.

### ***Parent’s Personality***

As in CS1, the mother’s personality and psychological attributes were factors likely affecting the formation of attachment. Mikaela’s PSI scores were quite concerning with most subdomains in the 90<sup>th</sup>-95<sup>th</sup> percentile. Her scores indicated that she was depressed and confirmation by Louise the key informant suggested she was most likely clinically depressed but was seeing a professional therapist. For much of the time, Mikaela’s mood and facial expressions during video-recorded therapy sessions were also observed to be low and flat. At times she did not comfort Luca when he was upset or having a tantrum. These behaviours are consistent with symptoms of depressed mothers. A study on clinically depressed and anxious mothers and their infants revealed that while anxious and controlling mothers acted as buffers during infant distress, the presence of depressed mothers failed to provide this same role to their infants (Granat et al., 2017).

Mikaela also displayed anxious behaviours during the therapy sessions, including nervous laughter, embarrassed facial expressions and comments, uncertainty and hesitance when interacting with Luca, and self-critical comments. Peter, Jasmine, and Mikaela herself

commented in the interviews how Mikaela was easily stressed and easily overwhelmed, and often found daily life a struggle. Further evidence of this aspect of Mikaela's personality was how Mikaela and Luca would often come late to the therapy sessions, and missed sessions due to Mikaela being ill. Mikaela's depression and anxiety were understandable given the trauma she had experienced, and were likely signs of prolonged grief and ongoing trauma.

Grief and fear were two other significant constructs that emerged from the data gathered. According to Jasmine's observations and "gut feeling", throughout the duration of the study, Mikaela was still grieving the loss of the healthy child she had expected, and still feared that she might lose Luca. This grief and fear are not unusual in parents who have a child with a disability, and often they live their whole lives with this chronic sorrow over the loss of a child without any special needs (Green, 2007; Kelso et al., 2005). Depending on the strength of their coping mechanisms and support systems, most parents and caregivers are able to function, despite the emotional upheavals they are likely to face through key points in their children's lives (Green, 2007). The case with this family was that Mikaela was still taking a long time to come to terms with what had happened, and to cope with their new reality. In her follow-up interview, Mikaela admitted that it had taken 18 months to 2 years for her to move on from the traumatic events surrounding Luca's birth. Mikaela's preoccupation with what had happened to her and her baby, the sadness, loss and anxiety or fear of the possibility that she may lose Luca in the future, hindered her from being wholly present when playing and interacting with Luca.

One example given by Jasmine of Mikaela's lack of presence was that during a therapy session in which they were playing with sand, Mikaela suddenly looked up and exclaimed with surprise "Where did this sand come from?". Evidently, she had been too lost in her thoughts and emotions to be present in the therapy room. In this instance, Mikaela was unable to practise self-regulation or reflective functioning, as her mind was still too preoccupied with past trauma,



as well as unresolved with her child's diagnosis. Both self-regulation of emotions and reflective functioning are important factors in being able to support infants' affective development (Grienenberger et al., 2005; Rutherford et al., 2015). Along with caregiver sensitivity, the capacity of the caregiver to regulate their emotions and use reflective functioning contribute to the development of attachment security between infants and their caregivers. This is because such caregivers help their infants learn flexible self-regulation strategies in the face of negative emotion, and thereby develop their secure attachment relationships (Cassidy, 1994; Sroufe et al., 2005).

### ***Marital Relations***

Regarding her relationship with her husband Peter, Mikaela felt that he could have provided more emotional support. Her Spouse/Parenting Partner Relationship (SP) score on the PSI was high, sitting in the 90<sup>th</sup> percentile. This suggests that she does not have the "emotional and active support of the other parent in the area of child management and emotional support" (Abidin, 2012, p. 21). During her interview, when asked if her husband supported her well, Mikaela said he was supportive but then made strangling gestures, suggesting she often was also frustrated with him. However, Mikaela's adult romantic attachment score on the ECR showed that she was secure in her relationship with Peter.

When asked if he was supportive of Mikaela, Peter replied that they were 100% supportive of each other and described how he would often take care of Luca on his own during weekends where Mikaela suffered from migraines. However, he did admit that when it came to listening to Mikaela, he tended to have selective hearing, which suggests that perhaps the couple did not always provide the support for each other's needs, all of the time. Thus, his interview responses suggest he provides mostly practical help and support for Mikaela, and is lacking in providing more emotional support. This lack of emotional support is an added risk factor in Mikaela's parenting, and consequently, her developing attachment relationship with

Luca (Belsky & Jaffee, 2006). More so, Peter appeared ignorant of the stages in language development, commenting during his interview how Luca was still very much like a baby and thus did not yet know many words. This suggests that in terms of supporting Mikaela with Luca's language and communication development, Peter had room for improvement.

### ***Occupation***

Both Mikaela and Peter completed their tertiary education in the Czech Republic and Slovakia. Mikaela in landscape architecture, Peter in teaching. Peter went on to work as a handyman around schools, and Mikaela a drafter then manager of a landscape business. At the time of the study, Mikaela was working part-time, two days a week. This was likely due to financial or care burden reasons as most families with children living with disability experience changes in their work decisions, in order to care for the child with disability (Bumbalo et al., 2005; Caicedo, 2013). Although, the respite and support Mikaela and Peter received from childcare points to one study where families who received a high level of social support experienced average levels of family quality of life, despite the intensity of the child's impairments (McConnell et al., 2014). The nature of Peter's job also meant flexible working hours, with him being able to drop off and pick up Mikaela and Luca to therapy sessions, as well as attend a few himself.

### ***Social Network***

Mikaela's support systems were identified as both protective and risk factors. Having migrated from the Czech Republic, Mikaela and Peter had no relatives living in Australia. Thus, following the birth of Luca, they received no support from family, and little help from friends. In their interviews, Peter and Mikaela both mentioned the ENT specialist as the best there was and grateful for the role he played in Luca's treatment. This doctor removed Luca's tumor and continued to see him regularly after discharge from hospital. As their main service

provider, Jasmine supported Mikaela and Luca's development through their weekly therapy sessions. Jasmine also supported Mikaela emotionally by listening to her and giving advice. Though at times, as seen in the video-recorded therapy sessions, Jasmine was not completely tuned into Mikaela's emotional needs. Sometimes she would ignore Mikaela's comments and suggestions, being too focussed on Luca's therapy. In all, Mikaela's lack of support from friends and family, and only some emotional support from Jasmine, were added risk factors to her parenting.

### ***Attachment Relationships***

Luca's attachment relationships with his mother and service provider was seen to be developing over the course of the case study. With the understanding of the importance of self-regulation, reflective functioning and caregiver sensitivity to the caregiver-infant attachment relationship, interview and video data reveal that both Mikaela and Jasmine presented with issues in these areas. In the case of Mikaela, her ongoing grief and fear, as well as depression and related anxiety, appeared to have had a great impact on her daily life and mental health. Research surrounding the effects of maternal depression on attachment security points towards infants who have difficulties in self-regulation, behavioural and affective disorders, academic and attachment difficulties, likely as a result of mothers who are less sensitive and contingent to the infant's cues (Belsky & Jaffee, 2006). Though the external CARE-Index coder coded her and Luca's relationship as a 10 out of 14 on the synchrony scale, there are more data to suggest that this was perhaps not the case.

In most video-recorded therapy sessions, Mikaela was not completely attuned to Luca. Their play interactions lacked warmth and engagement from both sides. At times Mikaela would misinterpret Luca's behaviours and cues, which resulted in misattunement. Mikaela was more preoccupied with Luca's physical wellbeing – such as blowing his nose, ensuring he drank water, and not getting wet or messy – rather than his socioemotional wellbeing. Mikaela

seemed to be too rigid at times, with respect to her body language, not willing to be silly during play with Luca. Jasmine attributed Mikaela's behaviours to her chronic grief and fear that she may lose Luca, and therefore was too afraid to make a deep connection with him. As previously noted, Mikaela admitted to not being able to move forward from the events surrounding Luca's birth until he was at least 18 months old. Recent research on 'prolonged grief' could apply to Mikaela's experience as she showed a number of the symptoms associated with this classification of grief, e.g., emotional numbing, bitterness, difficulty accepting the loss, and difficulty moving on with life (Bonanno, Neria, Mancini, Coifman, Litz & Insel, 2007; Fraley & Shaver, 2018). Thus, during therapy sessions, Mikaela was often too overwhelmed with stresses in her daily life, or too preoccupied with her emotions of grief, fear, sadness and anxiety, to be truly present and attuned to Luca.

Analysis of the video data suggests that Jasmine was preoccupied with her own emotions towards the dyad's situation. Unable to help Mikaela out of her grief and fear – as well as struggling with their foreign language – Jasmine became too focussed on ensuring that Luca's language development progressed. Most videorecorded therapy sessions showed her exhibiting anxious behaviours in the form of rushing Luca from one toy activity to the next, not following his lead, misinterpreting or ignoring his cues and needs, taking over while Mikaela and Luca were interacting together, as well as ignoring or not completely paying attention to Mikaela's stories, suggestions and other emotional needs. Therefore, it was clear that both Mikaela and Jasmine were not always able to self-regulate their emotions, perhaps even feeding off each other's anxieties and fears about Luca and his growth and development.

There were some instances in the videos where Luca resorted to self-soothing as neither Mikaela nor Jasmine comforted him during distressing times. This may lend some evidence to the conclusions that because of their inability to fully self-regulate their own emotions and thus be attuned to Luca, mother and service provider were not helping Luca co-regulate his own

emotions, essential in developing secure attachment relationships (Cassidy, 1994; Sroufe et al., 2005).

Luca's father, Peter, seemed ignorant to any issues his son and wife may have been having in their relationship. When asked what he thought about their relationship, he described it as perfect though admitted that Luca did have tantrums, which he considered usual behaviour for a boy his age. While this is true to some degree, neither Peter nor Mikaela are cognisant that Luca's tantrums and other behavioural difficulties are likely a result of the way his attachment relationships were forming. Mikaela's depression and prolonged grief, Peter's ignorance of child development, and Jasmine's own anxieties as their service provider are risk factors that could lead to Luca developing insecure attachments with his caregivers.

Despite these obstacles, there were some video data to suggest that Mikaela and Luca did show improvement in how they played and interacted with each other in the therapy sessions. Mikaela's use of acoustic highlighting saw a marked improvement, with each subsequent video surpassing the first video's total of just five counts of acoustic highlighting. She and Luca completed numerous circles of communication together and held joint attention for prolonged periods of time, with some videos having more circles of communication and joint attention than Luca and Jasmine. Mikaela was also seen more at ease during the later sessions, able to smile and enjoy being with her son more. She followed Jasmine's coaching and a few times was confident enough to interact with Luca without any help from Jasmine. Also, in her follow-up interview Jasmine was hopeful that Mikaela and Luca would continue to improve. She noted that because Luca's complex needs were resolved, Mikaela had therefore begun to overcome her grief, and with the study ending, Mikaela might feel less pressure away from the video cameras.

In summary, based on Belsky's (1984) determinants of parenting, Mikaela appeared to have several risk factors affecting the quality of her caregiving, and thus her developing

attachment relationship with Luca. Her depression, anxiety and chronic grief, her poor coping strategies, the lack of support from family and friends, the lack of emotional support from her husband, and insufficient emotional support from her service provider, seemed quite detrimental to her relationship with Luca, preventing her from practising sensitive caregiving. However, a number of these risk factors have the potential for change in the long term as Mikaela comes to terms with the grief and fear she had been living with; comes to terms with, and learns to better address, Luca's hearing loss and complex needs, and continues to receive support from her husband Peter and the ECIC. Results from this second case study, together with those of the first case study, will form the basis for the following chapter, which will respond to the study's overarching research questions.

## Chapter 6 Discussion

The importance of attachment relationships is paramount since a secure attachment between infants and their primary caregiver has been positively linked to the social and emotional development of children (Ainsworth, 1972; Bowlby, 1980; Landy, 2009). With respect to infants with hearing loss and complex needs (HL-CN), little is currently known about the factors that surround their attachment relationships with their caregivers. The aims of the present study thus were twofold, firstly, to explore this gap in the literature in order to gain a more informed understanding of the nature of the attachment process in this population. Secondly, to discover what is the role played by service providers in helping facilitate developing attachment relationships between infants with HL-CN and their primary caregivers.

Results from two case studies suggest that infants with HL-CN work through the earlier phases of attachment at a slower pace than those infants without hearing loss and complex needs. The two case studies also indicate that a cumulative risk model may place infants with HL-CN at greater risk of developing insecure attachment relationships with their primary caregivers. This is consistent with the work of Belsky and colleagues on parental functioning and its effect on child development (Belsky, 1984; Belsky & Fearon, 2002; Belsky & Jaffee, 2006; Fearon & Belsky, 2016). In the same vein, protective factors can buffer the impact of risk factors. The service provider has been identified as one such protective factor.

This chapter will first undertake a cross-case analysis of the two case studies, and then present a summary of the key findings. The findings will then inform a detailed response to the present study's research questions:

- 1) What is the nature of the attachment process for infants with hearing loss and complex needs (HL-CN)?

- a. What do caregivers and service providers understand about the attachment process for infants with HL-CN?
  - b. What factors may affect attachment formation in infants with HL-CN?
- 2) What is the role of service providers in helping facilitate developing attachment relationships between infants with HL-CN, and their primary caregivers?

The chapter will conclude with a discussion of the implications of the findings for the fields of attachment, disability, and early childhood intervention, limitations of the study, and finally, suggestions for future research.

### **Cross-case Analysis**

A cross-case analysis allows the researcher to make sense of the various factors that may have influenced the outcomes of the case, as well as refine and develop concepts and build or test theories (Khan & Van Wynsberghe, 2008). Yin (2018) noted that it is one of the five techniques of case study analysis, and can strengthen the analytic generalisations made from a single case study. The current study took a case-oriented approach to its cross-case analysis, and specifically looked at the typologies within the case studies (George & Bennett, 2005). In other words, the two individual case studies were examined for any similarities and differences in the key constructs that emerged, and how these constructs were categorised. As Yin explained, “the analysis can start to probe whether different groups of cases appear to share some similarity and deserve to be considered instances of the same “type” of general case” (Yin, 2009, p. 160). Cross-case conclusions are thus strengthened and findings more robust than having only one case study (Yin, 2018). To help make this analysis clearer for the reader,



participants from the two case studies will not be referred to by name, rather by their role e.g. ‘infant’, ‘mother’, ‘service provider’.

The researcher used the summaries of Case Study 1 (CS1) and Case Study 2 (CS2) as the basis for the cross-case analysis (see Chapters 4 and 5). Belsky’s (1984) determinants of parenting model was used to make sense of the various factors affecting the parenting of the mothers (see Figure 4.37 in Chapter 4, and Figure 5.28 in Chapter 5), and thus their developing attachment relationships with their infants with HL-CN. Under the five domains of Child characteristics, Parent’s personality, Marital relations, Occupation, and Social network, the researcher examined both similarities and differences that emerged across the two case studies. These similarities and differences were used to draw cross-case conclusions about the nature of the attachment process in infants with HL-CN.

### ***Summary of Cross-case Analysis***

In both case studies, the infant’s hearing loss and complex needs, including a difficult, traumatic start to life and extended hospitalisation negatively impacted on their developing attachment relationships. Importantly, both case studies showed evidence that the attachment process took longer in the two infants with HL-CN. Compared to typically-developing infants, both CS1 infant and CS2 infant were not meeting attachment phases appropriate for their age.

In both case studies, the impact of the infant’s hearing loss and complex needs on the mother’s personality and psychological resources (e.g., depression, anxiety, and ability to cope) was detrimental to their parental functioning. In CS1, a results-driven attitude heightened the mother’s anxiety around her infant meeting developmental milestones. Nevertheless, the mother’s proactive personality and ability to draw upon problem-solving strategies helped her to cope with the stresses and anxiety. However, in CS2, despite resolution of the infant’s complex needs, the mother’s depression, anxiety and chronic grief continued to have a negative

effect on the attachment formation between infant and mother, with the CS2 mother experiencing challenges in regulating her emotions and being fully present during play interactions with her infant.

Regarding marital relations, both case studies recognised that a lack of emotional support from one's spouse was a risk factor, despite both mothers receiving practical support from their spouses, and having a secure romantic attachment-related score on the *Experiences of Close Relationships Scale*. In CS1, the mother's occupation in childcare and primary education were seen as both risk and protective factors. Finally, in both case studies, a lack of practical and emotional support from most family and friends were considered risk factors. In CS1, emotional and practical support was given by their service provider, which served as an important protective factor. This same level of emotional and practical support was not afforded by the service provider in CS2.

Thus, it appears that in both CS1 and CS2, an accumulation of risk factors affected the attachment process, and it was recognised that in infants with HL-CN, the attachment process takes longer when compared to typically-developing infants. The following section will draw from these cross-case conclusions to respond to the study's research questions.

### **Research question 1: What is the nature of the attachment process for infants with hearing loss and complex needs (HL-CN)?**

Despite the significance of attachment security in young children's development, there is a scarcity of research on the attachment process for infants with hearing loss and complex needs (HL-CN). The literature on attachment and infants who are deaf or hard-of-hearing attest that hearing status is not directly linked to attachment security (Lederberg & Mobley, 1990; Meadow-Orlans et al., 2004). However, sufficient evidence indicates that with the presence of

other risk factors, an infant with HL-CN may develop an insecure attachment with their primary caregiver (Spencer & Koester, 2016; Thomson et al., 2011).

Moreover, results from the two case studies of this current research project point towards a longer attachment formation process for infants with hearing loss and complex needs (HL-CN). The key informant for the study and the coordinator of the ECIC, proposed that this was often the result of the children's developmental delays, the emotional and psychological impact on the parents, as well as the time lost before the infants began to use their cochlear implants or hearing aids. Thus, often infants with HL-CN are often much older when they reach certain attachment phases, in comparison to typically-developing infants. In CS1, the mother recognised that her daughter had only begun to show signs of having formed a specific attachment to her (e.g. crying when the mother left the room) at 18 months old. In typically-developing children, this phase of attachment development – Phase III: Maintenance of Proximity to a Discriminated Figure by means of Locomotion as well as Signals – begins between 6 and 9 months of age (Bowlby, 1969). Similarly, in CS2, the service provider observed how the infant, at 2 years of age, rarely referenced his caregivers during play. This is a key behaviour in the development of Phase II: Orientation and Signals Directed towards One (or More) Discriminated Figure(s), with infants increasing their tendency to initiate social interactions with familiar caregivers by 3 months of age (Bowlby, 1969). This finding that infants with HL-CN take a longer time to form an attachment with their caregivers is also reflected in the literature, where Reda and Hartshorne (2008) found that children with CHARGE syndrome took longer to develop attachment relationships. By understanding that attachment forms at a slower pace in infants with HL-CN, caregivers and service providers may be more able to recognise at what phase of attachment an infant is currently, regardless of their age.

The following section describes what caregivers and service providers understand about the attachment process in infants with HL-CN, from the two case studies.

*What do caregivers and service providers understand about the attachment process for infants with HL-CN?*

Results from the case study interviews and videotaped observations reveal that caregivers have a limited understanding of attachment, if at all. With the exception of the CS1 mother who worked in childcare and was studying to be a primary school teacher, no other caregivers could describe what attachment involved. CS2 mother believed attachment was more about herself than her child, and CS2 father thought that it was about the child being clingy to their parent. When asked, CS1 father described it as “[an] emotional connection there with the child”. Finally, CS1 mother described attachment as:

if you want a child to be able to learn they need to be comfortable in their surroundings and in a trusting you know honest, kind of reciprocal love relationships, you know you can't expect a child to thrive in an environment where they don't feel safe and secure in.

Overall, findings show that caregivers did not have a good understanding of attachment relationships, which CS1 service provider commented in her interview as being typical for the parents at their ECIC. This reflects the literature on parent's knowledge of attachment, or rather lack thereof. While there has been much research on how parents' attachment styles and their mental representations of their early attachment experiences, affect their parenting behaviour and subsequently their child's attachment security (George et al., 1996; Feeney & Woodhouse, 2016; van Ijzendoorn, 1995; De Wolff & van Ijzendoorn, 1997), there has been little research

on what parents actually understand about attachment. A study reviewing attachment-based interventions showed that while these interventions successfully worked towards improving parents' caregiver sensitivity, parenting behaviours and their child's attachment security, only one intervention program – the *Circle of Security* (COS) program (Powell, Cooper, Hoffman, & Marvin, 2014) – explicitly taught parents about attachment and attachment theory (Berlin et al., 2016). Many of the attachment-based intervention programs that are available focus on enhancing the parent's sensitivity to their child or the parent's mental representation (Juffer, van Ijzendoorn, & Bakermans-Kranenburg 2008). And though some programs discuss with parents their early attachment experiences (Juffer et al., 2008), none educate parents about attachment theory and its importance to child development (with the exception of COS). This gap in the literature may be worth further exploration, as parents of infants with HL-CN, as well as parents of typically-developing children, may gain much from understanding attachment and attachment theory.

The service providers from both case studies showed an in-depth understanding of attachment and explained in their interviews that their early intervention model had its foundation grounded in attachment theory. Both service providers were knowledgeable of attachment theory and attachment relationships. CS1 service provider noted:

the attachment is when the mother, or the parent, or the caregiver... is in tune with their child and is absolutely at their level and so the child then gives back and responds and you get this two-way, rhythm or dance, ...which is very different to just a one-way bond.

This finding reflects the results from an Australian study that explored early childhood intervention (ECI) professionals' knowledge of attachment and found that overall the ECI

professionals understood that attachment plays an important role in a child's development (Alexander et al., 2018). Significantly, this study found that most professionals learnt about attachment 'on the job', with less than half having learnt attachment in their undergraduate training (Alexander et al., 2018). Similarly, CS1 service provider noted that it was through reflecting on her work with parents and attachment that she was able to better understand attachment and learnt how to help parents understand the process and value of attachment: "I've changed the way I work... All new families... we talk about the attachment, and we talk about the two-way, and I comment and parents really understand what we're, looking for and doing, and it's much easier for them". This finding that most ECI professionals learnt about attachment 'on the job' (Alexander et al., 2018), suggests that more work needs to be done in ensuring all ECI service providers have a thorough understanding of attachment and its importance to child development.

Furthermore, the service providers from the ECIC of this study, understood how the attachment process differed in infants with HL-CN and their caregivers, in comparison to typically-developing infants. These differences included a longer process of attachment formation, where the infants were often much older when they met attachment phases, infants who were disengaged or found it difficult to self-regulate, and primary caregivers who were dealing with emotional issues that may have prevented them from providing sensitive caregiving. As seen in the case studies, within this population of infants with HL-CN, delays in meeting the phases of attachment formation were likely due to a number of factors surrounding the infant and their caregivers. Thus, if service providers are more knowledgeable of the ecological and social-contextual factors that support or hinder attachment formation in infants with HL-CN, they may be in a better position to provide more focussed intervention and support.

### *What factors may affect attachment formation?*

In infants with HL-CN, the infant's hearing loss is complicated with co-morbid conditions or disabilities that often lead to several factors that can hinder the formation of attachment relationships. Belsky's (1984) determinants of parenting model highlights two proximal domains – the child's characteristics and the parent's personality and psychological attributes – that can strongly influence the trajectory of how the caregiver parents. In infants with HL-CN, both proximal domains may pose as risk factors, and consequently affect the attachment relationship that develops between infant and primary caregiver.

Complex medical issues at the start of the infant's life leave little time and space for the parent and infant to bond, thus impacting the developing attachment relationship. In the two case studies, a difficult start to life, with medical operations and extended hospitalisation, negatively impacted on the children with HL-CN and their families. In CS1, the infant had a profound bilateral sensorineural hearing loss and CHARGE syndrome. Her mother's pregnancy, and subsequently the birth, was complicated by a misdiagnosis, an early heart surgery at just 18 hours old, as well as numerous other medical complications associated with CHARGE syndrome. In CS2, the infant was born prematurely with a mass in his throat. As the parents commented, a misdiagnosis of the nature of the mass led to incorrect treatment, with the antibiotics involved in chemotherapy most likely having caused their child to have a moderate bilateral sensorineural hearing loss.

In both cases, this intense post-birth period resulted in something akin to trauma as the infants were subject to numerous tests, operations, and treatments to address their immediate medical needs. With CS2 infant, the misdiagnosis and therefore incorrect treatment led to his tumour growing in size rather than reducing. Several weeks spent in the neonatal intensive care unit in an incubator kept him away from his parents, with little skin-to-skin contact and opportunity to bond. Research on mothers and their premature infants who used skin-to-skin

contact, showed improvement in maternal physiological and psychological outcomes, and an increase in their sense of attachment as well as lower stress and anxiety levels, in comparison to mothers whose infants were in an incubator (Campbell-Yeo, Dishar, Benoit, & Johnston, 2015; Jones & Santamaria, 2018). Thus it appears that CS2 mother and infant had very few experiences to bond in this way, which may have hindered their attachment formation.

Service providers at the ECIC attest that experiences such as these leave the infants detached from their environment and those in it. CS1 service provider described how the infant was unable to focus her gaze; emotionally indifferent. CS2 service provider noted that the infant was disengaged: “I think because he was so, poked and prodded and, traumatised in hospital that he just ... turned off, that would be my guess, to everything around [him]”. Upon discharge, infants with HL-CN and their families are subject to ongoing appointments, hearing tests, medical tests, treatments, therapy and early childhood intervention. Parents are expected to navigate through this maze of medical and service provision, as well as coordinate these services (Cohen et al., 2011). At the same time, parents grieve over the loss of the child they had imagined, and learn to cope with a diagnosis of hearing loss and additional disabilities child (Fletcher, 2016; Godress et al., 2005). More so, the infant with HL-CN may exhibit atypical or subtle attachment behaviours that may confound caregivers and thus require them to be more sensitive and attuned towards the infant, at a time when it may be quite difficult for them (Howe, 2006; Warren & Brady, 2007).

The infant’s complex medical and emotional needs also affect the primary caregiver’s personality and psychological attributes. As Belsky and colleagues have stressed, the parent’s personality and psychological resources greatly impact on their ability to parent, with conditions such as clinical depression having quite a detrimental effect on the parent-child relationship (Belsky & Jaffee, 2006; Fearon & Belsky, 2016). In the current study, parenting stress scores that were defensive or clinically high revealed that the primary carers of these



infants with HL-CN, their mothers, experienced guilt, anxiety, depression, fear, and even grief. CS1 mother's defensive responding during the *Parenting Stress Index* (Abidin, 2012) as well as CS1 service provider's interview responses, painted a picture of a mother in denial of the stress she experienced, guilty and anxious about the development of her child with multiple needs. The mother's focus on her infant's therapy and ensuring she met developmental milestones became harmful to her infant's overall development. As their service provider noted, the mother needed to spend time simply enjoying and playing with her infant, without the guilt and anxiety surrounding her infant's progress.

In the second case study, the mother's *Parenting Stress Index* results revealed a very high score in the Depression subdomain, within the 90<sup>th</sup> percentile. Her interview responses showed that she found it quite difficult to function as a parent to her infant, describing it as "everything was too hard". Moreover, from her own and the service provider's interview responses, it can be surmised that the mother was experiencing chronic grief. The service provider spoke about the fear that prevented the mother from connecting with her infant on a deeper, emotional level. The mother spoke of the lengthy period in which it took her to come to terms with her infant's traumatic start to life, only being able to cope with their reality almost 2 years after her infant's birth. Clearly, these parents of infants with HL-CN experienced intense emotions of grief, depression and anxiety, as well as a higher level of daily parenting stress.

To form secure attachment relationships, parents need to be sensitive and attuned to their infants' cues and needs (Ainsworth et al., 1978; Bowlby, 1969). The intense emotions that parents experience affect their ability to provide sensitive caregiving and to use reflective functioning and mind-mindedness, key factors in developing secure attachments. As Ainsworth proposed, caregiver sensitivity has been empirically proven to possess a causal – albeit modest- link to attachment (Bakermans-Kranenburg et al., 2003). Thus, parents – such as the mothers in the two case studies – who are unresolved towards their child's diagnosis

and, as a result, are experiencing intense emotions such as grief, anger, denial or depression, may be less likely to provide sensitive caregiving (Howe, 2006). Further, reflective functioning – the ability of the parent to understand that their own and others' behaviours are related to one's feelings, desires and thoughts – is another factor contributing to attachment security (Fonagy et al., 1995; Slade, 2005). As suggested by the case study findings, it is unlikely that parents who are overwhelmed in their role of caring for an infant with HL-CN are able to engage in reflective functioning, experiencing difficulty in regulating their own emotions.

Parents' ability to cope with the stress of caregiving is crucial to ensure quality parenting (Åsberg et al., 2008; Marvin & Pianta, 1996; Neely-Barnes & Dia, 2008; Sloper et al., 2003). Parenting stress is heightened on a daily basis due to caregiver burden, including the navigation and coordination of medical and service provision to address the needs of infants with HL-CN (Kelso et al., 2005). However, coping with stress is more complex than straightforward, and is not dependent on the degree of the stress experienced, but rather the individual's perception of the impact of the stress (Green, 2007; Kelso et al., 2005; Kurtzer-White & Luterman, 2003). Research shows that caregiver burden is influenced by socio-cultural factors (objective burden), as opposed to the emotional distress that the individual experiences (subjective burden) (Green 2007). In other words, parents of children with disability are often influenced by societal and community perceptions about the difficulties in caring for a child with disability, despite the reality of their experience being a mostly positive one.

Evidence suggests that parents are able to identify the positive aspects of caring for their child with a disability, and that this experience is not in fact 'burdensome' (Green, 2007). Several studies give testament to how well some parents with children who have disability have coped (e.g., Åsberg et al., 2008; Green, 2007; Marvin & Pianta, 1996; Neely-Barnes & Dia, 2008; Sloper et al., 2003). Such parents have positive attitudes towards life; see their children

as a source of joy; and, are proactive, turning to problem-solving strategies to cope with the stressors that accompany parenting a child with a disability, and to improve their family's quality of life (Bingham et al., 2012; Glidden et al., 2006; Gray, 2006; Hastings & Taunt, 2002; Pepperell et al., 2018). With CS1 mother, she appeared to cope very well, being quite proactive and positive, always looking to the best professionals and techniques to help further her daughter's development. She appeared to have used a variety of coping mechanisms, including palliative, problem-solving and meaning-based strategies (Beighton & Wills, 2017; Bingham et al., 2012; Graungaard et al., 2011).

Thus in infants with HL-CN, it is not simply the infant's hearing loss that must be addressed, but a myriad of other factors unique to the infant-parent dyad's situation. Through research and investigation, these various factors can be identified, understood and addressed in order to help infants with HL-CN form healthy attachment relationships with their primary caregivers.

**Research question 2: What is the role of service providers in helping facilitate developing attachment relationships developing between infants with HL-CN and their primary caregivers?**

The two case studies showed how service providers helped facilitate attachment relationships between infants with HL-CN and their primary caregivers. This facilitation appeared to be contingent on key factors including the service provider's ability to: understand the attachment process and the different phases; identify and solve factors that may be hindering attachment formation; model and coach attachment and early intervention therapy techniques; build a relationship that goes beyond a typical client-therapist relationship, and act as a secure base for the parent.

*Service providers can identify and solve factors that may hinder the attachment process*

In typically-developing infants, an infant aged 3 months is capable of some self-regulation and can thus seek out interaction with a caregiver, eager to familiarise himself with the caregiver's face, clothing and voice (Bowlby, 1969; Marvin et al., 2018). For infants with HL-CN, their experiences may prevent them from reaching out to their caregiver, such as in CS1, where the infant was dysregulated and could not cope with sensory stimulation, thus would push things and people away. As the CS1 service provider explained: "she [the infant] hadn't got any visual acuity she wasn't focussing at all, so it's very difficult to get attachment when she's not visually fixing on anything". Indeed, an important part of the first attachment phase is the infant's ability to visually track objects, with a preference for the human face (Bowlby, 1969; Marvin et al., 2018). Having identified barriers to forming that attachment, CS1 service provider began to work with both infant and mother to facilitate their attachment relationship. The service provider worked on visual focussing with the infant by giving her lots of time to look at and explore her caregiver's face. Similarly, the CS2 service provider recognised that the CS2 mother was experiencing chronic grief and depression that she believed may have been impacting on the mother's ability to form a deep emotional connection with her infant. Though able to identify this barrier to the attachment process, the CS2 service provider was not able to provide all the emotional and practical support that the mother needed to overcome this barrier.

Another important aspect of facilitating attachment relationships is having a caregiver who is self-regulated, that is, able to manage their emotions. A caregiver who is capable of reflective functioning – an important factor in attachment security – is able to understand that one's behaviours are related to one's emotions (Slade, 2005). Therefore, emotion regulation – the ability to regulate one's own emotions – becomes necessary in order for the caregiver to

reflect on her own behaviours and the behaviours of the infant. CS1 service provider recognised the mother's stress and anxiety:

I have no doubt that she's stressed and that ... she's got that perfectionist streak... she's gotta have everything just right, ... she's the one whose said I'm a perfectionist and she wants it all right, and this constant pressure that she puts on herself.

It was likely that her stress prevented the mother from being completely present and attuned to her infant during play interactions, as was noted by the CARE-Index coder (see Chapter 4 Case Study 1 (Pilot Study)). Furthermore, CS1 service provider described how she needed to be regulated as well:

Yeah you can only have, a parent present in the room when they are actually regulated themselves... And part of our job is to recognise that, and actually check that ... we are actually regulated because, you know, that can actually de-regulate us too.

As CS1 service provider stated, having a parent who was de-regulated could impact on the service provider's ability to self-regulate. Since at this young age infants depend on their caregivers to help them make sense of their emotions, it is crucial that the caregiver can self-regulate and be attuned to the infant's emotional states (Rutherford et al., 2015).

### *Service providers can model and coach attachment and early intervention therapy techniques*

A major difference in the development of attachment between typically-developing infants and infants with HL-CN, is that infants with HL-CN may exhibit atypical or subtle

attachment behaviours, which their caregivers may not readily recognise (Warren & Brady, 2007). For example, in their CARE-Index video, the external coder noted that the CS1 mother was not able to accurately read CS1 infant's cues, and often gave her infant mixed signals. CS1 mother would ask her infant to do something, however she was not able to read her infant and wait for her to complete the action. CS1 mother would then complete the action herself, and thus would miss the infant's cues. As a result, their primary caregivers may not believe their infants as capable of connecting with them. CS1 service provider expressed how she felt that the mother needed to see that her infant was capable of engaging:

I think I had to get that belief for [the mother] that [her infant] could do these things. Um and she [the infant] would do it for me... and then, I'd give [the mother] a turn and [the infant] wouldn't respond in the same way and I could feel [the mother's] kind of, disappointment and the, and the bit of pressure that she's putting herself under.

Since infants with HL-CN are likely to present atypical attachment signals, their parents need professional support and training to learn how to read their infant's signals (Howe, 2006). CS1 service provider described how she would model the play for the mother and allowed them to try it on their own at home, therefore taking the pressure away from the mother. In this way, the service provider was able to help the mother better understand her child, and regulate her emotions, recognising that it was too stressful for her to interact with her infant during therapy sessions. As the videotaped therapy sessions progressed, through the service provider's coaching and modelling, the CS1 mother was able to improve in her use of techniques such as acoustic highlighting and circles of communication. Through an awareness of everyone's emotional needs, the CS1 service provider was able to create an environment where both the mother and infant became comfortable enough to interact and gradually connect with each

other during therapy sessions, thus helping to facilitate that attachment relationship. To a lesser extent, the CS2 service provider was also able to coach the CS2 mother in early intervention techniques, with the videotaped observations showing the mother's improvement in having joint attention and completing circles of communication with her infant.

***Service providers can build a relationship that goes beyond a typical client-therapist relationship***

A key finding from CS1 was the service provider's ability to create a positive rapport with the family, developing the therapist-client relationship into a partnership. CS1 service provider showed her developing relationship with the mother, practising active listening, coaching, modelling, and eventually working in partnership with the mother during therapy sessions. The service provider described:

I feel like [the mother] will often text me a photo or some news, at the weekend, and she'll often text me before she does her family because she knows that she'll get that reaction from me, that she, you know, that shared joy.

This growing partnership was also reflected in the mother's interview responses:

I know that I can contact [the service provider] whenever I needed to, and ... she came to [my infant] in hospital when she had her operation. ... I contacted her, the first person, after her heart surgery, over my family, I contacted her straight after her cochlear implant surgery because I just know that she [the service provider] loves this girl and she's not related to her.

Clearly, the service provider and mother from CS1 had a strong friendship and growing partnership, one that made the mother feel that her own emotional needs were also being met.

In contrast, as was observed in their videotaped therapy sessions, the CS2 service provider did not always take the time to listen to the mother and create a rapport with her to develop their relationship. Caregivers of infants with HL-CN are often emotionally vulnerable, requiring much social and professional support. Thus, it is helpful for professionals to have some understanding of parents' experiences, as well as a cognisance of the coping strategies that may best support parents (Jovanova & Radojichikj, 2013; Dunn et al., 2001; Hassall et al., 2005; Neely-Barnes & Dia, 2008). CS2 service provider was not always able to reach out to the mother and try to understand her issues, which likely prevented her from supporting the mother in a way that was unique to her situation. As a result, the service provider and mother's relationship did not go beyond that of a therapist-client relationship. Rather than instilling in the mother the belief that she could connect and interact with her infant, the service provider often focussed solely on the infant's needs. While CS2 service provider recognised the mother's fear and grief, she struggled with accepting that she could not help the mother cope with her difficulties: "that fear stops her from interacting in a natural playful way". This difference in the two case studies highlighted the significance of the service provider building a relationship with the mother, which appeared to have a positive impact on the developing attachment relationship between CS1 mother and infant.

### *Service providers can serve as a secure base for the caregiver*

For both case studies, risk factors surrounding the infant-caregiver attachment relationship were: the infant's traumatic start to life and complex medical needs; intense emotions experienced by the parents such as anxiety, guilt, depression and prolonged grief;



and, lack of emotional support from the spouse. Still, in CS1, the service provider became a protective factor, serving as a secure base to the mother, which appeared to have helped to facilitate the growing attachment relationship of mother and child. CS1 service provider developed the mother's trust and sought to understand her own attachment needs. The idea of the service provider providing emotional support to the parent can be found in the literature on attachment-based intervention programs (Berlin et al., 2016).

A review of attachment-based interventions revealed that the intervener (or service provider) serving as a secure base for the parent, played some role in all the intervention programs, with interveners providing therapeutic and emotional support for the parents (Berlin et al., 2016). Drawing on Bowlby's (1980) proposal that introducing new attachment relationships was an effective way to change a person's internal working model, Berlin and colleagues (2016) have highlighted the significance that the interventionist can have acting as the parent's secure base. Thus, the partnership between service provider and parent can become its own attachment relationship, facilitating the parent's attachment relationship with their infant. In her follow-up interview, CS1 service provider described her relationship with the mother:

with a mother whose finding it quite stressful and is unsure of her role...it takes time to build up. It's kind of like a duet that we play now. We totally are in tune with each other and totally get each other, but that takes time, it's not something that you can just have initially.

In CS2, the service provider did not serve as a secure base for the mother, and therefore was not able to have a more positive impact on the mother and infant's developing attachment relationship. For example, unlike the CS1 service provider, it appears that the CS2 service

provider was not always able to regulate her emotions, thus was not always attuned to the mother or infant's emotions. Her anxiety, as seen in the videotaped therapy sessions, suggests that the service provider became overwhelmed with the mother's emotions, and unable to self-regulate. The mother's prolonged grief and trauma left her unable to be present during therapy sessions and engage with her infant, or the play interaction that the CS2 service provider would model for her. As the service provider remarked: "I don't think she [the mother] has that...attachment. I don't think she has that deep attachment. I don't think she'll allow herself almost, to form that attachment for the fear, in case she loses him [the infant]". Moreover, when asked if she thought the family would have more difficulties in the future, CS2 service provider responded: "I'm not sure that it's just going to be smooth sailing, because it's not just going to happen without their input." This remark suggests that the CS2 service provider believed that the CS2 parents were not doing enough to support their child's needs. Indeed, the mother's response in this excerpt from her interview suggests much the same:

Researcher: As long as you've got [the service provider], he'll do well won't he?

Mother: Yeah. That's actually kind of good because she manages this part. And I kind of leave it up to her, you know?

The mother's lack of involvement in her infant's therapy perhaps led the service provider to experience anxiety, possibly feeling sole responsibility for the infant's speech and language development. Evidence of the service provider anxiety during their therapy sessions manifested in her misattunement of the infant's emotional needs, hastiness, and the several activities she would go through quickly in just one therapy session.

Furthermore, the CS2 service provider appeared to have a fixed perception of the mother, and believed she was unable to help the mother improve the way she interacted with her child. As remarked in her follow-up interview:

But I also think that she doesn't realise that she could make such a huge difference. And because of that she isn't doing it. I think if she realised she could, maybe she'd try. Or maybe she just can't, maybe she's just not capable of doing that now. ... that he would just gain language and she wouldn't actually have to change her day. She could just engage with him throughout the day. But, she's so busy trying to survive in her own life that she can't be there in that way.

In fact, there are several video-recorded therapy sessions where the service provider was coded as having less joint attention and circles of communication with the infant, in comparison to the mother, suggesting less emotional attunement with the infant. Moreover, results of the CARE-Index revealed that the relationship quality of CS2 mother and infant was not as dire as the service provider described, again suggesting that some of the challenges might be with the service provider (see Chapter 5 Case Study 2).

In CS1, the service provider proved to be a protective factor, perhaps buffering the mother and infant from other risk factors that were impacting on their attachment security. The service provider in CS1 always took the time to listen to the mother, for example, in the first live observation of a therapy session, the service provider took the time to listen to the mother update her on the latest test that her child had undergone, before proceeding with the therapy session. In contrast, in CS2 the service provider was not always attuned to the infant or mother's needs and did not act as a protective factor. For example, in the first videorecorded session, the CS2 mother tried a number of times to interest the service provider in a story she

was telling about a lunch she had with her infant during the week, but with little success. The CS2 service provider appeared too focussed on the early intervention therapy and did not always consider the emotional needs of the mother.

In sum, evidence from the two case studies suggests that the role of the service provider is significant, enough so that the relationship they build with the primary caregiver can act as a protective factor that may buffer the other risk factors caregivers and infants with HL-CN may face when developing their attachment relationship. In Belsky's (1984) determinants of parenting model, social support is one distal factor that impacts on the parent, however the findings of this study suggest that the service provider – as part of that social support – may play a bigger role in supporting the parent-child relationship. The following section discusses the implications of the service provider's role in facilitating attachment relationships, using the study's theoretical framework.

### **Implications for the Study's Theoretical Framework**

Belsky's (1984) determinants of parenting model proposes that a child's characteristics and their parent's personality and psychological resources are the most proximal domains of influence on parenting, and subsequently, the child's attachment relationship and development. Other domains such as marital quality, occupation and social network are considered more distal factors (Belsky, 1984). In infants with hearing loss and complex needs, these factors often accumulate into several risk factors that may more likely lead to attachment insecurity (Belsky & Jaffee, 2006; Fearon & Belsky, 2016). As the present study has shown, an infant's multiple disabilities and difficult, traumatic start to life, the impact of this on the parent's psychological resources and ability to cope, as well as a lack of emotional support from spouses, friends and extended family, can hinder the attachment formation between the infant with HL-CN and their primary caregiver. The attachment process in this population is thus

lengthened, with infants with HL-CN meeting attachment phases at much later ages than typically developing infants. To help facilitate these developing attachment relationships, the role of the service provider has emerged as important, despite the service provider being part of the more distal domain of social network. The service provider can act as a protective factor buffering against the cumulative risk factors (Belsky, 1984; Belsky & Fearon, 2002; Belsky & Jaffee, 2006; Fearon & Belsky, 2016).

Using Bronfenbrenner's (1977; 1979; 2005) bioecological systems model of human development, the connections between the various risk and protective factors surrounding attachment security can be mapped. In this model, "the ecological environment is conceived topologically as a nested arrangement of structures, each contained within the next" (Bronfenbrenner, 1977, p. 514). The infant lies in the centre of these nested systems, with their attachment security and overall development affected by the other systems. According to Bronfenbrenner's (1977; 1979; 2005) bioecological systems model, the relationship between the person's development and their environments is bi-directional. In the current study, the developing infant both impacts and is impacted by factors present in the outer systems. For example, the infant's characteristics (e.g., temperament, impairment) can influence their caregiver's parenting. A difficult temperament or multiple impairments may lead to the parent experiencing depression or anxiety, which may result in less sensitive caregiving and consequently impact the infant's attachment development. Thus, within the microsystem, the parent's personality and psychological resources, marital relations, occupation, and social network are potential risk and protective factors that can influence the infant's attachment security. For example, in CS2, a parent with depressive symptoms was a risk factor, and in CS1, a parent with high anxiety was also considered a risk factor to attachment security.

With the importance of early childhood intervention recognised in the attachment process of children with disability, the child's ECIC may be recognised as an important setting in the

child's microsystem. As seen in CS1, the ECIC had attachment at its foundation and understood the importance of attachment to the child's development. The CS1 mother not only received support from their assigned service provider, but accepted support from the ECIC as a whole system. She made use of opportunities to connect with other families at the ECIC, talk and listen to the ECIC Co-ordinator, and received advice from the other service providers. In contrast, the CS2 mother's relationship with the same ECIC was unidirectional and limited to a client receiving therapy services for her child. Consequently, in CS2, the connection between the child's family and ECIC was not as strong as in CS1. Thus, it appears that it is the strength of the relationship between the ECIC and the child's family that may help determine whether or not the ECIC and service provider can be a protective factor.

The finding of the importance of the service provider, attests to the significance of the mesosystem to the development of the infant with HL-CN. The role of the service provider in helping to facilitate developing attachment relationships between infants with HL-CN and caregivers, appears to rely heavily on the strength of the service provider's relationship with the caregiver. This relationship represents a connection across the nested systems surrounding the infant. In CS1, the service provider was able to provide the emotional and practical support that the CS1 mother needed and helped facilitate the mother's attachment relationship with her infant.

Currently, elements of the NDIS – a structure in the child's exosystem – may be counterproductive to facilitating secure attachment relationships (Alexander et al., 2019). Alexander and colleagues (2019) have found that NDIS elements such as “administrative hurdles”, the eligibility process, long wait times for planning meetings, and selecting a service provider, delay parents from ensuring that their children with disability receive the funds and services that they need (p. 190). Improvements in easing access to the NDIS, reducing the stress of service providers, and ensuring service providers are skilled and educated in early childhood

intervention and attachment need to be made to help foster attachment security in children with disability and their caregivers (Alexander et al., 2019). Such changes in the exosystem may impact on the other nested systems. Though structures in the exosystem do not contain the developing person, they nonetheless “impinge upon or encompass the immediate settings in which that person is found, and thereby influence, delimit, or even determine what goes on there” (Bronfenbrenner, 1977, p. 515). For example, changes in the NDIS may result in more early childhood intervention centres that may be better equipped and supported to provide attachment-focussed early childhood intervention. In turn, more service providers may have a better understanding of how to facilitate developing attachment relationships between children with disability, and their caregivers. Subsequently, such service providers may be able to form strong relationships with caregivers, therefore increasing the strength of the connections between the settings in the child’s microsystem.

Bronfenbrenner defined the macrosystem as “the overarching institutional patterns of the culture or subculture, such as the economic, social, educational, legal, and political systems, of which micro-, meso-, and exo-systems are the concrete manifestations” (1977, p. 515). Bronfenbrenner continued, stating “what place or priority children and those responsible for their care have in such macrosystems is of special importance in determining how a child and his or her caretakers are treated and interact with each other in different types of settings” (1977, p. 515). This statement is of great importance when considering how the nested systems affect the developing attachment relationships of infants with HL-CN, and vice versa. For example, a change in the macrosystem that may help with attachment development, is challenging popularly held cultural and societal beliefs that parenting children with disability is a predominantly negative experience. In her interviews, CS1 mother spoke about the negative perceptions and comments that she experienced from her community, and how they did not engender any sense of support. She also spoke about a lack of understanding from her

extended family and close friends on how they could support her and her family. Better understanding of the lived experiences of parents of children with disability is one area of change that may be helpful in fostering attachment relationships. Changes in these attitudes may influence the parent's social network, with extended family members and friends more readily offering practical and emotional support to parents of children with disability, if they are aware of the positive impact they can have.

Finally, the finding that the attachment process in infants with HL-CN takes longer highlights the importance and impact of the chronosystem. Bronfenbrenner used the term chronosystem to refer to "the person's development of changes (and continuities) over time in the environments in which the person is living" (Bronfenbrenner, 1986, p. 724). Since children with HL-CN are meeting the earlier attachment phases at ages much older than their typically developing peers, it is important that service providers support their families for the duration of the attachment process. Furthermore, it is important that service providers provide support from the earliest time possible, soon after the child's diagnosis. In this way, service providers can identify any barriers to attachment formation and work with the families to facilitate attachment security. Again, changes to the NDIS on the exosystem level may help ensure that service providers can support families of infants with HL-CN as soon as possible.

From an attachment perspective, the service provider serving as a secure base for the parent becomes crucial to helping facilitate the attachment relationship between parent and infant with HL-CN, especially in a parent and infant where a secure base and safe haven are missing. In the present study, it appeared that the service provider who acted as a secure base for the mother, challenged the mother's internal working models, and supported the mother towards healthier mental representations of herself and her infant (Bowlby, 1980; Berlin et al., 2016). This will hopefully lead to a secure mother-infant attachment relationship and improvement in their quality of life.



### **Researcher as Instrument**

As acknowledged from the outset, the researcher was aware of their role of researcher as instrument throughout the current study (see p. 90, 'Researcher as Instrument', Chapter 3 Methodology). The researcher was cognisant of the influence her familiarity and knowledge of the setting and service providers could have on the research study. The researcher therefore put measures in place to ensure she maintained an arms-distance from the participants and findings. In order to maintain the integrity and reliability of data collection and analysis, measures included member checking of interview transcripts, regular reporting of findings to the research supervisors, the use of an external coder blind to the specific objectives of the study, as well as ensuring inter-rater agreement during coding (Multon & Coleman, 2018; Stake, 2010; Yin, 2018). A particularly important measure were the discussions and consultations with Louise, the key informant, whose relationship with the researcher kept a distance between the researcher and the service providers, mothers and fathers. Together Louise and the researcher undertook action research in their exploration of how service providers helped to facilitate developing attachment relationships of infants with HL-CN, within this ECIC (Somekh, 2008).

As was to be expected, the researcher's understanding of attachment was enriched throughout the research study. This understanding was noted by the CS1 mother, who commented in her follow-up interview: "I don't think I realised how much you knew about attachment, and I think you've learnt a lot, since our first interview" and "...just from today's interview, I really think you have more of an understanding about ... what parents are going through". This unanticipated outcome from CS1, reveals a major strength of the researcher as instrument - the notion of the researcher being embedded in the ECIC setting of the research study and somewhat a part of the microsystem (Bronfenbrenner, 1977). Had not this deep relationship with the setting and participants existed, the researcher may not have been able to extract such information, adding to the in-depth nature of the study.

## **Limitations**

The present study was conducted as a mixed-method multiple-case study design, with participants taken from one ECIC located in metropolitan Sydney, Australia. Regarding the conclusions that can be drawn from the study, attention must be paid to the study's design, sample size, representativeness of the sample, and generalisability.

Regarding the study's design, the study originally included three case studies. However, unforeseen factors prevented the research design from including three case studies, and arguably, having only two case studies decreases the replication logic behind the multiple-case study design, and perhaps the strength of the conclusions made (Yin, 2018). Purposive sampling, a form of convenience sampling, makes it impossible to generalise the study's findings to the broader population of infants with hearing loss and complex needs, and their caregivers and service providers (Bryman, 2016; Yin, 2018). Being a convenience sample, the participants from the two case studies were simply available to the researcher, and not necessarily representative of a range of infants with hearing loss and complex needs, and their caregivers and service providers (Bryman, 2016). Undoubtedly, the unique setting from which the participants came from, distinguishes them from this population in general (Bryman, 2016). Therefore, the two-case studies cannot claim to be representative of this population, however small it may be. Thus because of these limits to generalisation, any findings from the study cannot be seen to have broader applicability (Bryman, 2016).

There were a range of data collection and analysis methods that the current study employed and thus reliability needs to be considered. The reliability of the researcher's video-coding analysis method could have been increased had an external coder blind to the study's aims been employed. Also, use of the CARE-Index as a video analysis tool was a first for this specific population, with no method for testing its reliability for infants with HL-CN. The

participants may not have been acting naturally during the videotaping sessions, having altered their behaviour with the knowledge that they were being observed by the researcher, a term known as the reactive effect (Bryman, 2016).

Another possible limitation was the researcher's relationship with the early intervention centre. The researcher had previously conducted a research project at this intervention centre, and had also volunteered regularly at this centre, for the duration of data collection and analysis. The researcher's relationship with the participants, in particular the key informant and service providers, may have unconsciously biased the researcher when conducting data analysis and drawing conclusions (despite measures to maintain transparency). In the same way, the service providers in the two case studies may have altered their behaviour and interview responses as a result of their previous relationship with the researcher. The impact of this should be taken into consideration when interpreting the study's findings.

Finally, the nature of this study was an exploratory one, without pre or post measures. That is, there were no instruments that could definitively measure improvement in the attachment or parenting outcomes of the participants, perhaps as a result of the intervention of the service provider. For example, the *Parenting Stress Index* was only used to measure the primary caregiver's parenting stress levels at the beginning of the study. The study could have benefitted from also using the *Parenting Stress Index* at the end of the study to see if there were any changes in the caregivers' stress levels. Future research in this area could include attachment-focussed intervention and longitudinal studies that track the progress of the infants and primary caregivers, perhaps measuring their attachment security at the beginning and end of the intervention.

## Implications

Understanding the developing attachment relationships of infants with hearing loss and complex needs and their caregivers is an under researched area, yet one with promising implications for the larger research field of attachment, disability, and early childhood intervention. This study is in agreeance with the wider literature on attachment and hearing loss, providing evidence that the presence of more than one risk factor may lead to insecure attachments, and not the presence of hearing loss alone (Spencer & Koester, 2016; Thomson et al., 2011). Findings from this study suggest that the attachment process in this specific population is much longer, with infants reaching the earlier attachment phases at ages much older than that of similar aged peers. There has been no literature to date, however, that suggests that this might be true for all children with multiple or complex disabilities. Factors that may influence this longer process include the infant's complex needs, but more importantly, the primary caregiver's emotional response to these needs. Therefore, what is crucial is the support that is given to the parents of infants with HL-CN, in particular, emotional support that can buffer the other risk factors that surround this population.

While much of the literature on attachment security has looked at the importance of caregiver sensitivity, this study gives support to the role of other factors that lead to attachment security, namely, mind-mindedness (Meins et al., 2001) and reflective functioning (Grienenberger et al., 2005). Parents who experience anxiety, and depression; who are unresolved to their child's diagnosis or are experiencing prolonged or chronic grief are unable to practise sensitive caregiving, reflective functioning or mind-mindedness. They are unable to regulate their own emotions, let alone be attuned to and help manage the emotions of their child. The present study proposes that the infant's early childhood intervention service provider can provide emotional support to the parent by building a relationship of trust that goes beyond the therapist-client relationship. From here, the service provider can become a protective factor

against the other risk factors in the infant-parent relationship. Specifically, Case Study 1 has shown that this trustworthy and supportive partnership between service provider and parent can exist and can help facilitate the attachment relationship between the parent and infant with HL-CN.

### **Future Research**

This role that the service provider plays in facilitating the attachment relationship between caregiver and infant with hearing loss and complex needs is one avenue of research that could be pursued. Role release is a construct that occurs within educational or therapeutic teams, yet it is interesting that it was observed to occur between service provider and parent within these case studies. Further research into the mechanisms behind this exchange and how it can positively affect the infant-caregiver attachment relationship could be helpful. Also, the development of early childhood intervention models that are founded on attachment theory, as was the case with this ECIC, is another area of research worth pursuing. Research has shown the effectiveness of attachment-based interventions in improving the behaviours and attachment security of at-risk parent-infant dyads (Berlin et al., 2016). However, participants in these intervention programs have not targeted infants with disabilities and their parents, except for the *Video-feedback to promote Positive Parenting for Children with Autism* (VIPPAUTI) (Poslawsky et al., 2014). Thus, early childhood intervention models that adopt attachment-based interventions that have proven effective (Berlin et al., 2016; Poslawsky et al., 2014) may benefit the population of infants with HL-CN, and their caregivers.

The current study was limited in its exploration of the secondary caregiver's role in the infant's developing attachment relationships. The field of attachment theory and early intervention would greatly benefit from more studies that investigate how the infant and secondary caregiver's attachment relationship develops, and if the service provider can also

help facilitate this relationship. Finally, the mother of CS1 appeared to have been empowered as a result of the study. Though she admitted the study was “confronting” and “long”, she willingly captured a video of herself speaking about the study process to other parents, in hope that other parents would find it “beneficial” and therefore help their own understanding and experiences of parenting an infant with hearing loss and complex needs. This unanticipated outcome of the study speaks to the value of the study and its value to the parents who participated and thus gained a sense of empowerment. Further research into this may also benefit the field of early intervention.

## **Conclusion**

The present study has sought to gain a deeper understanding of the developing attachment relationships of infants with hearing loss and complex needs, and their caregivers. Guided by Belsky’s (1984) determinants of parenting model, within a bioecological systems theory framework (Bronfenbrenner, 1979), the research study was able to explore the factors surrounding the attachment relationship of this niche population.

A mixed-methods, two-case study design revealed that in the two infants with HL-CN, the attachment process takes longer, with the two infants reaching the earlier phases of attachment at ages much later than typically-developing infants. Furthermore, it was found that an accumulation of risk and protective factors influenced the likelihood of secure attachments. Not one risk factor alone determined a trajectory towards insecure attachment, rather multiple factors, including the infant’s hearing loss and other disabilities, the impact of this on the parent’s personality and psychological resources, and the strength of the parent’s other sources of support. Significantly, the infant’s service provider was identified as being a powerful protective factor for the infant and parent, providing not only early intervention therapy for the infant, but also emotional and practical support for the parent.

The construct of 'self-regulation' emerged as important, with therapists stating that having a parent who was de-regulated present in the early intervention therapy room as quite unhelpful. Indeed, the study's outcomes showed that if a parent incapable of emotion regulation was present during the therapy sessions, the service provider was unable to self-regulate and therefore provide enough emotional and practical support to either parent or infant. Though presenting findings from only two-case studies, the depth and breadth of the case studies give some evidence that the attachment process of infants with HL-CN and their caregivers can be complex, involving various factors, hence supporting the title 'infants with hearing loss and *complex* needs'. It requires understanding of the unique situations that these families find themselves in, and the dedication of the service providers privileged enough to work with them, to ensure that the child and their family live the quality of life they deserve.

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## Appendix A

### Participant Information Sheet – Service Provider



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#### Understanding Attachment: Young Children with Additional Needs

#### PARTICIPANT INFORMATION STATEMENT

##### (1) What is this study about?

The aim of the study is to investigate the developing attachment relationships of young children with hearing loss and complex, additional needs, and their caregivers. Young children with hearing loss and additional needs often receive varied services to support their learning and development. A key part of any child's development is forming secure relationships with their caregivers. This study seeks to examine how young children form attachments with their caregivers; in particular, how attachment develops between children with additional needs and their caregivers. The study also seeks to enhance the services and educational programmes of families with children with additional needs.

You have been invited to participate in this study because we have recognised the pivotal role that service providers play in the lives of young children with additional needs. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. So it's up to you whether you wish to take part or not.

A \$50 retail gift card will be given to you as gratitude for your participation.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read

- ✓ Agree to take part in the research study as outlined below
- ✓ Agree to the use of your personal information as described.

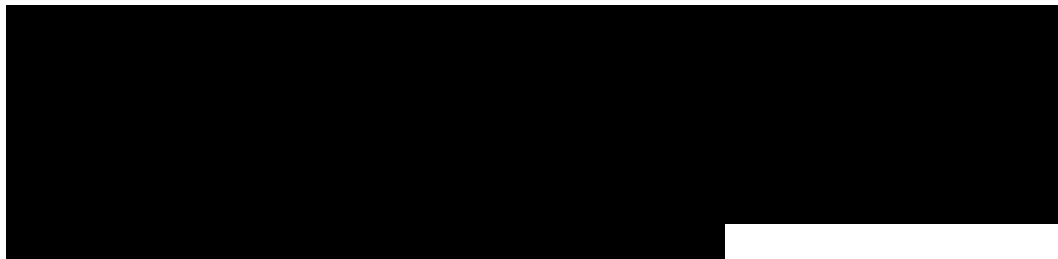
You will be given a copy of this Participant Information Statement to keep.

## **(2) Who is running the study?**

The study is being carried out by the following researchers:

- David Evans, Associate Professor of Special Education at The University of Sydney
- Cathy Little, Lecturer, Special Education at The University of Sydney
- Samantha Bernardo, PhD Student at The University of Sydney

The study is being conducted by Ms Samantha Bernardo, PhD Student, and will form the basis for her thesis, which is a requirement of the degree of Doctor of Philosophy at The University of Sydney. Ms Bernardo will work under the supervision of Dr David Evans and Mrs Cathy Little.



## **(3) What will the study involve?**

A key focus of the study is the attachment between caregivers and their child. Therefore, you, the caregiver and their child will be asked to take part in video recording of therapy sessions at [REDACTED]. The initial part of the study seeks to investigate your understanding of attachment, early intervention and the caregiver and child you are working with. You will be asked to participate in an interview on such issues, as well as provide some evidence of your qualifications as a service provider in early intervention. We are also asking that you participate in an interview at the end of the study.

We also wish to examine the relationship you have with the child and their caregiver over time. We would like to video the caregiver and child together, and you, their service provider. The video recorded data will assist the researcher's undertaking a detailed analysis of the interactions between child, caregiver and service provider. Findings from the results will be included in the thesis.

## **(4) How much of my time will the study take?**

Due to the nature of early childhood intervention, and also based on the pilot case study, the study will take anywhere from 22 weeks to 30 weeks. You will be interviewed for approximately one hour at the beginning of the study; this interview will be audio-recorded for later analysis. We then plan to collect a series of video observations of you, the caregiver and their child engaging during early intervention sessions. We plan to collect this video-recorded data 5-6 times, over a period of six months. After this period of video recording is completed, we will conduct a follow-up interview that will take approximately one hour.

**(5) Who can take part in the study?**

Participants who can take part in this study include young children with additional needs, their primary caregiver (i.e., the person having cared for the child most since birth [e.g. mother/father/guardian]), family and primary service providers at [REDACTED]

**(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney or at [REDACTED]

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by notifying the chief investigator in written form (email or letter). If you do choose to withdraw from the study you are required to help the researchers find an appropriate participant/s in replacement of your self.

During the study, you are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

If you decide to withdraw from the study, we will not collect any more information from you. Please let us know at the time when you withdraw what you would like us to do with the information we have collected about you up to that point. If you wish your information will be removed from our study records and will not be included in the study results, up to the point that we have analysed and published the results.

**(7) Are there any risks or costs associated with being in the study?**

This study presents a low-risk to the therapists or service providers, as the focus of the study is mostly on the mother and child. Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

**(8) Are there any benefits associated with being in the study?**

There are potential benefits to the broader community of early childhood intervention and childhood disability. The participants (mother and child) are also expected to benefit from the early intervention. This research study may also benefit the [REDACTED] in terms of research supporting its practices and curriculum. Apart from this, we cannot guarantee or promise that you will receive any direct benefits from being in the study.

**(9) What will happen to information about me that is collected during the study?**

You will be required to participate in interviews, which will be audio recorded, and transcribed verbatim to be analysed, and video recorded during therapy sessions with the mother-child dyad, with participants' interactions and behaviours to be analysed. Analysis will be based on an attachment theory framework. Results from this data will be

published in the PhD student's thesis, as well as any possible journal publications and conference presentations. All personal information will be kept confidential. The data will be stored in the chief investigator's office for a minimum of 20 years or until participants are 25 years of age (as is the requirement for research involving children), after which the data will be disposed of appropriately.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

We will keep the information we collect for this study, and we may use it in future projects. We don't know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

**(10) Can I tell other people about the study?**

Yes. If they wish to know more about the project please have them contact Ms Bernardo.

**(11) What if I would like further information about the study?**

When you have read this information, Samantha Bernardo will be available to discuss it with you further and answer any questions you may have. She may be reached via email at sber4601@uni.sydney.edu.au. If you would like to know more at any stage, please feel free to contact Dr Evans on 9351 8463.

**(12) Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one page lay summary. This summary will be explained and contextualised by Ms Bernardo, in person, should you have further questions. You will receive this feedback after the study is finished.

**(13) What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [2014/790]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

## Appendix B

### Participant Information Sheet – Parent/Caregiver



**Faculty of Education  
and Social Work**

ABN 15 211 513 464

**DAVID EVANS PhD**  
*Associate Professor of Special Education*

Room 707  
Education Building | A35  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9351 8463  
Facsimile: +61 2 9351 2606  
Email: david.evans@sydney.edu.au  
Web: <http://www.sydney.edu.au/>

#### Understanding Attachment: Young Children with Additional Needs

#### PARENTAL INFORMATION STATEMENT Primary Caregiver

**(14) What is this study about?**

The aim of the study is to investigate the developing relationships of young children with additional needs with their caregivers. Young children with additional needs often receive varied services to support their learning and development. A key part of any child's development is forming secure relationships with their caregivers. This study seeks to examine how young children form attachments with their caregivers; in particular, how attachment develops between children with additional needs and their caregivers.

A service provider has nominated you and your child as potential participants in this study. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you and your child want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. So it's up to you whether you wish to let yourself and your child take part or not.

A \$50 retail gift card will be given to you as gratitude for your participation.

By giving your consent you are telling us that you:

- ✓ Understand what you have read
- ✓ Agree for you and your child to take part in the research study as outlined below
- ✓ Agree to the use of yours and your child's personal information as described.



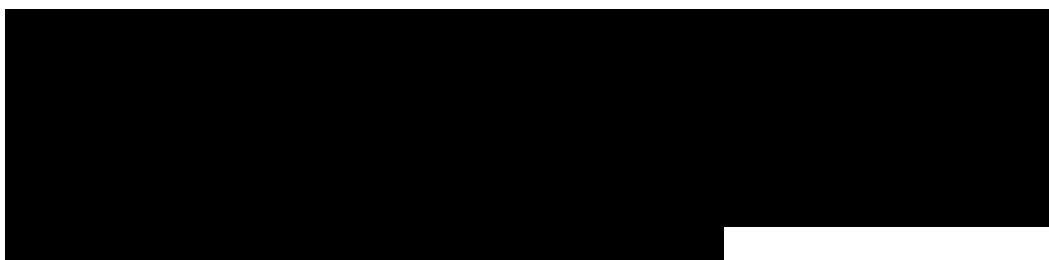
You will be given a copy of this Parental Information Statement to keep.

**(15) Who is running the study?**

The study is being carried out by the following researchers:

- David Evans, Associate Professor of Special Education at The University of Sydney
- Cathy Little, Lecturer in Special Education at The University of Sydney
- Samantha Bernardo, PhD Student at The University of Sydney

The study is being conducted by Ms Samantha Bernardo, PhD Student, and will form the basis for her thesis, which is a requirement of the degree of Doctor of Philosophy at The University of Sydney. Ms Bernardo will work under the supervision of Dr David Evans and Mrs Cathy Little.



**(16) What will the study involve?**

A key focus of the study is the attachment relationship between you and your child. Therefore, you and your child will be asked to take part in video recording of therapy sessions at the early childhood intervention centre you attend. The initial part of the study seeks to develop an understanding of you and your child (e.g., examine medical records confirming your child's diagnosis, interview with yourself and other service providers). We will also ask you to complete two questionnaires: the Parenting Stress Index (Abidin, 2012), and the Experiences in Close Relationships Scale (Fraley, Waller, & Brennan, 2000). We are also asking that you participate in an interview at the end of the study.

We also wish to examine the relationship you have with you child over time. We would like to video you and your child together, and with your service providers. The video recorded data will assist the researcher's undertaking a detailed analysis of the interactions between yourself and your child. Findings from the results will be included in the thesis.

**(17) How much time will the study take?**

Due to the nature of early childhood intervention, and also based on the pilot case study, the study will take anywhere from 22 to 30 weeks. You will be asked to complete the Parenting Stress Index (Abidin, 2012), which will take about 20-30 minutes. Following this, you will be interviewed for approximately one hour at the beginning of the study; this interview will be audio-recorded for later analysis. At the completion of this interview, you will be asked to take home, complete, and return the Experiences in Close Relationships Scale (Fraley, Waller, & Brennan, 2000).

We then plan to collect a series of video observations of you, your child and service provider engaging during early intervention sessions. We plan to collect this video-recorded data 5-6 times, over a period of six months. A part of each video-recording session will involve only yourself and your child, without the service provider in the room. After this period of video recording is completed, we will conduct a follow-up interview that will take approximately one hour. Finally, we also ask for your spouse/partner to participate in the study through an interview.

**(18) Who can take part in the study?**

Participants who can take part in this study include young children with additional needs, their primary caregiver (i.e., the person having cared for the child most since birth [e.g. mother/father/guardian]), family and the primary service provider at [REDACTED].

**(19) Does my child have to be in the study? Do I have to be in the study? Can we withdraw from the study once we've started?**

Being in this study is completely voluntary and you and your child do not have to take part. Your decision whether to let them participate will not affect your/their relationship with the researchers or anyone else at the University of Sydney or [REDACTED], now or in the future.

If you decide to let you and your child take part in the study and then change your mind later, you are free to withdraw from the study at any time. You can do this by notifying the chief investigator in written form (email or letter).

If you and your child withdraw from the study, we will not collect any more information. Please let us know at the time when they withdraw what you would like us to do with the information we have collected up to that point. If you wish, the information will be removed from our study records and will not be included in the study results, up to the point that we have analysed and published the results.

**(20) Are there any risks or costs associated with being in the study?**

This study presents a low-risk to the primary caregivers and their children, as data collection procedures are non-invasive. Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

**(21) Are there any benefits associated with being in the study?**

There are potential benefits to the broader community of early childhood intervention and childhood disability. You and your child may benefit from the study upon reflection of your interaction and behaviour towards your child. This research study may also benefit the [REDACTED] in terms of research supporting its practices and curriculum. Apart from this, we cannot guarantee or promise that you will receive any direct benefits from being in the study.

**(22) What will happen to information that is collected during the study?**

Your child will be video recorded during therapy sessions with yourself and the service provider, with participants' interactions and behaviours to be analysed. Analysis will be based on an attachment theory framework. Results from this data will be published in the PhD student's thesis, as well as any possible journal publications and conference

presentations. All personal information will be kept confidential. The data will be stored in the chief investigator's office for a minimum of 20 years or until participants are 25 years of age (as is the requirement for research involving children), after which the data will be disposed of appropriately.

By providing your consent, you are agreeing to us collecting personal information about your child for the purposes of this research study. Their personal information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your child's information will be stored securely and their identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but your child will not be individually identifiable in these publications.

We will keep the information we collect for this study, and we may use it in future projects. We don't know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

**(23) Can I or my child tell other people about the study?**

Yes. If they wish to know more about the project please have them contact Ms Bernardo.

**(24) What if we would like further information about the study?**

When you have read this information, Samantha Bernardo will be available to discuss it with you further and answer any questions you may have. She may be reached via email at sber4601@uni.sydney.edu.au. If you or your child would like to know more at any stage, please feel free to contact Dr Evans on 9351 8463.

**(25) Will we be told the results of the study?**

You and your child have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one page lay summary. This summary will be explained and contextualised by Ms Bernardo, in person, should you have further questions. You will receive this feedback after the study is finished.

**(26) What if we have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [2014/790]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you (or your child) are concerned about the way this study is being conducted or wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)

- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

## Appendix C

### Child's Medical and Audiological Events - Case Study 1

Date/Age	Medical/audiological Event	Place
<p>[REDACTION]</p> <p>Birth</p>	<p>Child's mother was induced at 39 weeks GA due to child's known heart defects – ventricular septal defect (VSD) and coarctation of the aorta; antenatal diagnosis, confirmed shortly after birth.</p> <p>Diagnosed with suspected 22q deletion (incorrect diagnosis).</p> <p>Required CPAP for 5 minutes. Naso-gastrically tube fed.</p> <p>Failed initial newborn hearing screen.</p>	Hospital
<p>19/12/ [REDACTION]</p> <p>18 hours old</p>	Heart surgery - Coarctation of the aorta repaired.	Hospital
<p>20/12/ [REDACTION]</p> <p>One day old</p>	Failed extubation post heart operation. Ventilated for 24 hours. Endoscopy showed swollen vocal cords, stridor, and 'tugging of the neck'.	Hospital
<p>28/12/ [REDACTION]</p>	Abdominal ultrasound showed moderate left pelvicalyceal separation.	
	Hypoglycaemia where the child stopped breathing. Hospitalised for three weeks.	NICU
<p>2/01/ [REDACTION]</p>	Facial nerve palsy, MRI showed no cause. Recovered after one month.	
<p>13/01/ [REDACTION]</p> <p>Three weeks old</p>	<p>Child correctly diagnosed with CHARGE Syndrome, with a likelihood of hearing and vision loss. CT Petrous Bones – marked abnormality of the inner and middle ears.</p> <p>Eye test confirmed a retinal coloboma in her right eye.</p> <p>Issues with her calcium levels, went from low to high, and a low calcium formula exacerbated her lactose intolerance that resulted in bloodstained stools.</p>	Hospital
<p>16/01/ [REDACTION]</p>	Discharged:	

Four weeks old	<ul style="list-style-type: none"> <li>- Diuretics for child's heart problems.</li> <li>- Needed ongoing assessment of her growth and development as she was only receiving 75% of the nutrition she needed.</li> <li>- Continued to have stridor with intermittent mild work of breathing at rest.</li> <li>- Three-month appointment with Geneticist upon discharge.</li> <li>- Visits to feeding team every 6-8 weeks. Child would vomit after tube feeding as she was being fed too much, though the amount was advised by the feeding clinic team. Mother decided to reduce tube feeding and increase oral feeding.</li> </ul>	Feeding Clinic
22/01/ [REDACTED]	Weight gain review with General Paediatrician Team, Gastro specialist and Dietician.  Eye review.	Hospital  Eye clinic in hospital
23/01/ [REDACTED]  Five weeks old	Audiology follow up.	Hospital
27/01/ [REDACTED]	Blood tests for immunology.	Immunology clinic in hospital
29/01/ [REDACTED]  Six weeks old	Hip ultrasound. Wore a hip harness for five weeks due to dislocated hips.	Imaging clinic in hospital
13/02/ [REDACTED]  Eight weeks old	Heart review.  Diagnostic testing for audiology – Brainstem Evoked Response Audiometry (BERA). Bilateral profound hearing loss.	Hospital  Hearing clinic in hospital
14/02/ [REDACTED]	Transient Evoked Otoacoustic Emissions (TEOAE) testing in child's right ear. Audiogram showed absent responses.  Audiologist confirmed child had a bilateral, permanent sensorineural hearing loss of 40dB HL or greater, and indicated that the audiogram showed child's hearing levels to be: Left 120dB HL, Right 120dB HL.	Hearing clinic
18/02/ [REDACTED]	Renal ultrasound.	Hospital

19/02/ [REDACTED]	Heart review.	Hospital
24/02/ [REDACTED]	Facial nerve palsy review.	Hospital
27/02/ [REDACTED] Ten weeks old	Fitted with bilateral Siemens Motion Micon 5 P behind the ear hearing aids.	Hearing clinic
29/05/ [REDACTED] Five months old	Cortical Auditory Evoked Potential (CAEP) testing (measures brain's responses to sound).  Child lost her right hearing aid therefore test only conducted with left hearing aid. Test showed no responses to mid- and high-frequency sounds - /g/ and /t/ respectively. Thus child received limited benefit from wearing her left hearing aid, and would possibly benefit from cochlear implantation.	Hearing clinic.
May [REDACTED]	Laryngomalacia.	Hospital
12/06/ [REDACTED] Six months old	Heart surgery – closure of VSD.	Hospital
26/06/ [REDACTED] Six months old	CAEP testing for child's right ear. Tests showed response only for high-frequency sound, /t/, despite recent MRI report that indicated absent right auditory nerve. Results indicated child received limited benefit from wearing her right hearing aid.	Hearing clinic
30/06/ [REDACTED]	Feeding assessment with new feeding team. Summary and recommendations indicated that the child had a challenging start to oral feeding. She was tube fed since birth due to fatigue from her heart condition. Post her heart surgery, the mother was advised to ween the child off being tube fed and start her on oral feeding. However the mother had little support in this goal and thus sought out a new feeding team. In sum, the new team advised the mother to feed her child based on her hunger cycles, allowing demand feeding during the day (bottle and solids) and tube top ups overnight.	Feeding clinic in a different state.

September 20 <sup>REDACTED</sup> Nine months old	Cochlear implantation surgery.	
27/11 <sup>REDACTED</sup> 11 months old	VROA testing. Consistent reliable responses: 1kHz = 40dB SPL (above the speech spectrum can access even the softer components of sound); 4kHz = 50db SPL (needs sounds to be moderate intensity to access them).	Audiology clinic
19/12 <sup>REDACTED</sup> 12 months old	Mapping for cochlear implant.	Early childhood intervention centre
6/02 <sup>REDACTED</sup> 14 months old	Mapping for cochlear implant. Investigation into whether a second cochlear implant for child's right ear begun. Hearing aid on right ear enhanced child's ability to localise sound, despite child's abnormal right auditory nerve.	Early childhood intervention centre
18/06 <sup>REDACTED</sup> 18 months old	VROA testing. At 4kHz = 30dB, 20dB poorer than child's test in November 2014. Mother noted child twitched at high frequency sounds like /s/ and /sh/ which could have contributed to these results.  Child's audiogram showed a hearing range of 50dB-70dB.	Audiology clinic



## Appendix D Interview Schedule



**Faculty of Education  
and Social Work**

ABN 15 211 513 464

**DAVID EVANS PhD**  
*Associate Professor of Special Education*

Room 707  
Education Building| A35  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9351 8463  
Facsimile: +61 2 9351 2606  
Email: david.evans@sydney.edu.au  
Web: <http://www.sydney.edu.au/>

### Understanding Attachment:

#### Young Children with Additional Needs

### INTERVIEW SCHEDULE

Semi-structured interview with open-ended questions that are linked to the literature review.

#### Caregivers

*The focus of this interview is on your relationship with your child, and any factors surrounding this relationship. I'd like the interview to be as naturalistic as possible, and more like a conversation. I'll ask some guiding questions here and there, but on the whole I'm interested in your story, and your experiences. Remember that you do not have to answer any questions that you do not want to.*

1. Caregiver's background:

Age, gender, marital status, education, occupation, family, socioeconomic status (income p.a.), postcode, cultural background

*Let's start by telling me a bit about yourself. What is your current occupation? Your cultural background? Are you married? What are some hobbies or recreational activities that you like to do? ...*

2. Caregiver's experience of parenting:

Experience during pregnancy- expectations. Challenges, stresses, child's hospitalisations/operations, child's issues/needs, Emotional trauma, experience of child's diagnosis, spouse's experience of parenting and coping.

*What has been your experience of parenting so far? How has your spouse coped?*

*What are some of the challenges and stresses you have experienced so far? What would be the number one challenge/stress you have faced?*

*How do you overcome these challenges? How do you cope with these stresses?*

*Do you feel that you are well supported? - By your spouse? Extended family? Friends? Community?*

*Describe your relationship with your spouse.*

*Do you receive and funding and/or respite?*

*Do you feel that you have enough access to information about early intervention services, therapies and your child's disability? What was your experience at the time of your child's diagnosis?*

3. Caregiver's child:

Age, gender, temperament, characteristics, disability/condition, age at diagnosis

*Tell me about your child- what do you like about him/her? What are his/her favourite things to do?*

*Is he/she easy-going? A bit fussy?*

4. Caregiver's experience at the early intervention centre:

General atmosphere of centre. Services provided. Experience and relationship with their service provider. Strategies the parent has observed.

*Do the service providers at the centre help you to address any factors that may impact on your relationship with your child?*

*What are some of the strategies that your service provider uses, which you think are helpful or not helpful to your child?*

5. Caregiver's relationship with child:

*How would you describe your relationship with your child? Do you feel close to your child? Do you feel that you understand him/her? Do you feel that he/she understands you?*

6. Caregiver's understanding of attachment:

*What do you know about attachment?*

7. Caregiver's hopes and concerns for their child:

*What are your future hopes for your child? Do you have any concerns for your child? E.g. preschool, schooling etc.*

## Service Providers

*The focus of this interview is on you as a service provider to a young child with additional needs and their caregiver/s, your relationship with this child and caregiver, as well as your understanding of attachment. I'd like the interview to be as naturalistic as possible, and more like a conversation. I'll ask some guiding questions here and there, but on the whole I'm interested in your story, and your experiences. Remember that you do not have to answer any questions that you do not want to.*

### 1. Service provider's background:

*Let's start by you telling me about yourself. How long have you been in the field of early intervention? Where did you gain your qualifications? What has it been like working in this field? How long have you worked at this early intervention centre?*

### 2. The early intervention models used at the centre:

*How would you describe the early intervention models and practice at this centre?*

### 3. Service provider's attitudes/beliefs about working with children with additional/complex needs:

*What has been your experience working with children with additional needs? In general, what do you think about the experiences of families with a child with additional needs?*

*What do you think are some of the challenges/stresses that such families face?*

*What do you think families/parents do to overcome challenges/stresses? Coping strategies?*

### 4. Service provider's relationship with the caregiver and child:

*How long have you worked with this particular caregiver and child? How would you describe your relationship with them?*

5. Service provider's knowledge of attachment and attachment theory:

*What do you know about attachment and attachment theory? Do you think the way an adult has been parented impacts on their own parenting?*

*What are the possible factors that may affect the attachment relationship?*

*What do you think is the impact of a child's disabilities on their attachment relationships?*

*What do you perceive is the impact of the parent/caregiver on the attachment relationship?*

6. Parents' knowledge of the importance of attachment.

*What do you think parents know about attachment?*

7. The service provider's belief of their practice as informed by attachment theory.

*Do you think that your practice is informed by attachment theory? Describe any experiences you have had with families where you think attachment has played a crucial part in the intervention.*

## Appendix E

### Video coding scheme

<u>Code category:</u>	
Code	Description
<b><u>Attachment:</u></b>	<b>Codes that describe the bi-directional emotional relationship between a child and their caregiver</b>
Self-regulation	Child behaviour that functions to regulate or soothe one's emotions e.g. Child sucks thumb
Proximity-seeking	Child exhibits proximity-seeking behaviour either to Mother or Service provider e.g. moves closer, cries
Face to face (ranged event)	Child shares a face to face interaction with either Mother or Service provider
Sensitivity	Mother or Service provider responds appropriately and sensitively to Child's proximity-seeking behaviours, emotions and other signals e.g. comforts and embraces Child when Child is upset
Attunement	Mother or Service provider recognises Child's emotions and signals e.g. when Child is visibly upset, voices the Child is upset
<b><u>DIR/Floortime:</u></b>	<b>Codes that describe key elements of the DIR/Floortime therapy strategy</b>
Child initiates	Child initiates interaction e.g. picks up a rattle and starts shaking it
Follows child's lead	Mother or Service provider follow the Child's interest or interaction e.g. Child picks up rattle and starts shaking it, Mother also picks up a rattle and starts shaking it
Brings child into shared world	Mother or Service provider build on or challenge interaction with Child e.g. Child is shaking a rattle, Service provider shakes rattle and bangs on a drum
Turn-taking	Child and Mother or Child and Service provider take turns in an interaction or activity e.g. Child shakes rattle, then Mother shakes rattle = one turn-taking round
Joint attention (ranged event)	Child and Mother or Child and Service provider are engaged together in an activity, with or without a toy e.g. Service provider and Child playing with rattles
<b><u>Auditory-verbal therapy:</u></b>	<b>Codes that describe auditory-verbal therapy techniques</b>
Child vocalises	Child makes a vocalisation in response to, or towards Service provider or Mother e.g. babbles, cries, laughs or says a word
Child signs	Child signs a word in sign language in response to, or towards Service provider or Mother
Child gestures	Child gestures or moves body in response to, or towards Service provider or Mother e.g. reaches for Mother's hand, reaches for toy/object, moves from a face down position to an upright position
Acoustic highlighting	Service provider or Mother varies quality of their voice (pitch, tone, rhythm, speed) to emphasise a word or phrase for Child
Ling sounds	Service provider or Mother use a ling sound e.g. 'aah', 'mm'
Motherese	Service provider or Mother speak in a sing-song, high-pitched voice to Child. Also called 'infant-directed speech', and is typically used by adults when speaking to infants
Singing	Service provider or Mother sing

Pausing and waiting (ranged event)	Service provider or Mother use of pauses and waiting when interacting or conversing with Child
Signs	Service provider or Mother signs
Hand cues	Use of hand cues to help Child listen
Amplification devices	Maintenance of Child's amplification device e.g. Service provider adjusts Child's cochlear implant when it falls off
<b><u>Interactional elements:</u></b>	<b>Codes that describe other elements observed in interactions between Child and Service provider or Mother</b>
Silly fun	ability to be silly, playful and fun
Affect	use of one's affect (face, body and voice) to engage Child e.g. exaggerated facial expressions to show happiness, being cross etc.
Praise	Use of praise
Instruction	instructing or teaching child to do something
<b><u>Other therapy codes:</u></b>	<b>Codes that describe other types of therapy used</b>
Sensory-integration therapy	any therapy techniques that help the child with sensory processing issues
Occupational therapy	any therapy techniques that help the child function, e.g. fine motor skills
Feeding therapy	any techniques that address child's feeding issues
Vision	any techniques that address a child's vision impairment issues
Physiotherapy	any therapy techniques that focus on helping the person with mobility and stability e.g. gross motor skills
Balance	specific physiotherapy techniques to improve child's balance
Strength	specific physiotherapy techniques to improve child's strength
Interdisciplinary approach	Use of therapy from various disciplines to support the child's needs;
Role release	when one professional releases discipline-specific skills to another professional, usually by teaching or modelling, in order for that professional to carry out therapy strategies not in their own discipline
<b><u>Service provider and Mother relationship:</u></b>	<b>Codes that describe the relationship of the Service provider and Mother</b>
Triadic relationship	three-way relationship between caregiver, child and service provider during therapy e.g. Service provider supports play interaction between Mother and Child
Family-centred therapy	therapy that is centred on the family's needs and goals; evidence of Service provider meeting or incorporating Mother's goals for the Child
Modelling	service provider modelling therapy techniques and strategies for the caregiver and/or teaching and discussing therapy techniques
Parent doing therapy (prompted)	Parent does therapy with Child after being prompted by the Service provider

Parent doing therapy (unprompted)	Parent does therapy with Child without being prompted by the Service provider
Sympathy – empathy	service provider providing sympathy, understanding or affirmation towards the caregiver e.g. listening to concerns, acknowledging Child's progress



## Appendix F Ethics Approval



**Research Integrity**  
Human Research Ethics Committee

Thursday, 23 October 2014

Assoc Prof David Evans  
Education Faculty Admin; Faculty of Education & Social Work  
Email: david.evans@sydney.edu.au

Dear David

I am pleased to inform you that the University of Sydney Human Research Ethics Committee (HREC) has approved your project entitled "**An inquiry into understanding attachment and young children with additional needs.**".

Details of the approval are as follows:

**Project No.:** 2014/790  
**Approval Date:** 23 October 2014  
**First Annual Report Due:** 23 October 2015  
**Authorised Personnel:** Evans David; Bernardo Samantha; Little Cathy;

**Documents Approved:**

Date Uploaded	Type	Document Name
6/06/2014	Other Instruments/Tools	Instruments
1/08/2014	Participant Consent Form	Participant Consent Form (Parent/Carer)
1/08/2014	Participant Consent Form	Participant Consent Form (Service Provider)
12/10/2014	Participant Info Statement	PIS ParentCarer v4-1 2014-790
12/10/2014	Participant Info Statement	PIS Provider v4-1 2014/790

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

**Condition/s of Approval**

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.
- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

Research Integrity  
Research Portfolio  
Level 6, Jane Foss Russell  
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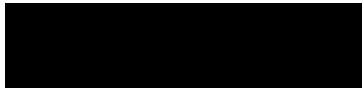
- Any changes to the project including changes to research personnel must be approved by the HREC before the research project can proceed.
- Note that for student research projects, a copy of this letter must be included in the candidate's thesis.

**Chief Investigator / Supervisor's responsibilities:**

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.
2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely



**Dr Stephen Assinder**  
**Chair**  
**Human Research Ethics Committee**

**This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.**

## Appendix G

### Participant Consent Form – Parent/Caregiver



Faculty of Education  
and Social Work

ABN 15 211 513 464

**DAVID EVANS PhD**  
*Associate Professor of Special Education*

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Education Building | A35  
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#### Understanding Attachment: Young Children with Additional Needs

#### PARENT/CARER CONSENT FORM

I, ..... [PRINT PARENT'S/CARER'S NAME], consent to my child ..... [PRINT CHILD'S NAME] participating in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what my child will be asked to do, and any risks/benefits involved.
- ✓ I have read the Information Statement and have been able to discuss my child's involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary and my child does not have to take part. My decision whether to let them take part in the study will not affect our relationship with the researchers or anyone else at the University of Sydney or [REDACTED] now or in the future.
- ✓ I understand that my child can withdraw from the study at any time.
- ✓ I understand that personal information about my child that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I

understand that information about my child will only be told to others with my permission, except as required by law.

- ✓ I understand that the results of this study may be published, and that publications will not contain my child's name or any identifiable information about my child.

I consent to:

- |   |     |                          |    |                          |
|---|-----|--------------------------|----|--------------------------|
| • <b>Audio-recording of my child</b>                          | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Video-recording of my child</b>                          | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Photographs of my child</b>                              | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Receiving feedback about my child's personal results</b> | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

**Would you like to receive feedback about the overall results of this study?**

YES  NO

If you answered **YES**, please indicate your preferred form of feedback and address:

Postal: \_\_\_\_\_  
\_\_\_\_\_

Email: \_\_\_\_\_

**Parent's/carer's signature:**

.....  
**Signature**

.....  
**PRINT name**

.....  
**Date**

**Understanding Attachment:  
Young Children with Additional Needs**

**PARTICIPANT CONSENT FORM**

I, ..... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney or [REDACTED] now or in the future.
- ✓ I understand that I can withdraw from the study at any time.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- ✓ I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I consent to:

- |   |     |                          |    |                          |
|---|-----|--------------------------|----|--------------------------|
| • <b>Audio-recording</b>                      | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Video-recording</b>                      | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Photographs</b>                          | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Reviewing transcripts</b>                | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Being contacted about future studies</b> | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

- Receiving feedback about my personal results      YES         NO

Would you like to receive feedback about the overall results of this study?

YES         NO  

If you answered **YES**, please indicate your preferred form of feedback and address:

Postal: \_\_\_\_\_

\_\_\_\_\_

Email: \_\_\_\_\_

.....  
**Signature**

.....  
**PRINT name**

.....  
**Date**

## Appendix H

### Experiences in Close Relationships-Revised Scale



**Faculty of Education  
and Social Work**

ABN 15 211 513 464

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#### Understanding Attachment:

#### Young Children with Additional Needs

#### The Experiences in Close Relationships-Revised (ECR-R) Questionnaire

#### Fraley, Waller, and Brennan (2000)

The statements below concern how you feel in emotionally intimate relationships. We are interested in how you generally feel in your relationship with your romantic partner (i.e., girlfriend, boyfriend, or spouse), as well as how you generally experience relationships. Respond to each statement by filling in a circle to indicate how much you agree or disagree with the statement. The questionnaire will take about 5 to 10 minutes to complete.

1. I worry a lot about my relationships.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
2. I talk things over with my partner.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree

3. I'm afraid that I will lose my partner's love.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
4. I often worry that my partner doesn't really love me.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
5. I do not often worry about being abandoned.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
6. It's not difficult for me to get close to my partner.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
7. When my partner is out of sight, I worry that he or she might become interested in someone else.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
  
8. I find it easy to depend on romantic partners.
  - Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree



- Somewhat agree
  - Agree
  - Strongly Agree
9. I often worry that my partner will not want to stay with me.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
10. I often wish that my partner's feelings for me were as strong as my feelings for him or her.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
11. I rarely worry about my partner leaving me.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
12. My romantic partner makes me doubt myself.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
13. I find that my partner(s) don't want to get as close as I would like.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
14. Sometimes romantic partners change their feelings about me for no apparent reason.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree

- Somewhat agree
  - Agree
  - Strongly Agree
15. I'm afraid that once a romantic partner gets to know me, he or she won't like who I really am.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
16. It makes me mad that I don't get the affection and support I need from my partner.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
17. My partner really understands me and my needs.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
18. My partner only seems to notice me when I'm angry.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
19. I feel comfortable sharing my private thoughts and feelings with my partner.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
20. I find it difficult to allow myself to depend on romantic partners.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree

- Somewhat agree
  - Agree
  - Strongly Agree
21. I tell my partner just about everything.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
22. I don't feel comfortable opening up to romantic partners.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
23. I worry that romantic partners won't care about me as much as I care about them.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
24. I prefer not to be too close to romantic partners.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
25. It helps to turn to my romantic partner in times of need.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
26. I prefer not to show a partner how I feel deep down.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree

- Somewhat agree
  - Agree
  - Strongly Agree
27. I worry that I won't measure up to other people.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
28. I get uncomfortable when a romantic partner wants to be very close.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
29. When I show my feelings for romantic partners, I'm afraid they will not feel the same about me.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
30. I find it relatively easy to get close to my partner.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
31. I usually discuss my problems and concerns with my partner.
- Strongly Disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly Agree
32. I am nervous when partners get too close to me.
- Strongly Disagree
  - Disagree
  - Somewhat disagree

- Neither agree or disagree
- Somewhat agree
- Agree
- Strongly Agree

33. It's easy for me to be affectionate with my partner.

- Strongly Disagree
- Disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Agree
- Strongly Agree

34. I am very comfortable being close to romantic partners.

- Strongly Disagree
- Disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Agree
- Strongly Agree

35. My desire to be very close sometimes scares people away.

- Strongly Disagree
- Disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Agree
- Strongly Agree

36. I feel comfortable depending on romantic partners.

- Strongly Disagree
- Disagree
- Somewhat disagree
- Neither agree or disagree
- Somewhat agree
- Agree
- Strongly Agree

## Appendix I Participant Consent Form – Service Provider



**Faculty of Education  
and Social Work**

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Web: <http://www.sydney.edu.au/>

### Understanding Attachment: Young Children with Additional Needs

#### PARTICIPANT CONSENT FORM

I, ..... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney or [REDACTED] now or in the future.
- ✓ I understand that I can withdraw from the study at any time.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.

- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- ✓ I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I consent to:

- |   |     |                          |    |                          |
|---|-----|--------------------------|----|--------------------------|
| • <b>Audio-recording</b>                              | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Video-recording</b>                              | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Reviewing transcripts</b>                        | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Being contacted about future studies</b>         | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Receiving feedback about my personal results</b> | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

**Would you like to receive feedback about the overall results of this study?**

YES  NO

If you answered **YES**, please indicate your preferred form of feedback and address:

Postal: \_\_\_\_\_

\_\_\_\_\_

Email: \_\_\_\_\_

.....  
**Signature**

.....  
**PRINT name**

.....  
**Date**

**Appendix J  
PSI results of Case study 1**

Name: A				Gender: Female				Date of birth: [REDACTION]									
Marital status: Married				Ethnic group: Australian (Child is half Swedish)				Date PSI completed: 14/11/2014									
Child's name: R				Child's gender: Female				Child's date of birth: [REDACTION]									
	Child Domain							Parent Domain							Defensive Responding: 25		
	DI	AD	RE	DE	MO	AC	Child Domain	CO	IS	AT	HE	RO	DP	SP	Parent Domain	Total Stress	Life Stress
Percentile (%)	21	33	37	65	10	64	34	42	35	33	13	26	44	22	22	26	59
T score	40	44	43	51	35	51	44	46	44	42	36	42	46	40	42	42	49
Raw score	17	21	8	18	5	14	83	27	11	8	6	14	16	10	92	175	11
	Distractibility/Hyperactivity	Adaptability	Reinforces	Demands	Mood	Acceptability	Child Domain	Competence	Isolation	Attachment	Health	Role Restriction	Depression	Spouse	Parent Domain	Total Stress	Life Stress



Normative tables used (child age):	90+ %ile and <15%ile (critically outside normal range) = yellow
Percentile (%) Table A.1	85-90%ile (outside normal range) = light orange
<i>T</i> score Table B.1	60-85%ile (upper normal range) = dark orange
	Attachment subdomain = green

## Appendix K Nvivo Interview Nodes

**Key**

**Parent node theme)**

- Child nodes level 1
  - Child nodes level 2
    - Child nodes level 3
      - Child nodes level 4

Understanding of attachment	Attachment relationships	Caregivers' attitude towards pregnancy	Caregivers' hopes and concerns for their child
<ul style="list-style-type: none"> <li>• attachment</li> <li>• bond</li> <li>• coordinator's understanding of attachment</li> <li>• father's understanding of attachment</li> <li>• mother's understanding of attachment                             <ul style="list-style-type: none"> <li>○ attachment and speech development</li> <li>○ reciprocal</li> </ul> </li> <li>• service provider's understanding of attachment                             <ul style="list-style-type: none"> <li>○ self-regulation</li> </ul> </li> <li>• Stages towards attachment</li> </ul>	<ul style="list-style-type: none"> <li>• Attachment relationship of Child with Father</li> <li>• Attachment relationship of Child with Mother</li> <li>• Attachment relationship of Child with Service Provider</li> </ul>	<ul style="list-style-type: none"> <li>• abortion</li> <li>• amnio</li> <li>• married</li> <li>• pill</li> <li>• tablet</li> <li>• wedding</li> <li>• weight loss</li> </ul>	<ul style="list-style-type: none"> <li>• Child talking</li> <li>• concerns about child's physical features                             <ul style="list-style-type: none"> <li>○ hearing aids</li> <li>○ hip brace</li> </ul> </li> <li>• crawling</li> <li>• fitting in</li> <li>• mainstream-schooling</li> <li>• walking</li> </ul>

Factors around attachment	Early Childhood Intervention	Caregivers' experience of child's diagnosis
<ul style="list-style-type: none"> <li>• Distal factors                             <ul style="list-style-type: none"> <li>○ Additional stressors related to child's disability                                     <ul style="list-style-type: none"> <li>▪ 24-hour care</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Attitudes towards ECI                             <ul style="list-style-type: none"> <li>○ disagrees with physio</li> <li>○ lack of partnership or collaboration</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• bleeding issues</li> <li>• blind</li> <li>• caesarian</li> </ul>

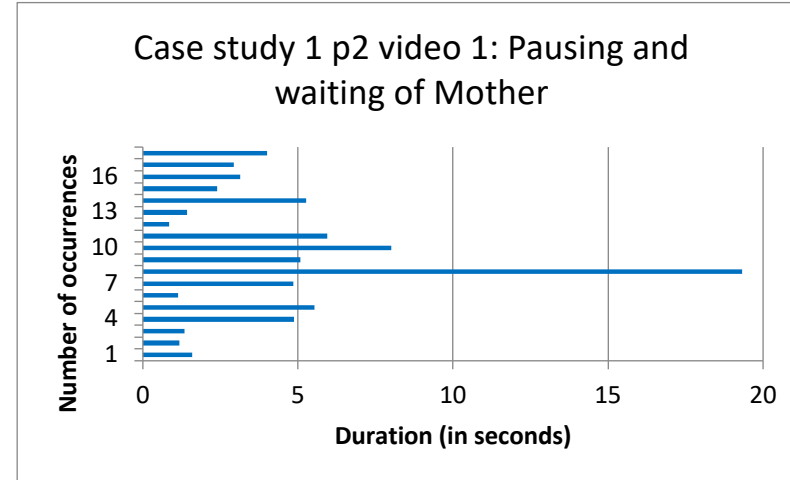
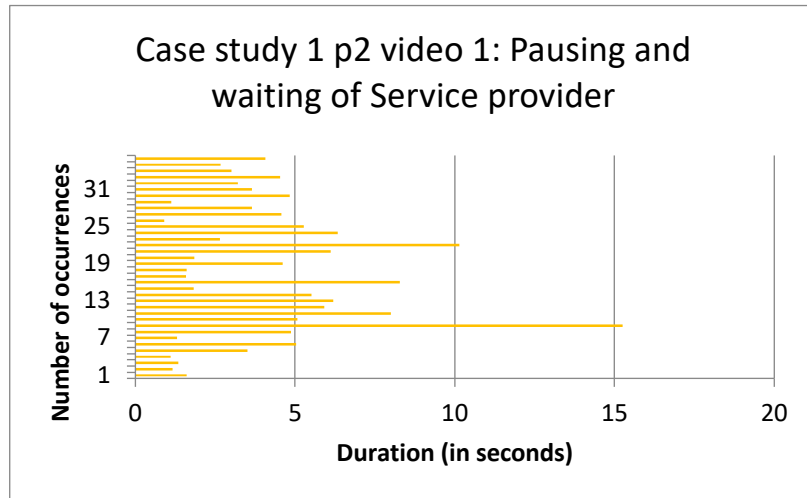
<ul style="list-style-type: none"> <li>▪ appointments</li> <li>▪ breathing issues</li> <li>▪ calcium issues</li> <li>▪ Child almost died</li> <li>▪ Child in pain</li> <li>▪ endocrine issues</li> <li>▪ financial burden or concerns</li> <li>▪ heart issues</li> <li>▪ hospitalisations</li> <li>▪ intensive care</li> <li>▪ issues</li> <li>▪ MRI</li> <li>▪ operations</li> <li>▪ pneumonia</li> <li>▪ questioning</li> <li>▪ recovery</li> <li>▪ sleep</li> <li>▪ testing</li> <li>▪ VROA puppet test</li> <li>▪ traumatic experiences</li> <li>▪ travel burdens</li> <li>▪ tube and feeding issues</li> <li>▪ waiting</li> <li>○ Marital quality and spousal support <ul style="list-style-type: none"> <li>▪ Father's background</li> <li>▪ Father's coping mechanisms <ul style="list-style-type: none"> <li>- eBay</li> </ul> </li> </ul> </li> <li>○ Mother's background <ul style="list-style-type: none"> <li>▪ beauty therapist</li> <li>▪ high school</li> <li>▪ preschool teacher</li> <li>▪ preschool teaching</li> <li>▪ R suburb</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Centres and hospitals <ul style="list-style-type: none"> <li>○ Australian Hearing</li> <li>○ G SCIC</li> <li>○ ECIC</li> <li>○ private clinic</li> <li>○ SC</li> <li>○ Sydney Children's Hospital</li> </ul> </li> <li>• ECI strategies, therapies and models <ul style="list-style-type: none"> <li>○ COMBINES methodology <ul style="list-style-type: none"> <li>▪ AVT or listening</li> <li>▪ ling sounds</li> <li>▪ DIR floortime</li> <li>▪ emilio reggio</li> <li>▪ feeding therapy or issues</li> <li>▪ more therapy</li> <li>▪ sensory integration and issues</li> </ul> </li> <li>○ deep pressure</li> <li>○ empowerment</li> <li>○ ensuring child is aided optimally</li> <li>○ family-centred</li> <li>○ gross motor</li> <li>○ having sympathy, empathy or understanding for the parents</li> <li>○ Humpty Dumpty</li> <li>○ involving fathers in ECI therapy</li> <li>○ music</li> <li>○ parent education</li> <li>○ parents doing therapy</li> <li>○ physiotherapy</li> <li>○ play</li> <li>○ singing</li> <li>○ Sounds connected to positive experiences</li> <li>○ strategies</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• chemotherapy</li> <li>• chin</li> <li>• chromosomal disorders</li> <li>• coloboma</li> <li>• cord blood</li> <li>• deaf</li> <li>• Di George's Syndrome</li> <li>• Downs syndrome</li> <li>• ears</li> <li>• eye</li> <li>• facial palsy</li> <li>• genetics</li> <li>• information sheet</li> <li>• low calcium</li> <li>• low immunity</li> <li>• meeting</li> <li>• photos</li> <li>• premature</li> <li>• syndrome</li> <li>• tumour</li> </ul>
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<ul style="list-style-type: none"> <li>▪ siblings</li> <li>▪ university</li> <li>○ Mother's personality and characteristics             <ul style="list-style-type: none"> <li>▪ attempts at positivity</li> <li>▪ battle</li> <li>▪ competence as a double-edged sword</li> <li>▪ decision</li> <li>▪ feeling pressure</li> <li>▪ focussed</li> <li>▪ judgement</li> <li>▪ perfectionist</li> <li>▪ perfection</li> <li>▪ positive attitude</li> <li>▪ re-evaluates</li> <li>▪ results-driven</li> <li>▪ sees information as important</li> <li>▪ using the internet as a source of information</li> <li>▪ self-reflection</li> <li>▪ stress</li> <li>▪ teacher</li> </ul> </li> <li>○ Mother's psychological attributes             <ul style="list-style-type: none"> <li>▪ Coping mechanisms                 <ul style="list-style-type: none"> <li>- acceptance of child</li> <li>- Denial or minimisation of stress</li> <li>- justify</li> <li>- over-speaking</li> <li>- perceptions of others' perceptions</li> <li>- proactive</li> </ul> </li> <li>▪ Fear and anxiety over the unknown</li> </ul> </li> <li>○ Occupational stressors             <ul style="list-style-type: none"> <li>▪ Father taking time off work</li> </ul> </li> <li>○ Social support             <ul style="list-style-type: none"> <li>▪ ignorance</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ support through other families at the ECIC</li> <li>○ therapy</li> <li>○ training and experience</li> <li>• factors affecting ECI attendance</li> <li>• interdisciplinary approach             <ul style="list-style-type: none"> <li>○ types of service providers                 <ul style="list-style-type: none"> <li>▪ occupational therapist</li> <li>▪ physiotherapist</li> <li>▪ speech pathologist</li> </ul> </li> <li>○ whole family</li> </ul> </li> <li>• Relationship of Mother and Service Provider</li> <li>• Relationship of Service Provider with Mother and Child</li> </ul>	
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<ul style="list-style-type: none"> <li>▪ respite</li> <li>▪ Support from community</li> <li>▪ Support from doctors</li> <li>▪ doctors' priorities</li> <li>▪ Support from extended family</li> <li>▪ Support from Facebook</li> <li>▪ Charge Syndrome Group</li> <li>▪ Support from friends</li> <li>▪ Support from nurses</li> <li>○ socio-cultural factors <ul style="list-style-type: none"> <li>▪ language barrier</li> </ul> </li> <li>○ Impact of attachment on the family</li> <li>● Proximal factors <ul style="list-style-type: none"> <li>○ Child's disabilities <ul style="list-style-type: none"> <li>▪ Charge Syndrome</li> <li>▪ complex needs <ul style="list-style-type: none"> <li>- complex needs</li> <li>- multiple disabilities</li> <li>- special needs</li> </ul> </li> <li>▪ hearing loss</li> <li>▪ vision impairment</li> </ul> </li> <li>○ Child's temperament and characteristics <ul style="list-style-type: none"> <li>▪ Child's ability to learn</li> <li>▪ Child's coping and self-regulation</li> <li>▪ Child's progress <ul style="list-style-type: none"> <li>▪ determined</li> <li>▪ disengaged</li> <li>▪ easy going</li> <li>▪ emotion regulation</li> <li>▪ enigma</li> <li>▪ fighter</li> <li>▪ inspirational</li> <li>▪ interactive</li> </ul> </li> </ul> </li> </ul> </li> </ul>		
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▪ relaxed		
▪ resilience		
▪ smart		
▪ smile		
▪ strong		
▪ stubborn		
▪ Swedish		
▪ terror		
○ Quality of maternal care		
▪ Attunement		
▪ Intuition		
▪ Sensitivity		

**Appendix L**  
**Case study 1 Phase 2 video charts**



## Appendix M

### Revised video coding scheme

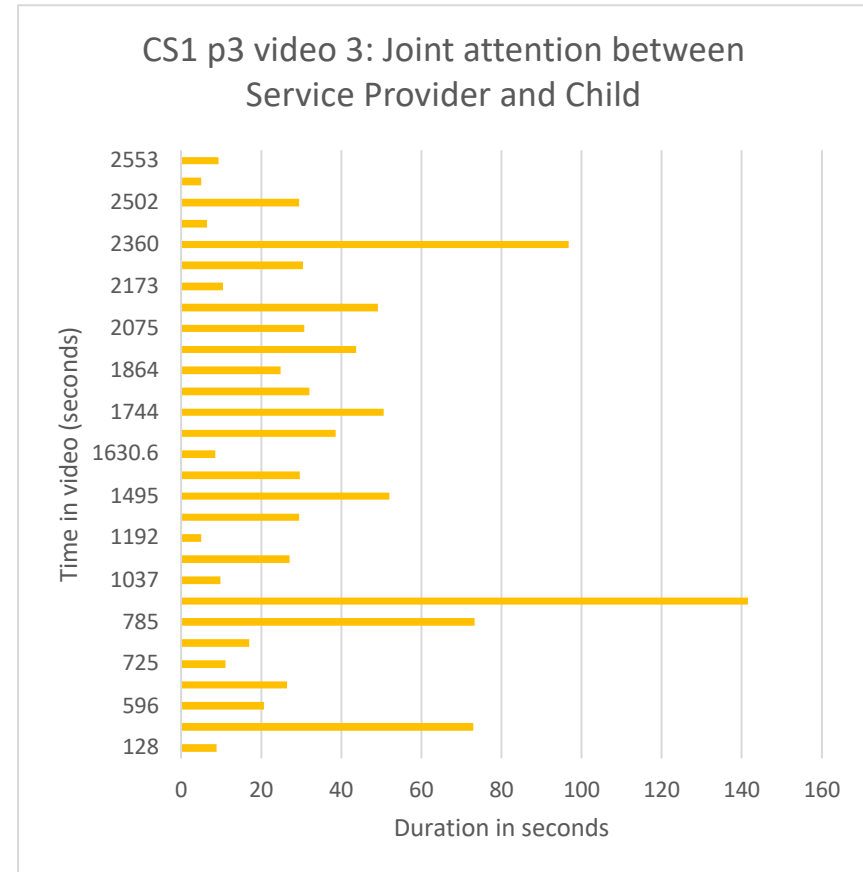
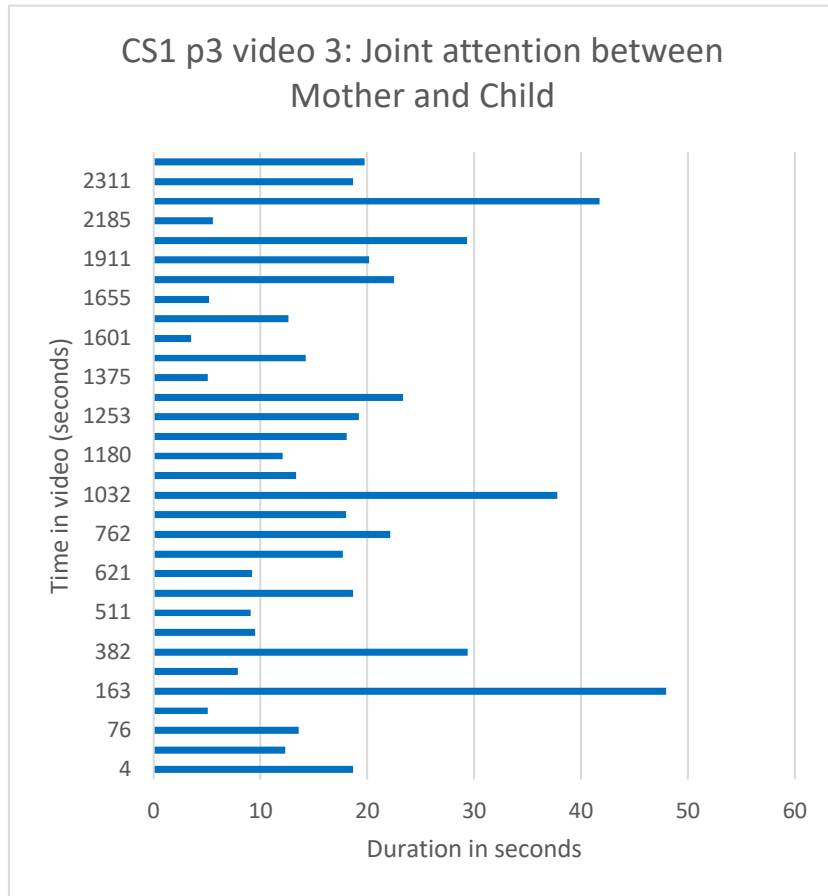
Code	Description
<b>Stage 1: Sensorimotor</b>	<p>Infants and toddlers “think” and experience their environment with their eyes, ears, hands, and other sensorimotor equipment (Piaget, 1926;1928).</p> <p>Service provider and/or Mother ‘wooing’ the child to gain intimacy and closeness; taking the time to comfort the child if they are distressed. Warm and sensitive in their interactions with the child (Ainsworth).</p>
1. Facial expression/Body language - <b>FE/BL (M)</b>	Service provider or Mother uses appropriate and prompt facial expressions and body language towards the Child, or in response to the Child’s own behaviours.
2. Touch/comfort – <b>T/C (M)</b>	Service provider or Mother uses touch or comforts the Child, in an appropriate and prompt way. Child may have tactile issues, therefore appropriate touch or comfort may be to not touch or comfort the Child
3. Follow child’s interest - <b>F (M)</b>	Mother or Service provider follow the Child’s interest or interaction e.g. Child shakes head or wriggles body, or Child picks up rattle and starts shaking it, Mother also picks up a rattle and starts shaking it
4. Motherese – <b>M (M)</b>	“known as infant-directed speech or motherese, is a special speech mode that is higher pitched, hyper-articulated, repetitive, rhythmic and melodic and has a slower tempo than typical talking... (Matsuda et al., 2011) ”(Estabrooks, MacIver-Lux & Rhoades, 2016, p. 295)
5. Acoustic highlighting – <b>AH (M)</b>	variation in vocal tone to provide emphasis; contrived e.g. simple vocal rhythms, repetition of sounds
6. Ling sounds – <b>LS (M)</b>	These six sounds are the particular sounds that occur at particular speech frequencies or pitches. They are required

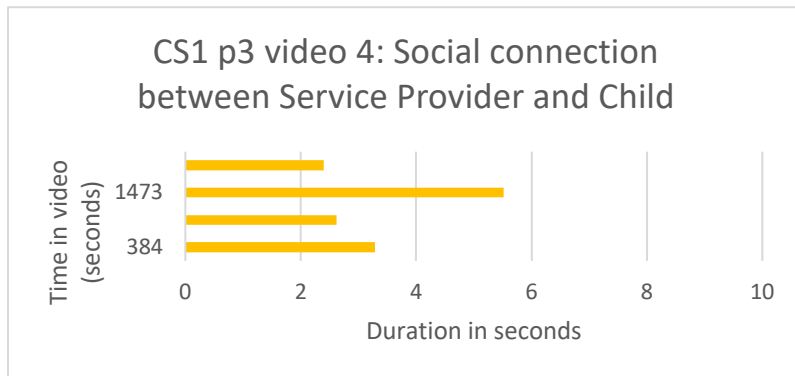
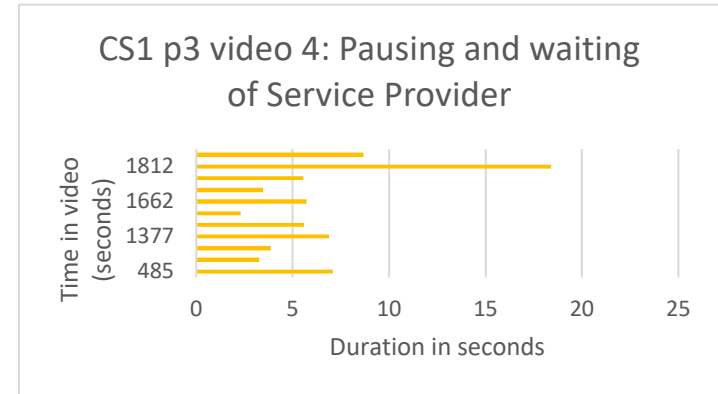
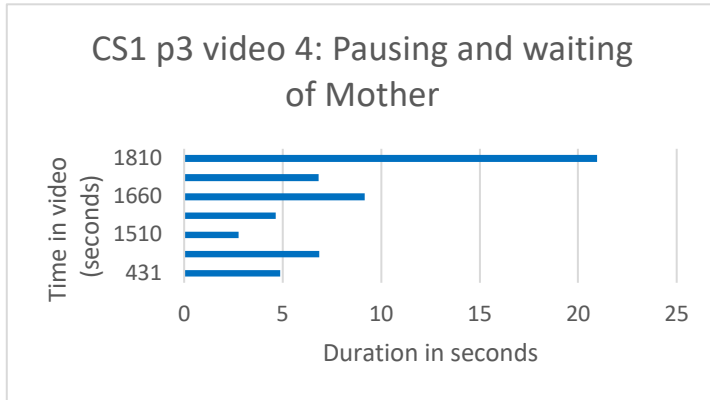


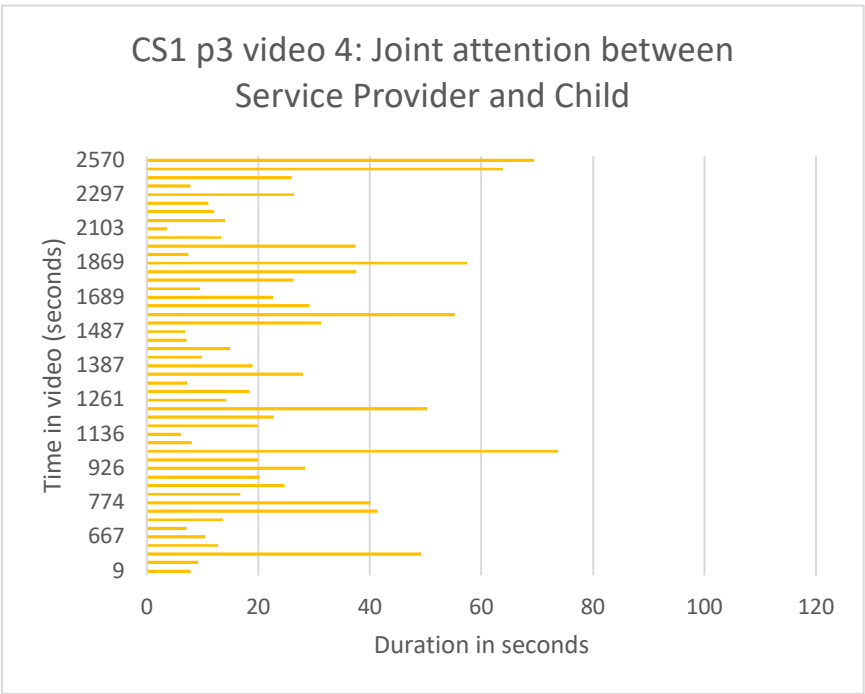
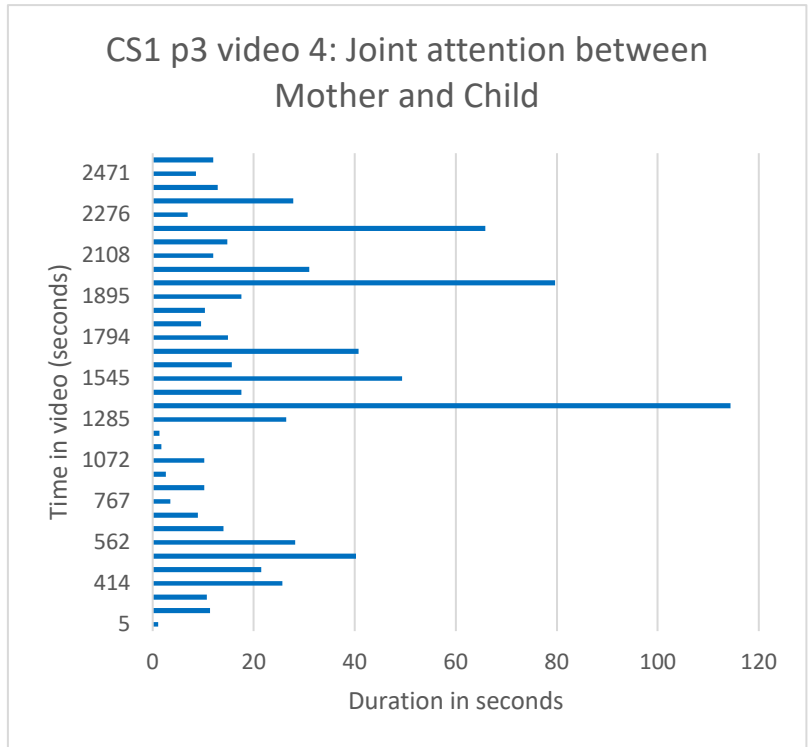
	<p>for a child to hear, understand, and learn speech (Ling, 1976;1989). They are as follows: “m” “ah” “ee” “oo” “sh” “s”</p>
7. Singing – S (M)	Service provider or Mother sing e.g. “This Little Piggy”
8. Pausing and waiting – P/W (R)	Service provider or Mother use of pauses and waiting when interacting or conversing with Child
9. Misattunement	<p>Disruption in caregiver-child affective communication (Grienenberger et al., 2005). The Service provider or Mother misinterprets the Child’s behaviour and/or intention. E.g. Mother does not acknowledge infant’s distress, bid for a toy, misses the Child’s action or vocalisation, and therefore does not respond in an attuned way</p>
<b>Stage 2: Two-way interaction</b>	
10. Joint attention – JA (R)	Child and Mother or Child and Service provider are engaged together in an activity, with or without a toy e.g. Service provider and Child playing with rattles
11. Social connection – SC (R)	two-way moments of shared joy and intimacy (e.g. smiling, gleam in eye, snuggling)
<b>Stage 3:</b>	
12. Circles of communication – CC (M)	<p>(Greenspan, 1997) Child reaches out and opens circle. The parent responds and builds on the child’s action. Child in turn responds to the parent and closes the circle.</p>
<b>Child’s behaviours/state</b>	
13. Referencing	Child looks to Mother or Service provider for recognition, when interested in an object or when performing an activity
14. Attentive/interest in the world	Child shows interest in the environment and/or is attentive
15. Child vocalises	Child makes a vocalisation in response to, or towards Service provider or Mother e.g. babbles, cries, laughs or says a word
16. Child gestures	Child gestures or moves body in response to, or towards Service provider or Mother e.g. reaches for Mother’s hand, reaches

	for toy/object, moves from a face down position to an upright position
17. Child signs	Child signs a word in sign language in response to, or towards Service provider or Mother
18. Child initiates activity/toy/object	Child initiates to begin an activity with Service provider or Mother e.g. a song or a toy, or may point to an object of interest

**Appendix N**  
**Case study 1 Phase 3 video charts**







## Appendix O

### Child's Medical and Audiological Events - Case Study 2

Date/Age	Medical/audiological Event	Place
[REDACTION] Birth	Child born premature at 33-weeks gestation. Birth complicated by polyhydramnios, resulting in an emergency caesarean section.  Respiratory distress from birth.  Difficult intubation – bleeding of pharynx.  Biopsy – suspected neuroblastoma.	Hospital
5/07/[REDACTION] 12 days old	Chemotherapy for 3 days  Tumour increased in size.  Treated for 48 hours with vancomycin and tasocin  Diagnosis revised to teratoma after re-examination of biopsy along with MRI  Feed intolerance	Hospital
24/07/[REDACTION] - 14/08/[REDACTION]	CICU stay	CICU
25/07/[REDACTION]	Excision of teratoma. Small amount of teratoma remaining  Tracheostomy  Central Hickman's line	Theatres
14/08/[REDACTION]	Discharged to ward  Improving oral feeds  Reviewed by ENT and Oncology regularly	Ward
26/08/[REDACTION] - 30/8/[REDACTION]	Re-admitted to CICU following a code blue.  Emergency tracheostomy change performed  Staph infection - resolved	CICU
31/08/[REDACTION]	Transferred back to ward  Continued to improve oral feeds	Ward
5/09/[REDACTION]	Attempted decanulation – unsuccessful	Theatres

	Histopathology – no malignant cells identified	
3/10/REDACTED	Successful decannulation	Theatres
10/10/REDACTED Three months old	Discharged Follow-up: ENT doctor – one month post-discharge Oncology – two months post-discharge. Child will need an MRI every 3 months for the first year of life	
25/10/REDACTED Four months old	Audiological assessment, Tested using BERA Diagnosis confirmation of a bilateral permanent sensorineural hearing loss of 40dBHL or greater. Child would benefit from amplification and early intervention services Management plan: <ul style="list-style-type: none"> <li>- Australian Hearing for introductory discussions and management of hearing loss</li> <li>- Hearing Support Services</li> <li>- Enrolment in an Early Intervention program to assist in speech and language development</li> <li>- Parent to parent mentoring program</li> </ul>	Australian Hearing
24/04/REDACTED 10 months old	Audiological assessment Tested using VROA Results indicate a supra threshold responses rather than deterioration Both ears clear of middle ear fluid	Australian Hearing
1/05/REDACTED 11 months old	Audiological assessment Tested using PEACH Results show child is at the lower end of the scale Mother does not think child's hearing has changed and believes his prematurity and complex medical problems are causing him to not meet milestones	Australian Hearing

	Child is behind in his physical milestones – unable to crawl yet	
26/06/2018 One year old	Audiological assessment Tested using VROA Results indicate a mild to moderate hearing loss Tympanometry results indicate poor compliance and pressure, consistent with middle ear dysfunction	Australian Hearing
23/12/2018 18 months old	Audiological assessment Tested using VROA Results indicate a mild to moderate loss showing child's hearing loss is stable He has patent grommets in both ears	
9/04/2019 22 months old	Audiological assessment Tested well, responded consistently Child has grommets	Australian Hearing
18/08/2019	Audiological assessment Tested using VROA Results indicate a moderate flat hearing loss, 15dB poorer than previous results Tympanometry results were flat indicative of middle ear effusion Results were sent to ENT specialist for recommendations	Australian Hearing



### Appendix P PSI Results of Case Study 2

Name:	M							Gender:	Female								
Ethnic group:	Czech							Marital status:	Married								
Date of birth:	[REDACTION]							Date PSI completed:	02/12/2014								
Child's name:	L							Child's gender:	Male								
Child's date of birth:	[REDACTION]																
	Child Domain							Parent Domain							Defensive Responding:	55	
	DI	AD	RE	DE	MO	AC	Child Domain	CO	IS	AT	HE	RO	DP	SP	Parent Domain	Total Stress	Life Stress
Percentile (%)	94	67	41	95	70	73	77	97	94	77	95	90	97	90	95	87	59
T score	64	55	44	68	40	54	58	69	63	52	68	62	70	62	67	64	51
Raw score	31	30	8	31	13	15	128	44	20	14	19	26	34	24	181	309	12
	Distractibility/ Hyperactivity	Adaptability	Reinforces	Demandingness	Mood	Acceptability	Child Domain	Competence	Isolation	Attachment	Health	Role Restriction	Depression	Spouse	Parent Domain	Total Stress	Life Stress
Normative table used (child age):	%					T score		90+ %ile and <15%ile (dangerously outside normal range) = yellow									

	Table A.2	Table B.2	85-90%ile (outside normal range) = light orange
			60-85%ile (upper normal range) = dark orange
			Attachment subdomain = green

## Appendix Q

### Feedback leaflet - Understanding developing attachment relationships: Infants with hearing loss and complex needs

*What are some research findings?*

- ☞ Multi-dimensional factors surround a young child with hearing loss and complex needs (HL-CN)
- ☞ These may affect the formation of attachment
- ☞ For example, a child's temperament, behaviours, and other characteristics may affect how the attachment relationship forms
- ☞ Also, a parent's emotional state can impact on the sensitivity, and attunement between parent and child
- ☞ The quality of sensitivity and attunement lead to the quality of the attachment relationship between parent and child
  
- ☞ In young children with HL-CN, it seems that the stages towards attachment develop over a longer period of time, in comparison to children without hearing loss, and even children with only a hearing loss
  
- ☞ **Those earlier pre-attachment stages that incorporate strong affect and suprasegmental parts of speech, through such techniques as acoustic highlighting and circles of communication, have shown to be of most significance in the developing attachment relationship**
- ☞ **In terms of speech and language development, the focus is BEFORE babbling**
  
- ☞ Service providers [REDACTED] are endeavouring to facilitate secure attachment relationships by working with both parent and child

*What can we improve on?*

#### Parents:

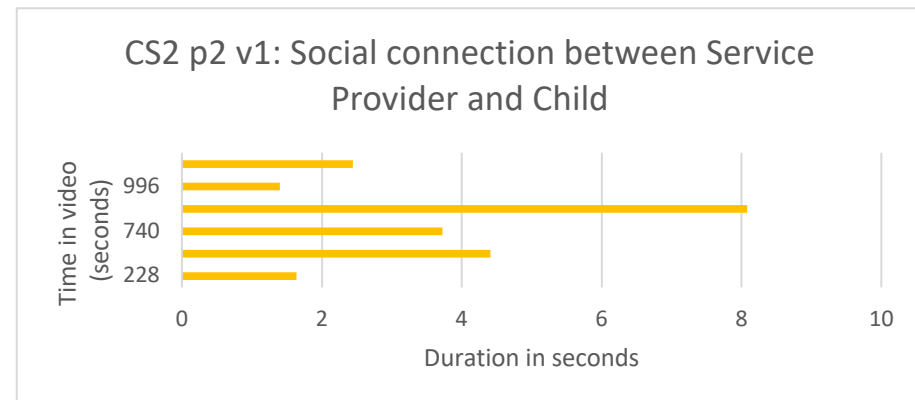
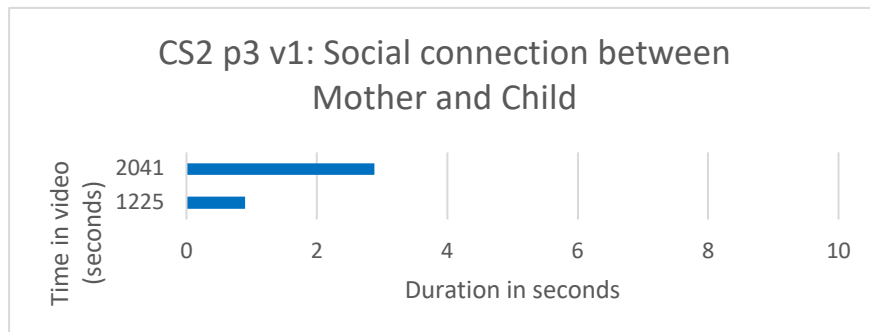
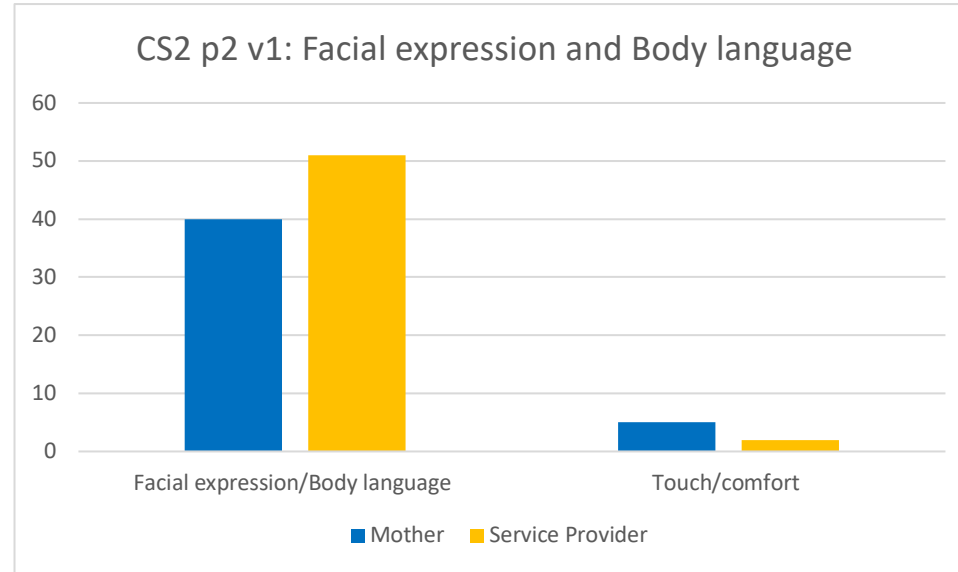
1. Be present
2. Be at your child's level and follow your child's lead
3. Try to be sensitive to all of your child's needs – e.g. emotional, physical, health, and social
4. Work with your service provider in providing for your child's needs
5. Be open to learning new ways of interacting with your child – e.g. being silly, playful, loud, over-the-top
6. Celebrate your child's achievements – whether big or small

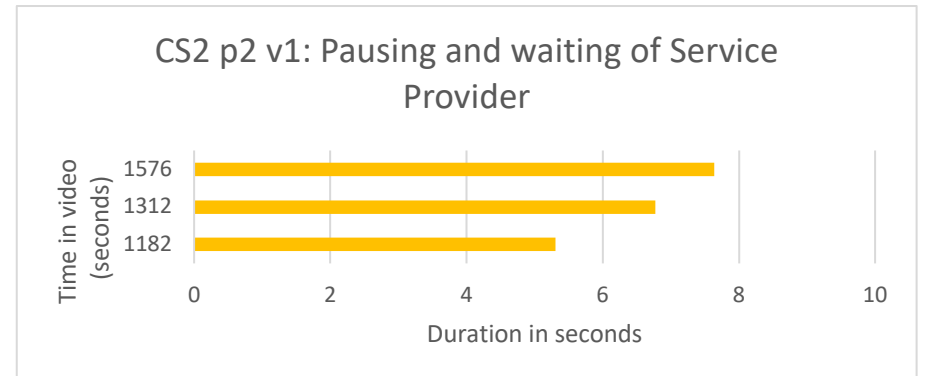
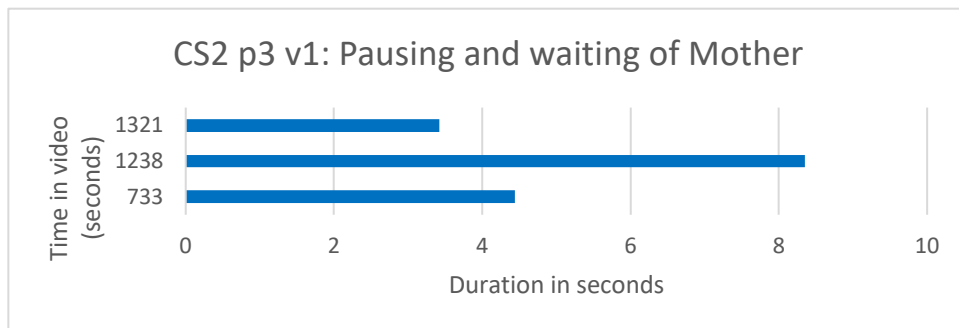
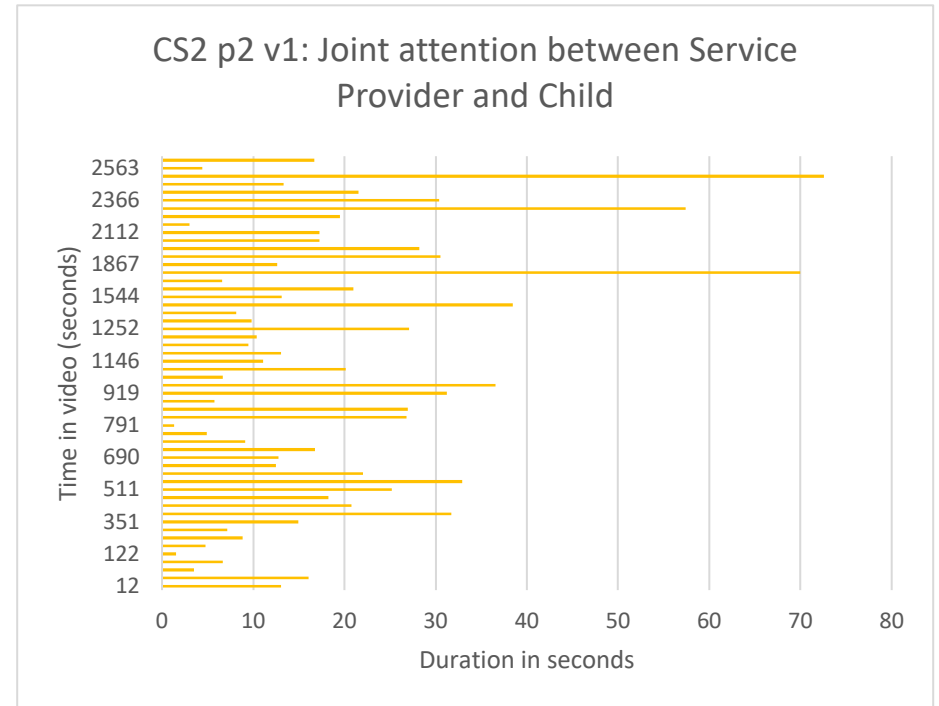
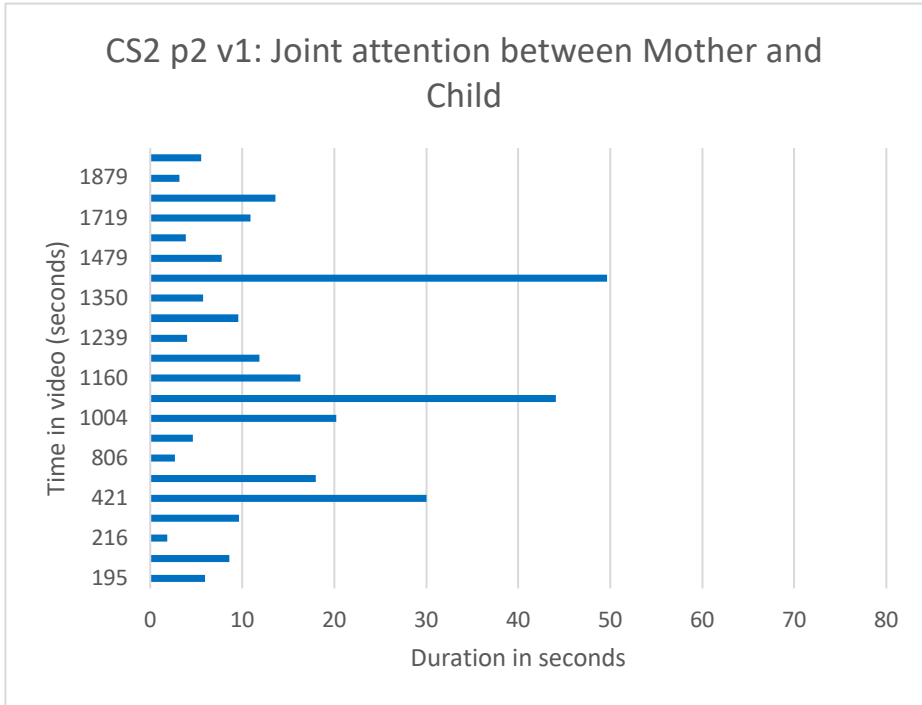
#### Service Providers:

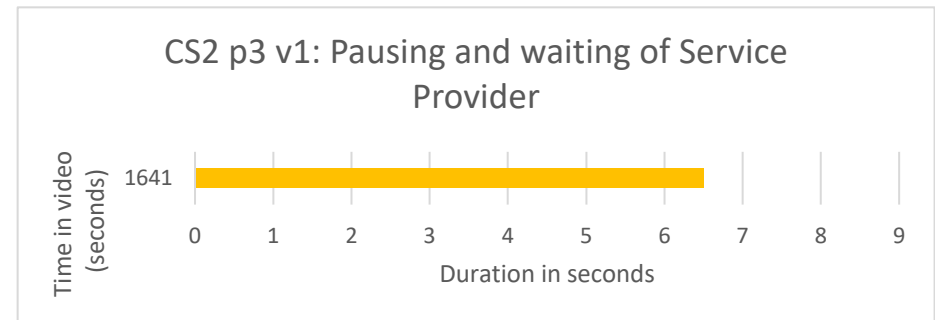
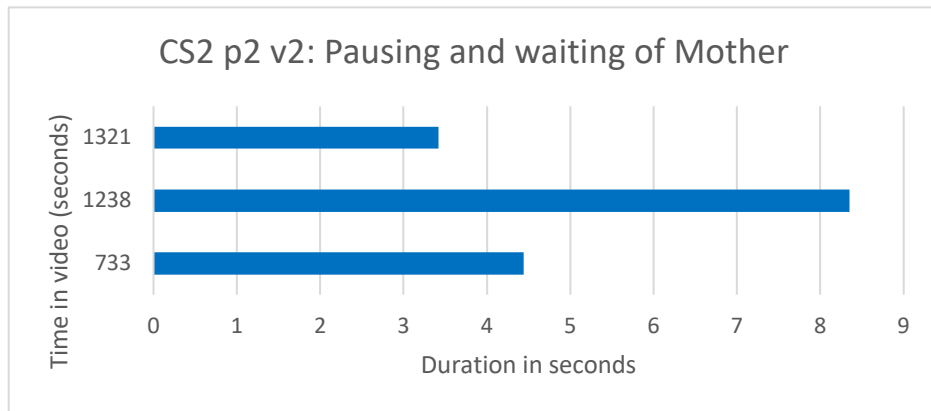
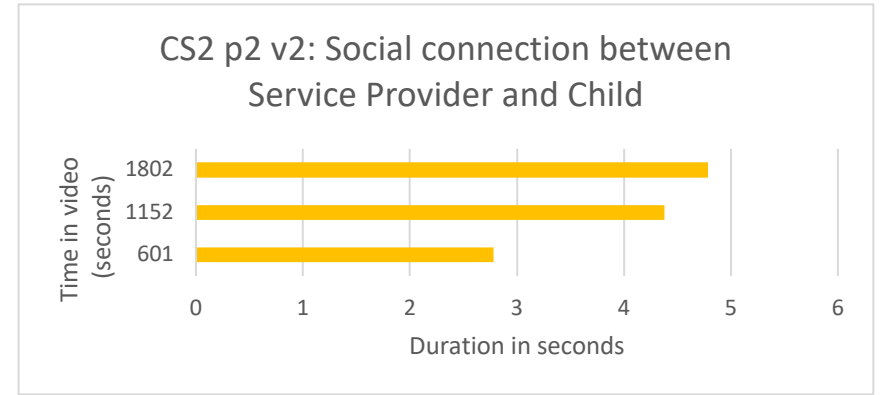
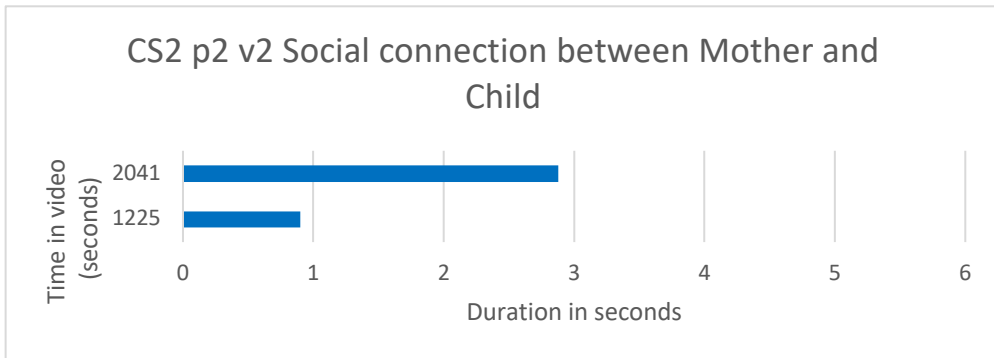
1. Realise the various factors surrounding a child with HL-CN and their family
2. Be attuned to the parent/caregiver - their current emotional and psychological state
3. Build rapport, trust, and an evolving relationship with the primary caregiver and whole family
4. Facilitate the developing secure attachment - a balance between modelling and 'stepping back' to allow sensitivity and attunement between parent and child to flourish
5. Realise that the stages towards attachment are ongoing and may fluctuate, and may develop over an extended period of time

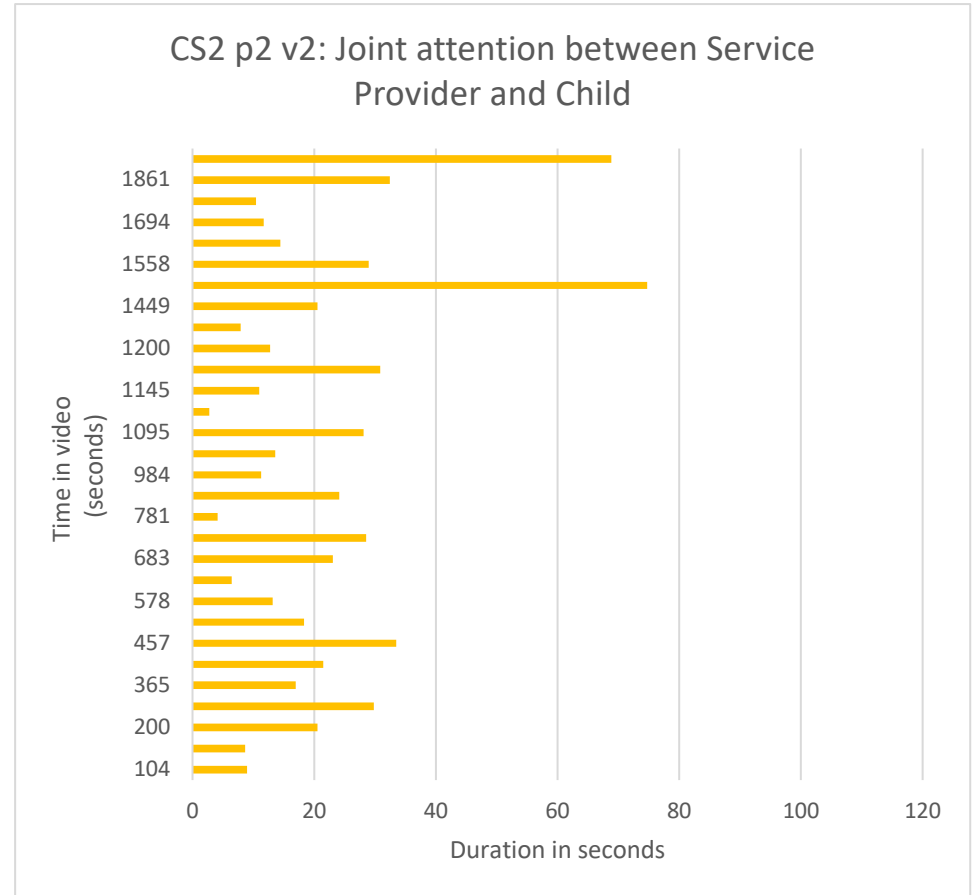
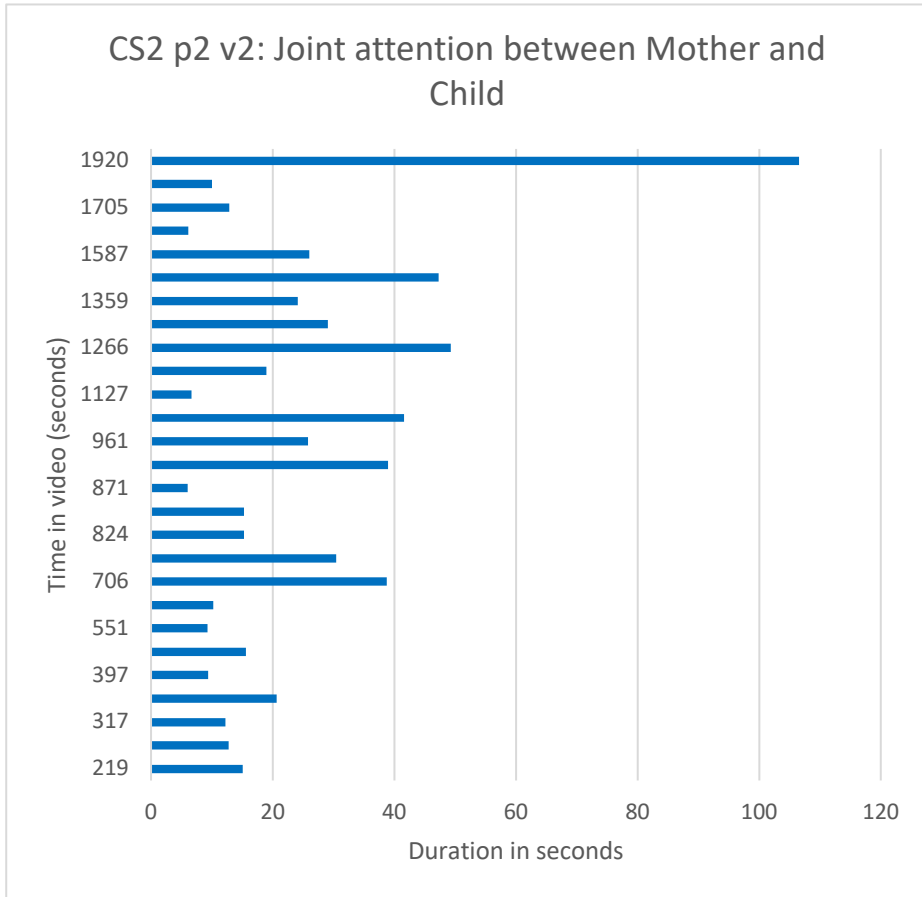
6. Focus on the earlier pre-attachment stages, which involve working on the foundations of communication, that is, strong affect and suprasegmental parts of speech

**Appendix R**  
**Case study 2 Phase 2 video charts**



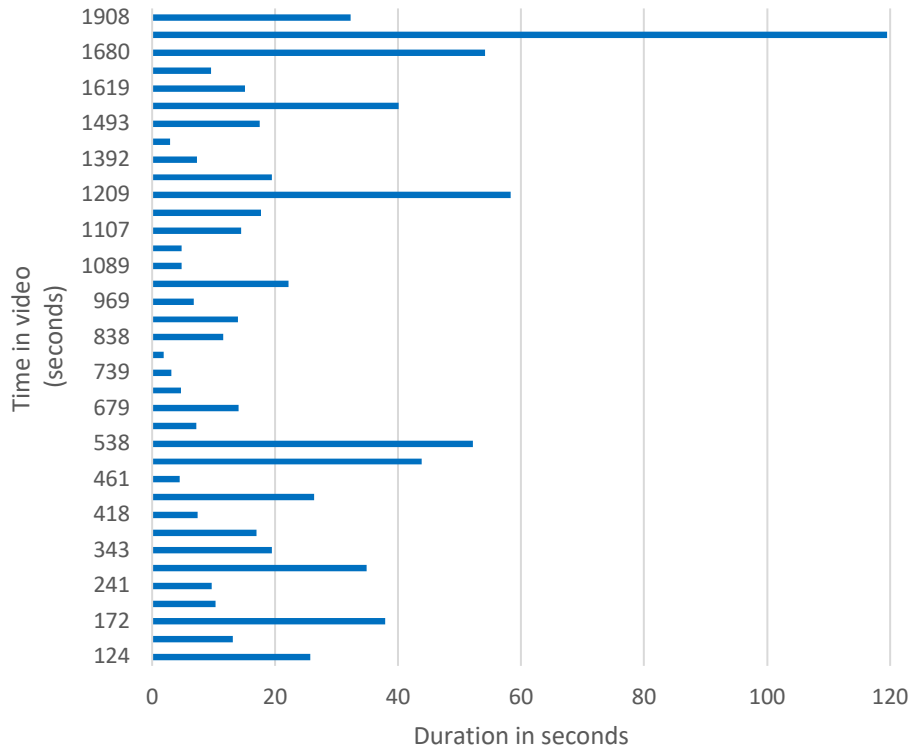








CS2 p2 v3: Joint attention between Mother and Child



CS2 p2 v3: Joint attention between Service Provider and Child

