“On the Journey with Us” – Caregivers’ Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry

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Abstract

Background

Babies born prematurely, at low birth weight and those requiring neonatal support are more likely to develop a childhood-onset disability. These babies require developmental screening to identify those at higher risk of adverse neurodevelopmental outcomes, such as Cerebral Palsy (CP). Screening ensures these infants receive early, targeted interventions from a range of therapy professionals during the critical window of the first 2 years, when the brain is rapidly developing, mitigating the functional impacts of early brain injury. Waikato Hospital implemented an early detection programme in 2017, aligning with international best practice guidelines. Caregivers' experiences of this service and engagement in early intervention (EI) had not been evaluated prior to this study.

Objective

This study explored the experiences of parents, caregivers and whānau of EI services following positive screening for adverse neurodevelopmental outcomes in infants born preterm or with health complications during the first 2 years of life in the Waikato region, Aotearoa New Zealand.

Participants

The 13 participants were parents, caregivers and whānau of infants who had received early screening and were identified as having a higher likelihood of adverse neurodevelopmental outcomes; therefore, they received EI within the Waikato. These whānau represented 9 children with developmental outcomes that were both CP and non-CP, ambulatory and non-ambulatory.

Methods

This qualitative study used a narrative inquiry methodology, informed by Dewey's (1938/1997) theory of experience. In-depth semi-structured interviews were conducted with individuals, parent dyads and whānau groups, using the strengths-based model, Te Whare Tapa Whā. The researcher restoryed the interviews as

narrative summaries, which were member-checked by the participants as a co-constructing process. Analysis examined the narratives individually to identify initial threads, followed by Braun and Clarke's reflexive thematic analysis to identify threads across all participants, attending to temporality, sociality and place. The overarching thread was "On the journey with us", along with three minor threads: uncertain beginnings, "we lacked nothing" and it takes time, with these being supported by eight sub-threads.

Conclusion

Common to all parents and caregivers was the importance of the nuanced, evolving relational needs required to holistically support them through the first 2 years. Parents experienced deficit-based discourses while being provided prognostic information in the NICU, which had long-lasting consequences. The lack of neonatal therapy services and inconsistencies in service delivery during the early discharge period likely contributed to the uncertainty experienced. Parents and caregivers valued the collaborative, non-judgmental therapeutic relationships they formed with the therapy team, in which therapists served as key workers. Coaching therapy practices, provided by skilful and knowledgeable therapists, built participants' autonomy and capacity, but only when they understood what therapy was for.

Participants explored the 'spaces' where therapy took place, including clinics, homes, virtual settings and early childhood centres. Home-based therapy offered many benefits and provided equitable services to rural and Māori families. However, participants also experienced vulnerability during home visits, particularly in the early days. This constitutes an important new finding that 'spaces' where therapy takes place require careful consideration by service providers and highlights the need for an individualised, flexible and nuanced approach to EI services. This emergent finding offers insight into why families may decline services, highlighting a knowledge gap that warrants further research.

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I want to acknowledge Māori as the Indigenous peoples of Aotearoa. I have used whakataukī (Māori proverbs) and te reo Māori (the Māori language) throughout the thesis to acknowledge the importance of this language within Aotearoa New Zealand.

I was grateful to receive a University of Waikato Research Master's and a Waikato Graduate Women's Educational Trust scholarship. Thank you for supporting this research financially.

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Thank you to my mum, Monica, who taught me how to be compassionate and loving. I am glad you have seen me complete this. To my dad, Chris, from whom I think I get my drive and work ethic.

Finally, to my incredible wife, Donna, who has supported and encouraged me to follow my dream. There have been sacrifices along the way. I look forward to a slower pace now that this chapter is complete. Thank you for allowing me to always pursue my ambitions and for being my greatest cheerleader.

Thank you all for joining me on this research waka.

Contribution

I, the researcher, undertook all aspects of this study under the direct guidance of my supervisor, Dr Sam Heath. This process entailed selecting the appropriate research design, conducting data collection and analysis and publishing the findings in this thesis.

Artificial Intelligence (AI) Statement

I used generative AI tools, Grammarly Pro, Co-pilot and ChatGPT for language refinement (spelling, grammar and sentence structure), and some understanding and exploration of ideas. No AI-generated content was used without critical reflection and evaluation, and all work reflects my own analysis.

Dedication

To the beautiful children and their families who teach me every day, as a clinician and researcher. Your capacity and resilience are inspiring. You have taught me to be curious and really see the uniqueness of each child. Without you all being so generous with your time and precious stories, this work could not have taken place.

Ka whāngaia, ka tupu, ka puāwai

That which is nurtured, grow then blossom

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Abbreviations and Glossary

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by deficits in social communication and the presence of restricted interests and repetitive behaviours (Hodges et al., 2020).

Cerebral palsy (CP) is a heterogeneous neurodevelopmental condition that begins in early life and is caused by a non-degenerative brain disturbance that affects motor abilities and often other aspects of functioning across the lifespan (Dan et al., 2025).

Childhood-onset disabilities (interchangeable with **neurodevelopmental disabilities, NDD)** are a "group of congenital or acquired chronic conditions that originate during pregnancy or infancy and comprise impairments in physical, intellectual, and/or behavioral function" (Peterson & Hurvitz, 2021, p. 1404).

Conductive Education (**CE)** is a unique classroom-based therapeutic system for instruction in movement education. The therapist or educators are called 'conductors' (O'Shea et al., 2020).

Corrected Age (CA) calculates a premature baby's age, taking their prematurity into account.

Developmental coordination disorder (DCD) is a neuromotor disability in which a child's motor coordination difficulties significantly interfere with activities of daily living or academic achievement (Zwicker et al., 2012).

Enriched environments (EE) involve increasing novelty and complexity in environmental conditions to enhance sensory, cognitive and motor stimulation (Morgan et al., 2016).

Global developmental delay (GDD) is defined as the failure to achieve developmental milestones (gross or fine motor skills, speech and language,

cognition, personal-social and activities of daily living) within the expected age range (Vasudevan & Suri, 2017).

Habilitation refers to optimising the development of individuals with developmental disabilities, those who may not have ever developed the skill, such as a child who is not talking as expected for their age (Sharma & Chaturvedi, 2023).

Intellectual disability (ID) "involves problems with general mental abilities that affect both intellectual functioning (such as learning and reasoning) and adaptive functioning (activities of daily living such as communication and independent living)" (Vasudevan & Suri, 2017, p. 558).

Foetal alcohol spectrum disorder (FASD) "is a diagnostic term for a neurodevelopmental disorder caused by exposure to alcohol before birth. Alcohol exposure mainly affects the brain, but it can also affect other parts of the body" (Health New Zealand Te Whatu Ora, 2026).

Visiting Neurodevelopmental Therapy (VNT) involves "either a physiotherapy or occupational therapy trained paediatric therapist, who has specialist knowledge in neonatal and early child development and works in a transdisciplinary and holistic model where all areas of development are supported" (VNT Association, 2024).

Chapter I. Background

Ko te ahurei o te tamaiti arahia ō tatou māhi
Let the uniqueness of the child guide our work

1.1Introduction

Babies born prematurely, at low birth weight and those requiring neonatal support are more likely to develop a childhood-onset disability. These vulnerable babies require developmental screening to identify those at higher risk of adverse developmental outcomes, necessitating early developmental support from a range of therapy professionals. Parent and caregiver experiences of early screening and subsequent engagement in contemporary early intervention (EI) offer key insights that can inform the delivery of EI services and may have consequences for policy development and implementation.

In this background chapter, why infants are at-risk infants and the importance of this will be discussed. It will examine reliable, evidence-based early detection processes and how screening tools identify babies with the greatest need for limited therapy resources. The chapter further emphasises the importance of early identification and intervention to support babies' physical, sensory, cognitive and communication development by optimising neuroplasticity in the first 1,000 days. The theories and philosophical foundations that underpin these interventions will be briefly discussed. Finally, the study's Aotearoa New Zealand and local contexts will be introduced, as it is conducted in the Waikato region. These discussions establish the background necessary to inform subsequent chapters, which examine parents' and caregivers' experiences of receiving EI services when their child is identified as at risk through follow-up services.

1.2 Prematurity, Low Birth Weight and Birth Complications

Babies born preterm (before 37 weeks), at low birth weight (less than 1,500 grams), from multiple gestation or with birth complications such as perinatal asphyxia and neonatal encephalopathy (NE) are at higher risk of ongoing health and

neurodevelopmental difficulties that can lead to lifelong neurological concerns, known as childhood-onset disabilities (Linsell et al., 2015; Ophelders et al., 2020; Spittle & Treyvaud, 2016; Wallois et al., 2020; Wang & Feng, 2025). The immature brain is particularly susceptible at this critical time, placing these babies at risk of brain injury (Inder et al., 2023; Ophelders et al., 2020; Wallois et al., 2020). This vulnerability is driven by numerous and complex internal factors (oxidative stress, sepsis, mechanical ventilation, haemodynamic instability and fluctuations in blood flow to the brain) and external factors (light, sound, pain from procedures) in the neonatal intensive care unit (NICU) environment (Spoto et al., 2024), initiating pathogenic mechanisms, including inflammation, infection and cerebral ischaemia (Ophelders et al., 2020; Volpe, 2009). The infant's brain vascular system and neural pathways are immature, leading to local and diffuse damage to grey and white matter, dysmaturation and disrupted oligodendrocyte maturation (specialised cells that produce myelin along neural axons) (Back & Miller, 2014; Molloy et al., 2024; Volpe, 2009). Often, the effects of these mechanisms on the brain are cumulative and multifactorial.

The younger the gestational age, the smaller the baby is born and the more challenging the birth history, the higher the likelihood that the babies will have developmental differences and ongoing concerns. Babies born under 37 weeks are considered preterm, with babies born before 28 weeks defined as extremely preterm. Babies born at a birth weight of 1,500 grams or less are classified as low birth weight and very low birth weight is babies born 1,250 grams or less (Linsell et al., 2015). NE is associated with late gestation and challenging births and is a complex and multifactorial condition (Chakkarapani et al., 2025). NE is an umbrella term for the "as altered neurologic function in a newborn infant, characterized by altered consciousness and abnormal tone and reflexes" (Chakkarapani et al., 2025, p. 2444). Hypoxic-ischaemic encephalopathy (HIE) is a subgroup of NE; however, in the literature, these terms may be used interchangeably (Dammann et al., 2011; Molloy et al., 2024). This term represents many babies who have detectable newborn risk factors and a higher likelihood of lifelong disability.

1.3 Childhood-Onset Disabilities – Cerebral Palsy and Non-Cerebral Palsy Outcomes

There are many types of neurodevelopmental disabilities, as they are often referred to in the literature, that fall under the contemporary umbrella term of childhood-onset disabilities, as a sequela of challenging births (Rosenbaum et al., 2025). Conditions include, but are not limited to, cerebral palsy (CP), global developmental delay (GDD), foetal alcohol spectrum disorder (FASD), autism spectrum disorder (ASD), developmental coordination disorder (DCD) and attention deficit hyperactivity disorder (ADHD), as defined in the glossary. While each condition has a distinct diagnosis, some overlap in presentation and management.

CP is a spectrum of impairments that is a non-progressive lifelong disability that causes difficulties with movement, balance and posture (Novak et al., 2025; Vitrikas et al., 2020), along with a wide range of co-existing concerns such as cognitive, feeding, visual, epilepsy and communication (Morgan, Badawi, Boyd, et al., 2023; Novak et al., 2025). CP rates are inversely related to gestational age: 14.6% of infants born at 22-27 weeks have CP, decreasing to 0.7% at 32-36 weeks (Wallois et al., 2020). The outcomes of NE are often more severe and affect all four limbs (Battin et al., 2025), with 13-30% of survivors of moderate to severe NE, who have received therapeutic cooling (early medical treatment for NE), developing CP (Badawi et al., 2005; Chakkarapani et al., 2025).

A combination of improvements in obstetric and neonatal care, public health and health care over the last 15 years has reduced the prevalence of CP by 40% (Novak et al., 2025; Ophelders et al., 2020). According to Novak et al. (2025), prevalence is now 1.6 per 1,000 live births in high-income countries such as Aotearoa New Zealand and Australia. Low and middle-income countries continue to have high prevalence (Novak et al., 2025). The exact prevalence of Nōkai Nukurangi (CP in Māori) in Aotearoa New Zealand is unknown but, using the New Zealand Cerebral

Palsy register, it has been estimated to affect approximately 1 in 500 babies (Mackey et al., 2022).

Not all children who develop CP are linked to prematurity or require a critical care admission (Novak et al., 2025), as injury can occur before, during or after birth. Therefore, not all babies who receive EI services are identified through early surveillance programmes; they may also be referred by other sources, such as general practitioners, as symptoms develop during infancy (Boychuck et al., 2020; Garfinkle et al., 2020).

There has been a wealth of research and advances in CP, including earlier diagnosis, improved management and better outcomes for these children and their families (Novak et al., 2025; Williams et al., 2024). However, it is important not to overlook that up to 40% of infants born very preterm, at low birth weight and with NE will go on to have non-CP outcomes, with moderate to severe deficits in the motor, cognitive, sensory, communication, social, attentional and emotional/behavioural domains of development (Battin et al., 2025; Caesar et al., 2021; Cameron et al., 2025; Chakkarapani et al., 2025; Linsell et al., 2015; Spoto et al., 2024; Wang & Feng, 2025). These children may develop a range of conditions that impact their functional ability and have lifelong consequences (Dan, 2025). These non-CP outcomes include developmental delay, GDD, Intellectual Delay (ID), FASD, DCD and ASD (Crump et al., 2023; Inder et al., 2023; Luke et al., 2025; Wang & Feng, 2025). Unlike reductions in CP incidence, the incidence of these adverse neurodevelopmental outcomes has not declined to a similar extent (Inder et al., 2023). Furthermore, these conditions can take longer to diagnose.

While it is reassuring that most babies born preterm do not develop a disability and have excellent developmental outcomes (Kallioinen et al., 2017), those who do develop a childhood-onset disability can experience a profound impact on the their health, learning, participation and function, as well as consequences for the entire family unit and communities. For society, there is an ongoing demand for health, education, disability and social services (Ophelders et al., 2020). This presents

opportunities to provide coordinated, inclusive and equitable early detection and intervention services to ensure that children reach their full potential.

1.4 Early Detection

Early detection of babies at high likelihood of ongoing challenges, including CP and non-CP sequelae of early or challenging births, is essential to ensure they receive early, targeted assistance and therapy to achieve the best developmental outcomes. A delayed detection and 'wait and see' approach miss opportunities for neuroplasticity and early learning (Morgan, Badawi, & Novak, 2023). Best practice guidelines for the early detection of high likelihood of CP (Cerebral Palsy Clinical Network, 2023; Harding, 2018; Kallioinen et al., 2017) provide pathways based on international guidelines (Novak et al., 2017) to ensure timely and accurate detection. These clinical guidelines recommend using term equivalent neuroimaging (MRI), Prechtl's General Movements Assessment (GMA) and the Hammersmith Infant Neurological Examination (HINE) to identify infants before 5 months (Alexander et al., 2024; Dathe et al., 2026; Einspieler et al., 1997; Fehlings et al., 2024; Novak et al., 2025; Spittle et al., 2018).

The GMA is a short, non-invasive assessment that utilises videos recorded at key time points in the infant's early life, including preterm, term and at 3 months corrected age. Trained professionals assess the short 2 to 3-minute videos and observe the infant's spontaneous (non-voluntary) movements. The absence of typical movement patterns or normal fidgety movements (spontaneous, small-amplitude, continuous, moderate-speed movements at the hands, wrists, feet, shoulders, hips and trunk) at 3 months corrected age indicates a likelihood of neurological concerns, in particular CP (Einspieler et al., 2019; Prechtl et al., 1997). The GMA has excellent inter-rater reliability and agreement (Alexander et al., 2024). In addition, the GMA video can be used to score the Motor Optimality Score-Revised (MOS-R), which assesses the motor repertoire (i.e., kicking, swiping and anti-gravity movements to the midline), providing insight into the topography and severity of CP (Alexander et al., 2024; Einspieler et al., 2019).

The HINE is a short neurological examination that assesses cranial nerves, tone and postural responses. Specific cut-off points identify those at high likelihood of CP and can characterise its topography and severity (Fehlings et al., 2024). Term equivalent neuroimaging, such as MRI, can be used alone to predict CP, but may not be necessary if there is a clear antenatal, perinatal or postnatal history that explains the symptoms (Dathe et al., 2026). MRI may be utilised at a later stage, as subtle changes may not be apparent until over 2 years of age (NICE, 2017). It can be used to rule out other causes of symptoms or to assess aetiology when it is uncertain, as other neurological conditions can mimic CP (Appleton & Gupta, 2019).

When triangulated (GMA, HINE and MRI), these test findings have a specificity of 97.56% and a sensitivity of 99.22% (Morgan et al., 2019), achieving high diagnostic accuracy. Using these best practice guidelines can allow the average age at diagnosis of CP or a provisional diagnosis of high probability (or 'risk') of CP to be given at approximately 4-5 months (Kwong et al., 2024). Over the last decade, a global effort has led to high uptake of these recommendations among medical and allied health professionals, ensuring early diagnosis and intervention for these infants.

While there is substantial evidence supporting the accurate diagnosis of CP as a distinct condition, early identification of infants with a high risk of non-CP outcomes remains more difficult. Recently, research has shifted towards diagnosing a more diverse group of children who experience a range of neurodevelopmental outcomes related to prematurity and difficult births. The MOS-R and the HINE can identify children who may go on to have non-CP outcomes (Jackman et al., 2025; Luke et al., 2025; Luke et al., 2024; Romeo et al., 2021). However, more research is required, as these tools within the non-CP group currently have only moderate specificity and sensitivity (Luke et al., 2025; Luke et al., 2024; Romeo et al., 2021). While the evidence is still evolving, these tools are being used to identify children with early biomarkers who need closer monitoring and early therapy services (Luke et al., 2025).

1.5 First 1,000 Days and Neuroplasticity

The first 1,000 days refers to the critical period from conception to the infant's second birthday and is a foundational concept in EI (Darling et al., 2020). The critical period describes how environments and infants' relationships can positively or negatively shape developmental outcomes (Inguaggiato et al., 2017). Neuroplasticity is the process by which the developing brain responds and changes in response to preconception parental experiences (experience-independent or genome expression) as an epigenetic process, gestational experiences (experience-expectant) and postnatal experiences (experience-dependent) (Kolb et al., 2017). Experience-dependent neuroplasticity is the process by which connections among sets of neurons are modulated by experience, beginning early postnatally and continuing throughout life (Kolb et al., 2016). These processes are highly complex and influenced by many factors, including experience richness, deprivation, prenatal and postnatal stress, parent-child relationships, peer relationships, diet, the gut microbiome and the immune system (Kolb et al., 2016). These complex relationships in neuroplasticity could be discussed in detail; however, they go beyond the scope of this thesis. This process is salient when thinking about EI and therapies.

1.6 Early Intervention

EI begins in the NICU and continues post-discharge for many infants and parents. EI may include physiotherapy, occupational therapy and speech language therapy. This critical period is used to mitigate potential functional impairments arising from early brain lesions or dysmaturation, when neuroplasticity is at its greatest (Inguaggiato et al., 2017; Kolb et al., 2017; Kolb et al., 2013).

EI is defined by Shonkoff and Meisels (2000) as

> Early childhood intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimise developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family function. (p. xvii)

Therefore, EI refers to the services and supports provided to infants, young children and their families at risk of, or with, identified developmental delays or disabilities, with the goal of optimising their development, including environmental adaptations as required and supporting families in promoting their child's optimal growth and learning. A key period within the EI window is the critical first 1,000 days.

Within neonatal units, neonatal therapists (physiotherapists, occupational therapists and speech language therapists) play a specialist role in supporting neuroprotective care and developmental interventions (Atkins et al., 2026). This acute care setting is often the first introduction to ultra-early preventive and habilitative strategies for parents and carers by allied health professionals.

Beyond the neonatal unit, the infant and their family require a multidisciplinary approach that has historically involved the neurologist, paediatrician, physiotherapist, occupational therapist, speech language therapist, dietitian, social worker and clinical nurse specialist. The medical team manages comorbidities and health concerns, such as epilepsy, sleep issues, feeding difficulties and secondary issues, including muscle shortening due to spasticity, respiratory concerns, sleep disturbances and gastrointestinal concerns (Smith & Kurian, 2012), which impact the quality of life and functioning of children and their caregivers. Allied health professionals, such as physiotherapists, occupational therapists and speech language therapists, provide therapeutic interventions to ensure children reach their full potential and to support parents and carers.

1.7 Evidence-Based Early Intervention and Underpinning Theories

The delivery of EI has changed over the past decade in response to research. The shift in practice has been away from therapist-led EI towards a parent-led model of care, in which therapists partner with parents, caregivers and extended family (Barfoot et al., 2024; Harniess et al., 2024; Morgan et al., 2021). Contemporary practices emphasise strategies to increase parental participation in EI and prioritise the parent-child relationship (Harniess et al., 2022; McCarty et al., 2023; Orton et

al., 2024). Morgan et al. (2021) provided a systematic review and an international best practice guideline for infants under 2 years of age with a high probability or a diagnosis of CP. Key interventions with strong evidence include coaching, task-specific motor training, constraint-induced movement therapy and cognitive interventions that encourage active, self-initiated, self-generated movements and multimodal learning (cognitive, language and motor) (Morgan et al., 2021). The guideline synthesises the evidence and its strength for each intervention, enabling families and therapists to make evidence-informed decisions for children. More recently, Damiano (2026) proposed the E words: "earlier, engagement, exploration, enriched environments, experiences, everyday, and exercise" (p. 20), which integrate many of the evidence-informed contemporary practices.

Early developmental intervention for the non-CP at-risk population has less established evidence. A Cochrane Systematic Review was published on interventions for preterm and low-birthweight infants aimed at improving motor and cognitive impairments after hospital discharge (Orton et al., 2024). Most interventions, as with the CP population, target the parent-child relationship and typically begin in the NICU. Interventions include positioning and handling, Goals-Activity-Motor-Enrichment (GAME), sensory strategies, activity-based motor training, family collaboration and environmental enrichment programmes. The authors found considerable heterogeneity across studies, with interventions, populations and outcomes highly varied. The conclusion was that while interventions may improve cognitive and physical development, the evidence is of low certainty, and there is a call for research into whether interventions provided in the first year of life improve outcomes for preterm and low-birthweight infants later in life.

Interventions are grounded in many theoretical frameworks, including attachment theory, coaching pedagogy, scaffolding theory, collaborative goal setting, motor learning theory, mechanism theory and dynamic systems theory, all of which are referred to in this thesis. Attachment theory describes how babies are biologically primed to signal for protection and nourishment and parents become attuned to

these signals. It emphasises the importance of parent-child interactions (Barfoot et al., 2024).

Coaching pedagogy has been defined in various ways and is also referred to in the literature as 'parent training' (Akhbari Ziegler & Hadders-Algra, 2020). Within a coaching model, the therapist helps the parent or caregiver become an active facilitator and equal partner in a therapeutic relationship. The therapist empowers parents to be involved in decision-making, joint planning of therapy provision and reflection on how this has worked (Akhbari Ziegler & Hadders-Algra, 2020). The coaching model partners well with collaborative goal- setting, in which parents and caregivers are active participants, moving from being instructed to being autonomous (Massey et al., 2025).

Motor learning theory encompasses the processes that promote brain changes affecting how the body moves, as well as the behavioural strategies that facilitate these changes, such as practice, dosage and feedback (Leech et al., 2022). Scaffolding theory is a core concept in early childhood education. Originating in the work of Lev Vygotsky, scaffolding strategies based on children's play encompass the zone of proximal development (a task that is too difficult to do alone but can be done with some help), temporary support and active participation, with the goal of the child working towards mastering a skill beyond their current ability (Zamkowska & Koczańska, 2025).

Dynamic Systems theory is a framework for understanding how motor learning and adaptive movement occur through complex interactions among neuromuscular, cognitive, sensory and environmental systems (Thelen & Smith, 1994). The mechanism theory or change theory approach is important because it moves beyond 'if' therapy works to 'how' it works, identifying active ingredients that drive improvement and examining the barriers and facilitators to change. For example, interventions that target the parent-child relationship and collaborative goal setting improve outcomes (Massey et al., 2025). These concepts will be referred to in Chapter 3 Methodology, and have been used to develop a conceptual framework.

Though the aforementioned theories are foundational, the literature almost universally agrees that whatever type of intervention is provided, from the NICU through to the community, best practice for services for children with disabilities needs to be underpinned by the strengths-based model of Family Centred Care (FCC) (Bamm & Rosenbaum, 2008; McCarty et al., 2023; Purdy et al., 2015; Yeomans et al., 2026). FCC is a philosophical approach rather than a set of interventions or therapies, built on three main tenets. First, parents and caregivers are the experts on their child and understand their child's needs best. Second, every family is unique and, finally, the family is the constant in their child's life (Rosenbaum, 2021; Rosenbaum et al., 1998). FCC as a collaborative way of working in partnership with families, considering all the family's needs. The foundation of the parent-professional relationship is respect. This concept will be a feature throughout the thesis.

1.8 Aotearoa New Zealand and Local Context

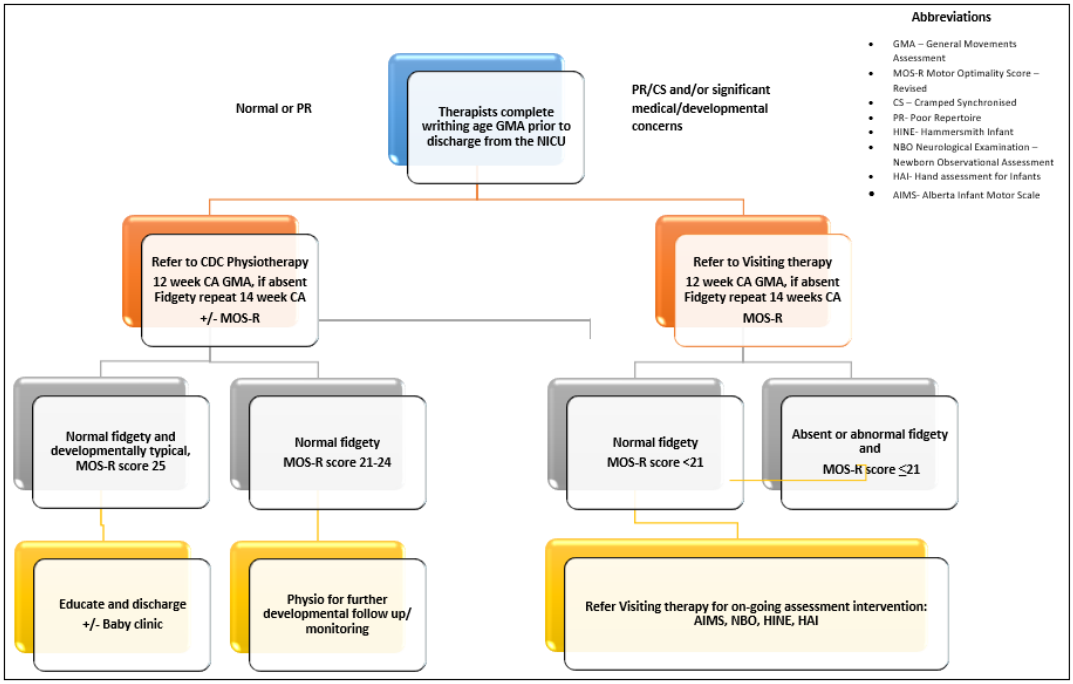
Each year, many babies in Aotearoa New Zealand have births that place them at higher risk of adverse neurodevelopmental outcomes. The international incidence of preterm birth is 4 to16 %, with incidences in Aotearoa New Zealand sitting near the middle at 7.6% or 4,500-5,00 births per year (Perinatal and Maternal Mortality Review Committee [PMMRC], 2021). The incidence of NE in Aotearoa New Zealand is around 1.25 per 1,000 term births (PMMRC, 2024). There are disparities in higher rates of preterm birth and lower survival rates across certain ethnic groups, including Māori (Indigenous peoples of Aotearoa New Zealand), Indian and Asian babies (Hunter et al., 2024). Studies have shown that Māori babies are more likely to be born preterm (Filoche et al., 2018) and maternity services favour 'whiteness', which has not changed over time (Edmonds et al., 2021). Given disparities in birth mortality and morbidity rates among certain ethnic groups in New Zealand, these groups may have a greater need for early detection and, subsequently, ongoing EI services. There are no data on the populations in Aotearoa New Zealand who receive follow-up and EI services.

Published guidelines enable professionals to identify risk and enable timely referral to the most appropriate early management and intervention; however, implementation can vary between countries and even within regions of the same country. Sandle et al. (2020) demonstrated that early detection services can be implemented in the Aotearoa New Zealand context. However, within Aotearoa New Zealand, there is significant regional variation in service delivery, including inconsistent follow-up for preterm and at-risk infants (Atkins et al., 2026; Gledhill et al., 2018). Chronic underfunding within Aotearoa New Zealand's public health system remains a barrier to implementing best-practice recommendations and likely has a greater effect on already marginalised groups, such as Māori and Pacific peoples (Atkins et al., 2026). Timely detection and intervention, therefore, is an equity issue for service providers and the literature identifies broader systemic issues.

Locally, in the Waikato region, physiotherapists established an early detection programme in 2017 to integrate international best-practice guidelines published that year into current services (Novak et al., 2017). Waikato was the first region in Aotearoa New Zealand, to fully implement these recommendations. Since then, more than 650 Waikato babies have been screened, and many have received additional surveillance and intervention as required. This has allowed limited therapy resources to be directed to those babies and families most in need, either to a hospital-based paediatric physiotherapy service for lower-risk babies or to the Visiting Neurodevelopmental Therapy (VNT) service for the highest-risk and medically complex babies. It has reduced the need for 'blanket' surveillance of all premature and low birth weight babies, most of whom have normal developmental outcomes. Following further training, updated pathways provide EI for children with biomarkers indicating a higher probability of non-CP outcomes, reflecting an evolving service in light of emerging evidence (Luke et al., 2024) (see Figure 1).

Figure 1.

Child Development Centre, Health New Zealand Waikato, Early Detection Pathway for Infants 'at risk' of CP. (author Tania Bright-Johnstone, 2024, edited 2026)



Waikato Hospital has no dedicated neonatal therapy services within the neonatal unit, with babies referred on an as-needed basis. These referrals are often made solely to complete neuromotor assessments (i.e., the GMA) or feeding assessments to ensure a safe discharge. The lack of a dedicated service therefore does not address essential neurodevelopmental needs or provide input to support the parent-infant relationship. This situation reflects the current state of neonatal services in the study.

There are follow-up pathways at Waikato Hospital available for lower risk groups of infants, to ensure these babies do not miss out on intervention if required. This group of children are not the focus of the current study.

This Waikato regional service development has successfully implemented best-practice guidelines using current staffing levels and without increasing therapy

funding. I am one of the therapists who implemented this pathway locally, am involved in its ongoing development and is an EI provider for these at-risk infants and their whānau. This background outlines the many benefits of early detection, including targeted early therapy but how parents receive or understand detection and intervention for this population within the local context remains unexplored. While there have been some changes to the early detection pathway, as explained above, there has been no formal evaluation of equity, acceptability and access since its inception. There has also been no evaluation of service users' experiences of the early detection pathway and subsequent EI when identified as at risk. The voices of those parents and caregivers whose infants are receiving what has now become routine practice in Waikato have not been heard, nor has there been any consideration of how their experience might influence the direction of future service and policy development.

1.9 Conclusion

Babies born prematurely, at low birth weight or challenging health births often have excellent developmental outcomes due to medical advances. However, some babies eventually develop a childhood-onset disability associated with these births. This chapter has outlined why these babies are at risk, how those at a higher likelihood of CP and non-CP outcomes can be identified and how they can then be engaged in evidence-informed early therapies. Some inequities faced by certain populations have also been outlined. Waikato's Child Development Centre therapists have been national leaders in implementing international guidelines; however, there has been no programme evaluation and no service user perspectives have been sought since implementation began.

Chapter 2 presents a literature review documenting the current understanding of parents' and caregivers' experiences accessing and engaging in EI after being identified as having a high likelihood of an adverse neurodevelopmental outcome, CP or non-CP secondary to prematurity or challenging births.

Chapter II: Literature Review

Whaowhia te kete mātauranga
Fill the basket of knowledge

2.1 Introduction

In the background chapter, vulnerable infants were introduced, the early detection process outlined, EI defined and the evidence informing current EI practices associated with better developmental outcomes summarised. The context in which the research was conducted was then discussed, laying the initial foundations for its significance.

This chapter is a narrative literature review that synthesises the literature on parents' and caregivers' experiences of early detection and of accessing and engaging with EI after their child being identified as having a high likelihood of an adverse neurodevelopmental outcome due to prematurity or a challenging birth. The chapter begins with a discussion of the method and search strategy used in the literature review, then the results of the narrative literature review are presented. The literature review demonstrates that this health and habitation journey is a continuum comprising many highly interconnected components that shape parents' and caregivers' experiences of early support. The review highlights that early diagnostic processes and EI occur concurrently, in parallel and overlapping ways.

2.2 Literature Review Process

The purpose of the literature review is to gain an understanding of what is currently known about a topic, identifying any same or similar studies that have been conducted, core concepts, contexts of previous research (e.g., countries), gaps in research and establishing the worthiness of the intended research (Savin-Baden & Major, 2025). In this way, the literature review "makes a case" (Braun & Clarke, 2013, p. 312) or justification for why piece of work is relevant, providing a clear rationale for its completion. The narrative literature review allows the researcher to critically engage with key works in their field of study, including conceptual articles

and opinion pieces (Creswell & Creswell, 2018; Savin-Baden & Major, 2025), thereby demonstrating the researcher's understanding of the topic's depth and breadth.

2.3 Narrative Literature Review

A narrative review was conducted, allowing broad consideration of the literature and flexibility to cover a range of topics (Baumeister & Leary, 1997). The review focused on the lived experiences of parents, caregivers and their whānau (family) in receiving EI during the first 2 years, commencing in the NICU and continuing beyond, including experiences of the early detection process as well as the contextual factors surrounding parental/caregiver experience, engagement and access.

2.4 Search Strategy

A research librarian at the University of Waikato assisted in developing the search strategy. The initial search was completed in July 2025 and updated throughout the research process. In addition, as this was a narrative review, seminal articles predating the search range were included as they are widely known to those working in this field. Further searches of the extant research were conducted after data analysis to help situate the findings.

The databases used to identify studies on this topic were PubMed, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane and Scopus. A combination of Medical Subject Headings (MeSH) and keywords was used for a comprehensive literature search. An iterative approach was employed, extending the search as new terms were identified. This approach was adopted to ensure the search was thorough. PICo (Population, Phenomena of Interest, and Context) was used to help formulate my questions. PICo is a common approach for writing questions in qualitative research, as these studies focus on participants' experiences of health processes and interventions (Hosseini et al.,

2024). Table 1 outlines the PICo search criteria and study design for this study's literature search, along with parameters.

Table 1.

PICo Criteria

Parameter	Criterion
Population	Parents, caregivers and extended whānau with a child referred into the early detection pathway (NICU and beyond)
Interest	Experience of early intervention/therapy in the first 2 years of life
Context	Low-middle-high income countries, broad, New Zealand
Study design	RCT, epidemiological studies, qualitative research, systematic, meta-analysis
Language	English

The searches were restricted to full-text, peer-reviewed, English-language articles published between 2015 and 2026. The original search was limited to the last 10 years because of the proliferation of research advances and subsequent publications during this period, which have resulted in changes in practice. The final search strategy was:

Infant OR Newborn OR preterm OR premature AND physiotherapy OR physical therapy OR “occupational therapy” OR “Speech Language” OR therapy AND “Early Intervention” OR “NICU follow-up” OR “early detection” OR “at risk” AND experience* OR stress* OR burden OR perception* OR coping OR copes OR resilience AND parent* OR caregiver* OR grandparent* OR family OR mother OR father AND exp Developmental Disabilities OR exp Neurodevelopmental Disorders OR Cerebral Palsy

Inclusion criteria included children under 2 years of age who were ‘high risk’ for an abnormal developmental outcome or had a diagnosis of CP, GDD or developmental delay. Parental, caregiver or extended family experience of the early identification process and/or EI that commenced in the NICU or after discharge.

Given the broad scope of the search, the exclusion criteria are documented in Figure 2.

Articles were initially screened by title and abstract; full text was sought if these met the inclusion criteria. To ensure the literature search was thorough, grey literature was reviewed, including Starship guidelines and National Institute for Health and Care Excellence (NICE) guidelines. Hand-searching the abstracts from the International Alliance of Academies of Childhood Disability (IAACD) – 2025, 37th Annual Meeting of the European Academy of Childhood-onset Disability (EACD) – 2025, American Academy for Cerebral Palsy and Developmental Medicine 2025 conference and the Oceania Academy 2026 Biennial Conference, abstracts published in special editions of the Developmental Medicine & Child Neurology, was completed. This extensive search yielded many peer-reviewed articles, systematic reviews, Cochrane reviews and guidelines.

2.5 Search Results

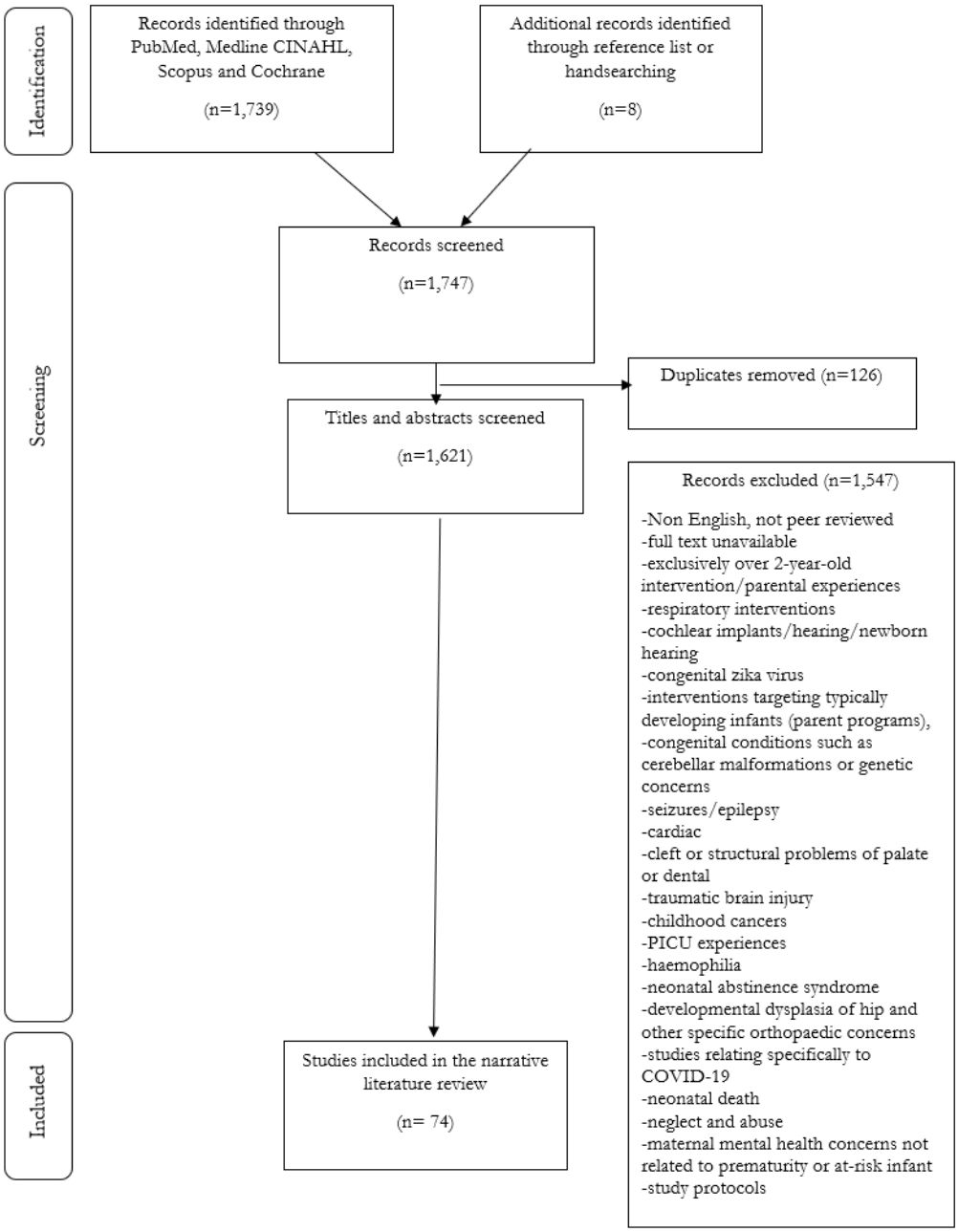
Initially, the search strategy yielded 1,739 results, with an additional 8 identified through handsearching and reference lists. A total of 1,747 records were screened. After removing duplicates, there were 1,286 articles. Titles and abstracts were screened and this process identified 74 articles which were synthesised. The results included one Early Detection Care Pathway with four additional resources to support the background chapter. Starship Guidelines provided one checklist for EI, one guideline for early detection and four additional articles. The 2025 and 2026 conferences yielded only one additional result, either because the articles were duplicates or because a full peer-reviewed journal article was unavailable and unpublished. Figure 2 illustrates my search outcome.

Each article was first reviewed to determine whether it was on the topic of the proposed study and then whether it was suitable for inclusion. Savin-Baden and Major's (2025) "questions for evaluating a qualitative study" (p. 132) were used to evaluate each article. This included if the research had a clear focus; the research question was well defined; the methodology was appropriate for answering the

research question; the population and sample size documented; data collection and analysis was clearly defined; results clearly and succinctly communicated and the researcher's attention to validity and trustworthiness, such as accounting for biases including positionality and stance; that there was sufficient detail to determine whether the findings were applicable to other contexts; and, finally, the references were reviewed. All studies were summarised in an Excel spreadsheet, and the final synthesis organised the literature into key themes and concepts (Savin-Baden & Major, 2025). This was used as the basis for the literature review.

Figure 2.

Search Process for Narrative Literature Review (Final update 16 April 2026).



2.6 The Early Intervention Journey – Introduction

Nau mai e te pepi. ki te Ao mārama

Welcome to the World little one

Following the thorough search, identification and interrogation of the relevant literature through the previously presented process, the following narrative review presents parents' and carers' experiences of the complex journey of NICU admission and the transition home, providing the initial framing. The review provides insights into what is currently known about parents' and carers' experiences of navigating hospital, early detection and intervention; key psychological and mental health factors; contextual and cultural factors; the importance of family and family constructs; and the geographical implications for accessing services, while also addressing the identified knowledge gaps in this field.

2.7 The NICU – A Complex Journey

The EI journey begins well before discharge from the NICU and engagement can be influenced by parents' early experiences from birth. Parental experience of their time within the NICU establishes a strong parent-child attachment (Øberg et al., 2023; Vigod et al., 2010) and shapes the experience and future relationships with health professionals supporting their child's EI beyond the NICU (Gibbs et al., 2019; Granero-Molina et al., 2019; Harniess et al., 2024; Øberg et al., 2023).

It is reported in the literature that having a preterm, low-birth-weight infant or one who experiences birth complications, such as NE, constitutes a highly stressful and traumatising experience for parents (Adcock et al., 2021; Fauth et al., 2023), marked by an emotional upheaval. This experience propels parents into a world they could not have anticipated, disrupting the imagery of what family looks like for themselves, their newborn and extended family or whānau (Adcock, 2021). Qualitative research indicates that mothers often encounter feelings of guilt and shame related to childbirth (Adcock et al., 2021; Harniess et al., 2024). Mothers of extremely preterm infants frequently report feelings of emptiness and bewilderment that may persist for up to a month following birth (Fernández Medina et al., 2018).

There is a new set of terminology and separation from their baby and natural support systems, compounded by the unfamiliar NICU environment, which may heighten confusion and stress (Ballantyne et al., 2016; Treyvaud et al., 2019). The transition to parenthood under these circumstances represents a profound life change, often accompanied by social and familial isolation (Harniess et al., 2024). The wide range of emotional reactions in this context can seriously impact the fundamental parent-child relationship.

Bonding and attachment are foundational for both the mother and the baby, with many physical and psychological impacts. Bonding can be disrupted when infants are medically unstable in the first days, weeks or months of life, leaving limited opportunities to touch and hold them (Eeles et al., 2021; Fernández Medina et al., 2018; Gibbs et al., 2019). Drawing on findings from reviews and qualitative research in Aotearoa New Zealand and internationally, parents may be hesitant to engage with their unwell babies, fearing they may hurt them, and may hand over care tasks to NICU nurses (Adcock et al., 2021; Raghupathy et al., 2025; Treyvaud et al., 2019). This limits opportunities to build confidence in caring for and parenting their newborn. Furthermore, parents have a high prevalence of depression and anxiety which can also disrupt bonding with their baby (Väliaho et al., 2021; Vigod et al., 2010). While there are many difficult times associated with preterm or difficult births, NICU professionals can support mothers, fathers and extended whānau in establishing strong parent-child relationships while their baby is still an inpatient.

Parent-child relationships can be supported by involving parents in care within a FCC model, as introduced in the background chapter. The importance of the parent-child relationship is informed by attachment theory (Barfoot et al., 2024). Secure attachments develop as parents learn to respond sensitively to an infant's needs. Infants born prematurely or with neurodevelopmental problems may not provide clear signals of their needs, hindering responsiveness. In addition, parents may be preoccupied with grief and distress, reducing their capacity to interpret these signals and placing a secure attachment at risk (Barfoot et al., 2024). Ways that mother-child attachment can be facilitated while an infant is an inpatient, include NICU

professionals partnering intentionally with parents by encouraging expressing breast milk, breastfeeding and conducting feeds (enterally or via a bottle); providing skin-to-skin kangaroo care; performing nappy changes; offering developmentally supportive touch and massage and encouraging talking, reading and singing to their baby (Adcock et al., 2021; Eeles et al., 2021; Fernández Medina et al., 2018; Fortune et al., 2023). This helps parents gain confidence in caring for their child, build their autonomy as parents and get to know their child. Parents can be included in decision-making about neuroprotective and developmental care tasks that reduce stressors on the newborn, such as positioning, clustering care and modifying the external environment (lights, noise) (Pineda et al., 2025). Parents are empowered by opportunities to complete care while also being supported in stepping back if they become overwhelmed (Fortune et al., 2024). A Delphi study of neonatal therapists' consensus on principles to support the transition from NICU to home identified building caregiver–child relationships, optimising infant development, education and knowledge and enriched environments (Miller et al., 2025). Each of these four principles is considered salient for maximising caregivers' confidence. An FCC approach informed by attachment theory fosters a strong parent-child relationship in the NICU, setting parents up for success when they go home with their infant.

Parents and caregivers receive a lot of information while they are in the NICU. Using Kaupapa Māori qualitative research methods, Adcock et al. (2021) found that the way parents were communicated with was important, including avoiding information overload, providing adequate time to process information, including bad news, and repeating important information. Parents often do not remember large parts of the NICU stay (Adcock et al., 2021). Work by other researchers demonstrated that ensuring parents understand assessments and conducting face-to-face sessions with neonatal therapists to reinforce key information needed beyond the NICU supported decision-making and built parents' confidence in their skills. (Fortune et al., 2024; Griffith et al., 2022).

While every parent experiences the stressors of the NICU, Indigenous and ethnic minority parents have been shown to have distinct experiences, with effects that

persist after hospital discharge, which can erode trust and relationships with health professionals. In a qualitative study of Māori whānau experiences, Adcock et al. (2021) highlighted that the NICU was isolating, excluding and discriminatory. In their follow-up study of Māori NICU graduates' Māori mothers' experiences at babies' first birthday (n=16), again using Kaupapa Māori methodology in the Aotearoa New Zealand context, Māori parents found the NICU environment hostile and mothers described their experiences as 'othering' (Adcock et al., 2022). This mirrors experiences for other Indigenous and marginalised groups. For example, in their review article, Johnson et al. (2023) found ongoing healthcare disparities with Black and Hispanic infants receiving lower-quality care in the NICU, resulting in lower rates of post-discharge follow-up. These disparities have been linked to institutionalised racism and social determinants of health. The research mentioned is within the general NICU population and there appears to be no research detailing the experiences of carers of higher-risk babies within Indigenous and minority groups, highlighting the need for further research.

The NICU journey, along with parents' and caregivers' traumatic experiences, places mothers and fathers at psychological and emotional risk, with Indigenous and ethnic minorities likely to be more affected. This highlights there is likely a tension between recommended practice and lived experience, with many contextual factors that influence how parents and caregivers access and engage with services post-discharge, that warrants further exploration.

2.8 Transitions – Preparation for Home

Discharge planning is of utmost importance in preparing parents and caregivers for home and the quality of transition planning sets them up for successful ongoing EI engagement. Evidence demonstrates parents can experience a range of ambivalent and conflicting feelings about going home (Fortune et al., 2024; Granero-Molina et al., 2019). Reported feelings can range from excitement, happiness and joy, including a sense of escaping the hospital environment, coupled with fear, guilt, and anxiety, especially for mothers (Dickson et al., 2023; Granero-Molina et al., 2018). Some parents felt unprepared for the transition home (DiBari & Rouse, 2023; Spence et al., 2023). Fortune et al. (2024), in their qualitative study of eight

parents' experiences attending a newly formed early detection follow-up clinic, showed that emotional support need not be formalised and can be provided by health professionals who take time to sit and listen, show understanding and offer encouragement. Acknowledging and normalising conflicting feelings supports gradual acceptance and relieves guilt, as demonstrated by Dickinson et al. (2023) in their qualitative study of 11 parents of eight infants newly diagnosed with CP. Feelings of safety are fostered by health professionals, who have been shown to become 'like family' through the provision of empathetic and culturally safe care (Adcock et al., 2021; DiBari & Rouse, 2023). Using a grounded theory methodology, Harniess et al. (2024) found that parents' experiences and framing are complex and fluctuate over time. Their research provided insight into the need for health professionals to take time to recognise the spectrum of feelings parents will experience during this period and to conduct psychological screening to identify those who need more targeted intervention as they prepare for discharge from the NICU. The literature assumes that services have processes in place to support this practice, which may not be available in all cases.

As parents of infants who have a NICU admission have a higher prevalence of anxiety and depression, screening and support are an essential part of the discharge process. Prior to discharge from the NICU, there needs to be screening for mental health symptoms and psychosocial risk for all parents, including fathers (Treyvaud et al., 2019). Adcock et al. (2021) recommend strengthening maternal and infant mental health supports as routine practice. A closer examination by Harniess et al. (2022), using a realist synthesis methodology and drawing on 26 articles, aimed to understand how and why EI strategies to support parents' engagement operate within their contexts. Their study was grounded in mechanism and change theory. The synthesis found that families with greater socioeconomic stressors have greater difficulty transitioning home and may require greater support to ensure a safe discharge (Harniess et al., 2022). Connecting the most vulnerable families to their EI provider, such as the community physiotherapist or visiting therapist, prior to discharge builds trust and understanding of the service (Harniess et al., 2022). As

part of their role, health professionals need to screen for socioeconomic and psychological risks and initiate early referrals for support.

Specific psychological support should continue in the community after NICU discharge (Fortune et al., 2024; Griffith et al., 2022; Røhder et al., 2025; Treyvaud et al., 2019; Williams et al., 2024). Even with compelling evidence highlighting the essential role of psychological support (Ropero-Padilla et al., 2025), the literature reports a lack of specific psychological support, including in the Aotearoa New Zealand context (Williams et al., 2024). With emphasis on early detection of risk of adverse neurodevelopmental outcomes, psychological support needs to be early and targeted (Dickinson et al., 2020; Røhder et al., 2025). Røhder et al. (2025) found in a cross-sectional study of 56 Danish families with both low- and high-risk infants that mothers of high-risk infants for CP were 15.6 times more likely to experience postnatal depression compared to mothers of infants without risk. Postnatal depression not only impacts the health and well-being of the parent, but maternal mental health has been shown to have a direct impact on infants' developmental outcomes (Treyvaud et al., 2019). One mechanism to explain this phenomenon is the powerful influence of the parent-infant bond on early brain development (O'Hara & McCabe, 2013). Furthermore, Jang et al. (2024) found that when EI (including early childhood educators, allied health therapists and psychologists) was provided both pre- and post-discharge, it had a positive effect on maternal mental health.

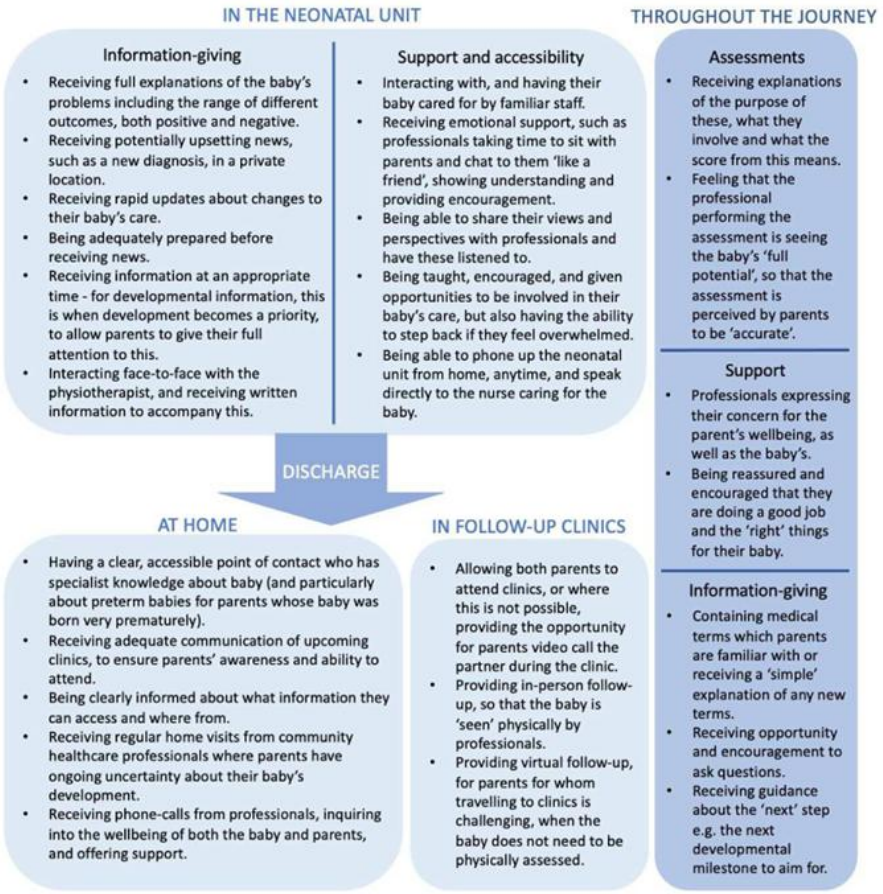
One effective CP-specific support, 'Early Parental and Acceptance Therapy' (PACT), is a non-pathologising psychological support that promotes acceptance (Dickinson et al., 2023). Other ways of supporting parents' psychological health include parent support groups (e.g., Little Miracles Trust Premmie playgroups), peer support, remote psychological services and individualised psychological therapy (Treyvaud et al., 2019; Vyas et al., 2021). Many of the evidence-based early interventions rely on this strong parent-child bond, providing a compelling case for greater psychological support at the outset (Barfoot et al., 2024). While the need for psychological support for these families is clear, what is not often commented on is

the impact on the wider family context and support beyond parental dyads. There again may be a misalignment between research and practice in the Aotearoa New Zealand context.

Practical, spiritual, emotional, cultural and the needs of the greater whānau must be addressed prior to discharge. Fortune (2023) proffered "A Good Journey Framework" to facilitate a coordinated transition home (Figure 3), derived from in-depth interviews.

Figure 3.

Facilitators to a 'Good Journey' through Neurodevelopmental Follow-up.



From "Managing mothers' and fathers' uncertainty during their journey through early neurodevelopmental follow-up for their high-risk infants—A qualitative account" (p. 8), by Fortune et al., 2024. Copyright 2024 *Child: Care, Health and Development*. Used with permission, see appendix T.

This framework was the outcome of a small study (n=8 participants) in Liverpool, England, as part of a pilot face to face physiotherapy led follow-up clinic for 'at-risk' babies, using in depth, one to one qualitative interviews at two time points, before and after the 12-week follow-up. The authors found that transitions can be well managed by teaching parents to care for their infants independently and by providing opportunities for 'rooming in' in the NICU. Uncertainty during this transition can be managed through clear communication and a designated post-discharge point of contact, including follow-up calls from professionals focused on the baby's and parents' well-being (Fortune et al., 2024), along with meeting the health professionals in the NICU who will support caregivers at home prior (DiBari & Rouse, 2023; Fortune et al., 2024).

While this framework highlights facilitators for a transition home, it does not account for the wider whānau context, focusing instead on the mother-father (parent-child) dyad. Spiritual practices and the importance of the whānau collective within the Aotearoa New Zealand context need to be explored, as non-parent whānau members play an integral part in a successful transition home by contributing to the whānau's overall well-being (Adcock et al., 2021). Further study within the Aotearoa New Zealand context could strengthen and build on Fortune and colleagues' (2024) findings from their small study by attending to the specific healthcare system, cultural and whānau contexts.

For a safe and successful transition home, health professionals need to consider the practical and emotional support leading up to and at discharge, as well as socioeconomic, spiritual and non-parent whānau supports, which can make all the difference to families by reducing stress and uncertainty. This literature review provides experience and recommendations; however, it is unclear how service providers operationalise these to ensure that infants and parents are optimally supported, especially within the Waikato context, where there is no dedicated neonatal therapist in the NICU. Most evidence focuses only on parental dyads, without considering other non-parent family members and networks that support

the infant and baby, as well as the unique contextual and cultural factors that shape their fulfilment of parental roles and resilience.

2.9 Experiences of Diagnosis

As outlined in Chapter 1, those babies most at risk will receive diagnostic and developmental monitoring support that begins in the NICU and continues through the early discharge period. While the literature documents parents' experiences are a traumatic, overwhelming and stressful time, early diagnosis is a priority for these parents (Byrne et al., 2019). Church et al. (2025), in their literature review on parental experiences of communication diagnosis of CP, found that delays in diagnosis lead to further frustration and stress and delayed access to EI. Åberg et al. (2025), using a phenomenological, reflective lifeworld approach involving 14 parents, found that when the GMA result was unclear, such as a possible risk for non-CP outcomes, uncertainty was heightened and prolonged. This contrasted with experiences in which the diagnosis and certainty were clear. Morgan et al. (2023) undertook a qualitative inquiry as part of a large randomised controlled trial (RCT) that included a cohort of mothers' experiences of the CP-specific early evidence-based intervention, GAME, in Australia. They found that diagnosis was a turning point for mothers' emotions and that all parents concluded that early diagnosis was beneficial despite prognostic anxiety. This finding highlights a gap between how parents experience non-CP and CP outcomes.

Within the Aotearoa New Zealand context, Williams et al. (2024) employed a participatory codesign approach, involving families of children with CP, two cohorts (Māori and non-Māori), and professionals to explore experiences of early diagnosis and management of CP. The main need identified was compassionate, clear communication during this diagnostic phase (Williams et al., 2024). The authors found many instances of miscommunication and frequent assumptions about what professionals had communicated. Families felt that professionals were hesitant to give a diagnosis of CP or that parents discovered the diagnosis by chance. This led to "feelings of fear, shock, feeling alone, unsupported, betrayed, excluded, and isolated, and a need to adjust to the new normal and 'simply trying

to cope'" (Williams et al., 2024, p. 4). Parental experiences in Aotearoa New Zealand parallel those observed in other high-income countries, such as Australia, the United States of America, and England (Harniess et al., 2024; Morgan, Badawi, & Novak, 2023; Van Der Kemp et al., 2024) where parents again discovered the diagnosis by accident (Morgan et al., 2023), and hesitation to provide a diagnosis and a lack of transparency were described as a "misalignment of knowing" (Harniess et al., 2024, p. 3069).

While the literature appears to be in consensus that early detection and diagnosis is a challenging path marked by upheaval and uncertainty. Timely, honest, validating and clear communication by health professionals with parents and carers represented a turning point and created opportunities to build strong, collaborative relationships. However, upon scrutiny of the literature, parents continue to have many negative experiences throughout this process, warranting further examination. Again, there is a disconnect between the evidence and implementation into practice.

Professionals may fear that early diagnosis will negatively affect parent-child bonding. This common belief has been largely disproven by many studies (Church et al., 2024; Dickinson et al., 2023; Morgan, Badawi, & Novak, 2023) which reveal that early identification of a high likelihood of a developmental difference had positive effects on parent-child bonding and helped parents make better decisions for their child. However, it needs to be noted that in tension within the literature regarding these previous findings, as Røhder et al. (2025) found that mothers of infants at high 'risk' of CP had a significantly higher risk of postnatal depressive symptoms (15 times more likely) than mothers of children without risk. This could decrease parent-child interactions, affecting bonding.

However, if there are barriers to accessing early detection services, parents are left in a stressful wait-and-see period, with delays in receiving EI (Davidson et al., 2025). This scenario is challenging for professionals, who must sensitively navigate this situation given these tensions. Consideration is required of the impact of early

diagnosis on parents' mental health and the parent-child relationship, as responses are likely to be highly individual, and of how this links to psychological services as needed.

In many cases, therapists conduct timely diagnostic assessments and initiate early therapy in parallel. Research also does not explicitly recognise this parallel process of diagnosis and the commencement of therapy. Medical professionals (neonatologists, paediatricians) are responsible for making the formal diagnosis, drawing on information from these assessments. This leaves the therapist in a position of 'knowing' without being able to provide a diagnosis. Therapists feel ill-equipped and lack formal training in negotiating these situations (Church et al., 2025; Dickinson et al., 2023; Elvrum et al., 2025; Williams et al., 2024) and may not have access to counselling for families (Novak et al., 2019). This creates ambiguity, placing therapists in a difficult ethical position. Dickinson et al. (2023) suggest that therapists working with this cohort of children should have formalised grief training, so they can support parents in ways that normalise feelings of grief and loss. A multidisciplinary (MDT) approach is required, in which parents are supported, provided with the right information to address knowledge gaps and communicated to with compassion by experienced medical and allied health professionals. To my knowledge, there are no condition-specific courses for therapists who work with at-risk babies and their families. In addition, there is a knowledge gap regarding whether the parallel process of assessment and early therapy hinders the establishment of the vital therapeutic relationship.

Recognising and diagnosing CP and non-CP outcomes can be complex for parents and professionals. Communication during this period should be clear, compassionate, honest and timely. The research indicates that providing both practical and emotional support early on, along with professional training, is essential to reducing the uncertainty and stress families might face. The research also highlights misalignments between policies and practice.

2.10 Experiences of the Concept of Neuroplasticity

As discussed in the background chapter, neuroplasticity is the brain's response to experience and is a foundational theory underpinning EI. Care must be taken when using terms such as 'neuroplasticity', as they can be barriers or facilitators. The way neuroplasticity and the 1,000 days concept are framed in health professionals' explanations to parents and caregivers can be mistakenly interpreted as the brain being able to 'fix' or 'reprogramme' itself, when this is simply not the case. It provides the best opportunity within a window when the brain is most responsive to change (Dan, 2025). Language can serve as a motivator and a means of proactivity (Harniess et al., 2024). Conversely, it can be viewed as a time limited period, as Harniess et al. (2024) found in a qualitative study of parents' experiences engaging in EI. These parents saw this idea of neuroplasticity or the 'critical period' similar to a 'sand timer effect' or language that creates urgency. This can lead to a feeling that time is running out or a loss of control, resulting in intense pressure. (Harniess et al., 2024). There is a dualistic tension between hope and pressure.

Furthermore, misinterpreting the process of neuroplasticity, such as viewing it as 'fixing' the child rather than 'changing' or reaching their potential, may reinforce ableist attitudes about disability that need to be addressed within the EI space (Paleg et al., 2025). Thoughts on the 'critical period', 1,000 days and experience-dependent neuroplasticity provide neuroscientific foundations for how the EI can harness a time when the brain most easily adapts, but the framing of these concepts for parents and caregivers should be balanced, honest, not alarmist or based on ableist attitudes. However, this literature appears to assume consistent access to services, which may not reflect the realities of regional or resource-constrained contexts.

2.11 Readiness to Engage in Early Intervention

The NICU admission, transition home and early diagnostic process set the scene for readiness to engage in EI, with parental trauma from birth and subsequent NICU journey, as well as parental mental health influencing engagement (Harniess et al., 2024; Lehtonen et al., 2022). Therapists often assume that parents and carers

understand what the various disciplines do. Parents in Gibbs et al.'s (2019) study were unclear about the specific roles of therapists, such as physiotherapists, occupational therapists and speech language therapists, and about what they would provide, which led to early misunderstandings. This could be an early barrier to engagement but it is largely unexplored.

Readiness to engage with EI was a feature of the selected qualitative research. Parents manage this time of engagement in many individual ways. Some adopt a pragmatic approach, with parents reporting that they compartmentalise their emotions and pain, while others take it one day at a time or adopt a protective psychological position of avoidance and denial (Dickson et al., 2023; Fortune et al., 2023; Harniess et al., 2024). Some parents described their experience as begrudgingly engaged in EI, describing feeling unwilling or not ready to accept that their infant has developmental delays (Harniess et al., 2024; Little et al., 2025). These highlights from the research identify some potential early barriers to engagement.

2.11.1 Building a Therapeutic Partnership – 'The Trusted Therapist'

In parallel with readiness for engagement in EI by parents and caregivers, the literature is in alignment that building a trusting and collaborative relationship is the foundation of successful EI. The 'trusted therapist' is seen as more than just a provider of therapy; they are a 'lifeline' (Wise & Gellasch, 2022) and become a source of strength to the parent and caregiver (Morgan, Badawi, & Novak, 2023). The concept of the 'trusted therapist' recurs throughout the literature (Harniess et al., 2022; Morgan, Badawi, & Novak, 2023; Øberg et al., 2023; Vurrabindi et al., 2025). The therapist both provides practical strategies and answers questions, offers crucial education, and maintains supportive, encouraging, sensitive and patient attitudes (Morgan, Badawi, & Novak, 2023; Wise & Gellasch, 2022). Skilled therapists working as a coach, empower the parent and caregiver in their confidence and capabilities in supporting their child's development (Massey et al., 2023). This fosters a sense of control, ameliorating uncertainty through this trusted partnership (Håkstad et al., 2016). When compassionate FCC is provided in a culturally

sensitive way, the health care professional is seen as a 'champion' (Adcock et al., 2022) and a source of reassurance, which is crucial for building trust.

Empowerment through partnership has been shown to be a key determinant of success, with parents valued as equals and experts in their own child (Gibbs et al., 2019), thereby elevating parental stress (Øberg et al., 2023). Øberg et al. (2023) conducted a synthesis of current research focusing on reconceptualising what parents perceive as meaningful and motivating when participating in EI programmes. The key findings indicated that parents need to take an active role in their child's EI, acting as 'interventionalists'. Regarding EI, key features of effective and rewarding participation involve focusing on parent-infant interactions and developing parental confidence through the guidance of a skilled therapist who helps them recognise their own capabilities as well as their infants'. This contrasts with seeing parental engagement as parents following a strict programme, which can undermine parents' confidence and lead to feelings of guilt and shame (Harniess et al., 2022). When therapists work in partnership with parents to co-design programmes and set realistic, collaborative goals, it has the knock-on effect of empowering parents (Harniess et al., 2022). However, relationships take time to develop (Kruijsen-Terpstra et al., 2016), may not be linear (Harniess et al., 2024; Harvey et al., 2025) and the therapist needs to be purposeful in fostering these vital relationships.

Therapist consistency can help establish an enduring relationship between therapist and parent; however, this is not strongly represented in the literature. Gibbs et al. (2019) found that having a consistent provider is considered essential to maintaining a strong, ongoing relationship with the therapist. While ideal circumstances would involve the same therapist, staff may leave their roles, necessitating a transition to a new therapist. This can be seen as a setback in a vital relationship, requiring time to reestablish the foundation of trust and confidence (Gibbs et al., 2019). Facilitators of a good transition included a carefully planned, well-communicated handover and, if possible, a face-to-face handover with the new therapist (Gibbs et al., 2019). These findings come from the experiences of only

mothers in a small cohort (n=6) within the English health system, and while they seem logical and practical, they need to be explored in other contexts.

Transitions from the NICU to home have been thoroughly explored; however, there is minimal exploration of the experiences of transitions between therapists or among different EI services for infants and their caregivers receiving EI who have been identified as at higher risk for adverse neurodevelopmental outcomes, representing a knowledge gap. As previously stated, given the service gaps and the lack of dedicated allied health in the NICU, it is unknown how this could affect readiness to engage with EI and the establishment of the therapeutic relationship beyond the hospital environment in the Waikato context.

2.11.2 Empowerment through Coaching

Coaching is a contemporary mode of delivering EI that involves a collaborative, reciprocal relationship between the caregiver and therapist (Seruya et al., 2022). It is a solution-focused, strengths-based approach in which the parent leads the intervention with their infant (Akhbari Ziegler & Hadders-Algra, 2020; Morgan et al., 2023; Morgan et al., 2021). Coaching parents to actively participate has been shown to support them in fulfilling their role as parents; enhance their confidence in their skills; and foster empowerment, self-efficacy and autonomy (Massey et al., 2025; Øberg et al., 2023; Ochandorena-Acha et al., 2022; Seruya et al., 2022). Coaching ensures infants receive adequate practice (dosing) beyond structured therapy sessions (Morgan et al., 2023). Research demonstrates that coaching promotes attachment by enhancing parenting skills and helping parents recognise the infant's cues, readiness for interaction and stress behaviours (Seruya et al., 2022). There is a shift towards coaching models of intervention, in which the parent leads the 'therapy' but this may not align with parents' concepts of what therapy should look like.

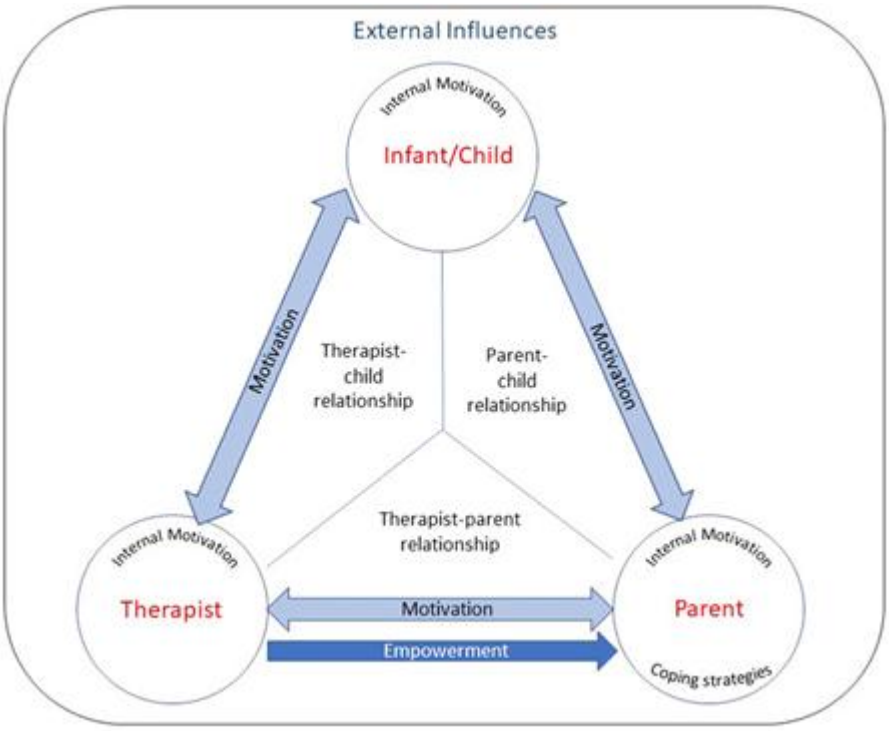
The literature details differing parental opinions on parent-led intervention in Western contexts. Some parents view active participation in therapy as overwhelming and stressful (Harniess et al., 2022). Parents' expectations may be

that the therapist 'treat' during the intervention and have a non-active role watching the session, then receiving information and advice (Akhbari Ziegler & Hadders-Algra, 2020). Others believe that if they are not involved in a hands-on capacity, it may lead to disengagement from therapy (Harniess et al., 2022) and that therapy can be viewed as the parents' responsibility (Hurd et al., 2024). In many cases, a coaching approach to therapy helped with sense-making and rebuilt a sense of control or agency (Øberg et al., 2023; Harniess et al., 2022). Parents and caregivers providing intensive practice as part of therapy, such as modified constraint induced movement therapy (CIMT), find it demanding but 'doable' (Verhaegh et al., 2022). The therapist needs to consider parents' preconceptions about what therapy looks like to avoid misunderstandings and explore ways to lighten the burden of therapy.

The key to parent-led intervention lies in the triad of relationships among the parent/caregiver, child and therapist. Key elements supporting parent-led interventions include providing timely feedback on parents' progress, as well as positivity and optimism (Verhaegh et al., 2022; Williams et al., 2019). Lord et al. (2018) used a literature review to identify the three main ingredients of successful parent-led interventions: empowerment, motivation and reciprocal relationships for children and young people aged 0–18 years with CP. These authors proposed a model of influences on parent-delivered therapy (Figure 4). This model links internal and external influences and relationships, providing a conceptual framework for therapists to consider how they frame EI when establishing a successful parent- or caregiver-led model of care. Due to the wide age range of children represented in the studies included in this review, the relationship between the therapist and infant/child is likely overemphasised for under 2-year-olds. As previously stated, during this developmental period, the parent-child relationship is the most salient.

Figure 4.

Model of Influences on Parent-delivered Therapy



From "Determinants of parent-delivered therapy interventions in children with cerebral palsy: A qualitative synthesis and checklist" (p. 666), by Lord et al., 2018. Copyright 2018 *Child: Care, Health and Development*. Used with permission see appendix T

Massey et al. (2025) examined barriers and facilitators to parent-delivered interventions for infants 'at risk' of or diagnosed with CP, using a behavioural change model to guide practice recommendations. Through their synthesis of the evidence, the researchers concluded that "addressing knowledge gaps, skill and capacity of parents and therapists. Therapists forming strong alliances with parents and setting collaborative, realistic goals are key to successful parent-delivered interventions." (Massey et al., 2025, p. 287). Harvey et al. (2025) used a constructivist grounded theory methodology within the Aotearoa New Zealand context, interviewing and filming occupational therapists (n=8) and parents (n=11) during therapy sessions to develop the "Responsive Learning: Learning from and with each other" theory (p. 6). This theory further highlights the dynamic, highly

relational, collaborative, adaptive and two-way nature of a therapeutic relationship, where mutual learning occurs.

Coaching is increasingly integrated into therapy practices (Akhbari Ziegler & Hadders-Algra, 2020). For coaching to be effective, it must focus on strengths, recognise the reciprocity of the relationship and consider the child, family, therapist and context. While the research highlights these highly relational strategies for effective EI, it remains unclear whether they align with parents' and caregivers' experiences in this research setting. Furthermore, other non-parental supports and their role in coaching have not been examined and are not represented in the conceptual models.

2.11.3 Collaborative Goal Setting

Collaborative goal setting that considers the family's unique needs helps parents and therapists stay aligned, a key feature of successful FCC EI (Elvrum et al., 2025). Momentum can build throughout the therapy journey as trust in the therapist increases, supporting the belief that the intervention will benefit their child. This fosters a sense of control and motivates ongoing engagement (Harniess et al., 2022). Harniess et al. (2022) also emphasised that realistic time commitments must be considered when therapists provide home programmes, as this helps parents see EI as achievable. These strategies can lead to increased parental self-efficacy, better adherence and commitment to home programmes and greater confidence in parenting.

2.11.4 Family Centred Care

The concept of FCC was discussed in the background chapter. While there is broad agreement across the medical and allied health communities, and a wide range of health and disability sectors, that FCC care is ideal, this may not be reflected in practice (Bamm & Rosenbaum, 2008; Purdy et al., 2015). McCarthy and Guerin (2022) found that implementing FCC is challenging in practice. Time pressures at appointments, staff changes, lack of insight, parents' and caregivers' perception that they are not being listened to and cultural misalignment have been cited as some

reasons why it may not be happening in practice (Adcock et al., 2021; King et al., 2025; McCarthy et al., 2020). McManus et al. (2020) in a cross-sectional study, found that families' needs and priorities are not always inquired into or addressed. In addition, these authors found that therapist and caregiver intervention goals may not be fully aligned. FCC, as a philosophical approach, offers many insights into how parents can engage with and access EI for their child; however, health professionals must be intentional in adopting this approach and in practice it may not be happening to ensure effective outcomes.

Balancing family life and therapy requires careful navigation, given the many demands of daily life, especially when there are other children. The therapist needs to be sensitive to the many roles parents play. The primary role of the parent is to nurture and love their child. Siblings and other activities essential to family life must also be considered. With the added role of being 'therapist', care must be taken to ensure that all the fun is not taken out of this precious stage of life, where every playtime becomes therapy (Harniess et al., 2024; Morgan et al., 2023). Maintaining a balance between therapy, having fun and unstructured exploration is essential (Church et al., 2024). There needs to be realistic expectations about the time commitments of home programmes (Harniess et al., 2022), for example, 20 minutes of practice per day, 5 days a week.

Interventions that recognise the family as the experts on their child within an FCC model, support the parent-child relationship and encourage parent-delivered interventions are likely to achieve the best developmental outcomes. While these approaches are well established, the extent to which they are experienced in practice remains unclear.

2.12 Communication and Information

Clear communication plays a vital role in parents' experiences of EI and warrants discussion, given the wealth of recent research on this topic specific to 'at-risk' infants and their families and the implications for EI engagement. Communication includes face-to-face meetings, providing diagnoses and prognoses, explaining

assessments and outcomes and discussing the benefits and risks of recommended treatments. Throughout the literature, another recurring theme is the need for clear, transparent communication by health care professionals (Church et al., 2024; Harniess et al., 2023; Håkstad, Obstfelder & Øberg, 2016; Williams et al., 2021; Williams et al., 2023). Clear, transparent conversations, including the translation of medical jargon, ease stress for parents and caregivers, enhance psychological well-being, and positively enhance parents' involvement in EI (Ropero-Padilla et al., 2025; Williams et al., 2024). Inconsistent, vague or poor communication has the opposite effect, exacerbating anxiety and distress (Håkstad, Obstfelder & Øberg, 2016). Explaining the types of therapies, the evidence for their effectiveness and the rationale for the chosen intervention has been shown to increase adherence and motivation (Harniess et al., 2022). Clarity around follow-up pathways and appointments booked in advance assists with planning and reduces uncertainty, anxiety and stress (Fortune et al., 2024).

It can be challenging for parents to recognise that their infant has a developmental need that requires EI, especially when the infant is very young (Little et al., 2015; Sapiets et al., 2021). Harniess et al. (2022) found that parents need to understand their infant's needs and how therapy can support development before they are open to investing time in EI. A balance between strength and a deficit focus is nuanced. A key ingredient in building greater parental awareness is sensitive, honest and clear communication that helps parents understand the importance or value of EI (Little et al., 2015). This is achieved through tailored parental education on the child's condition and the rationale for the interventions that can be provided, aiding parental understanding of the nature of the infant's concerns, which may not be entirely evident to the untrained caregiver.

Communication and information provision can take multiple forms, such as phone calls, teleconferencing, email and text messages. Digital reminders have been shown to reduce non-attendance at follow-up appointments (Fortune et al., 2024). Receiving check-ins via mobile or teleconferencing between visits can help with troubleshooting and support the application of suggested therapy or home

programme ideas (Raghupathy et al., 2025; Treyvaud et al., 2019; Whittingham et al., 2025). Use of diaries has been shown to be a useful resource for fostering focus and accountability (Harniess et al., 2022). Information provided in written form, such as programme ideas, aids with engagement (Raghupathy et al., 2025). Care is required to ensure that information is targeted at the appropriate health literacy level. Educational resources and guidance on next steps help reduce stress (Granero-Molina et al., 2018).

Seeking information online has been shown to be overwhelming and can lead to misinformation (Ropero-Padilla et al., 2025; Williams et al., 2024). Williams et al. (2024), in their participatory approach in the Aotearoa New Zealand context, found that parents do not receive information from health professionals; they seek answers elsewhere, such as the internet (e.g., 'Dr Google'). Ropero-Padilla et al. (2025), used a qualitative descriptive methodology involving interviews with 21 parents, and reported a persistent lack of structured communication and information practices. It is an ethical responsibility for health professionals to communicate options and evidence-based choices in EI. Many 'therapies' claim cures or extraordinary outcomes, often at great financial and social cost and require expert handling (Paleg et al., 2025). Therapists can direct families to credible websites and journal articles, including those on alternative therapies (Hurd et al., 2024). Novak et al. (2020) provided a traffic light for interventions to inform decision-making. Baraldi et al. (2020) discussed how social media groups in the Swedish context may fulfil roles of companionship and information sharing, especially in the absence of naturalistic supports. Parents and carers will seek out evidence but may be overwhelmed by the amount of information. Therapists can play a role in linking parents to resources that provide balanced, accurate information so they can make informed decisions about EI.

There is a paucity of literature on parental or caregiver health literacy and engagement in EI for this population. This is an important consideration when reflecting on communication and the provision of information. Children with childhood-onset disabilities are high users of healthcare services (Nevill et al.,

2025). This means parents and caregivers need to both communicate with healthcare professionals and understand and interpret the healthcare information provided. In a recent systematic review, Zaidman et al. (2023) found that poor parental literacy and low health literacy negatively impact health outcomes for children with chronic diseases such as asthma, cystic fibrosis, congenital heart disease and seizures. Generalising these findings to the study population can offer insights, given the complex nature of childhood-onset disability, allowing similarities to be drawn. However, specific research into this population is needed. In this study, lower socioeconomic status was associated with worse health outcomes in the same cohort but disease-specific knowledge, particularly targeted at mothers, can mitigate poor health literacy and improve health outcomes (Zaidman et al., 2023). There is much to learn about health literacy and its impacts, particularly within this cohort, and this warrants further investigation.

Complex language and jargon may further alienate families. Some information on the internet can be overwhelming and not country-specific (Williams et al., 2023). Williams et al.'s (2023) research has led to the production of a booklet for tamariki (children) with Hōkai nukurangi (CP) in Te Reo Māori (Māori language) (Cerebral Palsy Society, 2025). This has now been translated into Samoan and Tongan, providing clear, up-to-date, specific information which is culturally and linguistically accessible. This demonstrates a genuine effort to offer condition-specific information and enhance the accessibility of health information for parents and caregivers.

Parents value neutral language when it comes to diagnosis (Church et al., 2024; Kim et al., 2025), with a shift away from the term 'at- risk'. Value-neutral terminology used in the literature includes 'high probability of CP', 'high chance of adverse neurodevelopmental outcomes', 'high likelihood', 'suspected', and 'under surveillance' (Church et al., 2024; Williams et al., 2024). 'High- risk' labelling is seen as perpetuating ablism, automatically regarding differences as deficits (Kim et al., 2025). The terminology 'at risk' is currently used throughout the literature, predating this work. These researchers call for health professionals to

use non-pathologising and strengths-based language (Dickson et al., 2023; William et al., 2023). Accessible, strengths-based communication and information are essential ingredients identified in the literature as supportive of parents and caregivers along the EI journey. It will be noted on most occasions that this report uses 'high likelihood', whereas other literature uses 'high risk'.

Communication practices in the literature are varied, with the emergence of strengths-based language featuring strongly in recommendations. Given the time it takes to translate research into practice, it remains unknown what the experiences of Waikato's NICU graduates' parents and caregivers are. It is also unknown how their experiences prepares or affects readiness to engage in EI.

2.13 'Home Sweet Home' – Home-based Intervention

Providing therapy at home aligns with international guidelines for early support for children under 2 years of age (Morgan et al., 2021; Novak et al., 2017). The home environment can be arranged to provide many opportunities for infants to explore and practise task-specific skills. The therapist can guide parents and carers to create an enriched setting that offers a range of experiences, both challenging and supportive of the infant's development (Morgan et al., 2023).

In home-based settings, especially during the first 2 years, multiple studies have shown that EI is a strong facilitator with many benefits (Akhbari Ziegler et al., 2019; Morgan, Badawi, & Novak, 2023; van Maren-Suir et al., 2018). The advantages of home-based therapy include the ability to see 'the whole picture', which allows the therapist to offer more personalised advice and adopt an individualised approach, enabling the child to learn skills in their own environment (Elvrum et al., 2025). Home-based therapy is also considered more convenient because it removes the need to travel to a therapy centre (Morgan et al., 2023). It provides opportunities to discuss with parents and caregivers how to adjust programmes to suit the child's routines and needs. Caregivers often find that the child is more relaxed in a familiar environment, enabling the child to demonstrate a broader range of skills, which parents believe leads to better outcomes (Morgan et al., 2023). Additionally, the

child can be more rested and ready to play (Elvrum et al., 2025). It is also reported to be easier to establish a relationship with the therapist when the power dynamic is more equalised (van Maren-Suir et al., 2018). A qualitative study explored parental experiences of Parent-Delivered Baby modified CIMT, a therapy aimed at addressing unilateral upper limb concerns in infants. Semi-structured interviews with eight parents found that the home setting was more naturalistic, allowing parents to set up in their own environment and encouraging a solution-focused approach (Svenssson et al., 2024). Most of the cited studies were conducted in the European context (the Netherlands, Switzerland and Sweden), where therapy typically takes place in clinics and home-based interventions may not be considered standard practice (Akhbari Ziegler, Mitteregger & Hadders-Algra, 2019; van Maren-Suir et al., 2018). In Aotearoa New Zealand, however, home visits during the first 2 years of EI are common, which may have influenced the documented experiences. No studies have examined parental experiences of home-based therapy for infants at high risk of neurodevelopmental concerns, both CP and non-CP, in the Aotearoa New Zealand context.

Home-based therapy offers unique opportunities, such as involving siblings (Elvrum et al., 2025) and extended whānau/family as part of an FCC approach. Older siblings are rarely discussed in the literature; however, having a sibling with additional needs does affect children, with reports of jealousy towards the child with additional needs (Knis-Matthews et al., 2011). Caregivers need to balance competing demands on their time, especially when there are other children in the family (Gibbs et al., 2019; Verhaegh et al., 2022). Involving siblings in play activities makes activities more fun and salient while fostering sibling relationships and inclusivity, aligning with a family-centred approach that considers the needs of the whole family (Morgan et al., 2023).

Home-based therapy has certain limitations. Some EI providers mentioned that home environments can be noisy or distracting and therapists observed that they often stay too long at appointments (Van Maren-Suir et al., 2018). Others found it difficult to schedule because sessions were only available during working hours

(Gibbs et al., 2019). Long-term adherence to home-based therapy can be challenging to maintain amidst family pressures, which can also impact other children in the household. Adherence to programmes often declines over time, especially when therapist home visits are reduced (Seruya et al., 2022). Conversely, some parents find centre-based therapy more engaging because of its novelty and the variety of toys, which can be motivating (Hurd et al., 2024). Previous experiences with other agencies, such as child protection services, can be seen as a barrier to EI within the home (Little et al., 2015). Given these facilitators and constraints, a one-size-fits-all approach should not be taken. The limitations of home visiting have only been broadly explored, with the advantages receiving more attention in the current literature, creating an opportunity for further exploration of parents' and caregivers' perceptions. These could offer insights into barriers and facilitators to home visiting, providing a deeper understanding.

Sometimes parents need to step away from the home environment and seek support elsewhere. Workshop-style interventions, from a strengths-based perspective, aimed at resourcing and connecting with peers, can shift how parents view their situation and themselves as parents and reshape their relationships (Miller et al., 2023). While home-based interventions offer many benefits, they can also be isolating for parents, highlighting the need for a holistic FCC approach that considers each family's structure and unique needs, which may evolve over time.

2.14 Family Structures – Whānau Collectives

Successful parent-led EI is closely tied to family dynamics. Success depends on a supportive, collaborative family environment with shared responsibilities. It also relies on support from the entire family network, companionship, understanding and a balance between the demands of 'therapy' and everyday family life. Baraldi et al. (2020) discussed how preterm birth alters relationship dynamics, with varied experiences documented. These include relationship separation, while others feel they would never have made it through the year without their partners. This further highlights the complexity of this EI journey and the pressures the additional care burden places on the family unit.

Family structure, such as joint or nuclear, can influence caregiving dynamics. A joint family is an extended household where multiple generations live together. A nuclear family consists of two parents and their children. In joint family systems, such as those in India, other family members often serve as caregivers, assisting with care and EI activities (Ragupathy et al., 2025). Within the Te Ao Māori worldview, Adcock et al. (2021) highlighted the importance of non-parent whānau who support mothers and fathers as whānau collectives. The interaction among family dynamics, culture and values is highly complex and requires the therapist's consideration and understanding.

2.14.1 Roles of Fathers

Fathers are underrepresented in research on parenting and supporting children in the first 2 years in this field, with mothers' voices and perspectives typically dominating the documented viewpoints (Bogossian et al., 2019). The literature indicates that fathers face a unique set of challenges, including difficulty forming an attachment to their child, perceived role restrictions and difficulty gaining a sense of competence in caring for their infant (Bogossian et al., 2019; Raghupathy et al., 2025). Väliaho et al. (2021) found that fathers play distinct positive roles, such as caring for older children and supporting the family financially by continuing to work. Fathers can offer emotional support and companionship, which boosts the family's overall ability to engage in EI (Harniess et al., 2022; Väliaho et al., 2021). Elvrum et al. (2024) conducted a qualitative inquiry into parents' perceptions of the small-step program for children at risk of or diagnosed with CP in Norway. The study included participants with both parents living at home (n=8) within a traditional nuclear family but did not explore how gender roles might influence the results. The researchers recruited five fathers from the 13 participants; however, they did not examine differences between fathers' and mothers' perspectives. Although not the original aim of the research, doing so may have offered useful insights into how family structure influences engagement. Bogossian et al.'s (2019) scoping review identified areas for further research on fathers of children with neurodisability and offered recommendations, such as gaining insight into the roles

fathers play and the unique challenges they face, which may have clinical relevance for service delivery.

2.14.2 Non-Traditional Family Structures

Non-traditional family structures, including single-parent households and LGBTQ+ families, may influence how EI services are engaged in, yet are underrepresented in the literature. Yinger et al. (2024) found in an integrative review of LGBTQ+ parents whose babies had a NICU admission that they experienced health disparities, including higher rates of stress, anxiety, depression and avoidance or postponement of medical care due to fear of discrimination. These factors could lead to negative outcomes for both parents and their infants, highlighting a potentially socially disadvantaged population. Although this study focused specifically on NICU experiences, the small number of parents represented (n=12) stresses the need for further investigation, particularly regarding how these factors might influence engagement in EI. EI providers need to be sensitive to the needs of LGBTQ+ families to remove barriers to care and align with the principles of FCC to ameliorate potential disparities.

2.14.3 Role of Grandparents

Grandparents and extended whānau, as non-parent whānau, have been shown to play key support roles, including financial and practical help (Baraldi et al., 2020; Granero-Molina et al., 2018; Raghupathy et al., 2025; Väliaho et al., 2021). However, there is limited research on EI experiences within this group. Working together as a collective with non-parent whānau supports parental resilience (Adcock et al., 2022). Grandparents provide emotional and financial support, manage practical tasks such as childcare and housework, and sometimes assume therapeutic roles (Novak-Pavlic et al., 2022). They have unique experiences with their grandchildren and have been reported to feel guilt like that of their adult children. This is described as ‘double grief” or suffering twice (Rosenbaum, 2016). It involves concern for their grandchild and their own child (the parent), who is going through a difficult time (Findler & Taubman-Ben-Ari, 2016; Novak-Pavlic et al., 2022; Rosenbaum, 2021). Inviting extended family, such as grandparents, to

appointments and therapy sessions so they can also receive information and be active participants may help lessen this grief (Rosenbaum et al., 2021).

Some grandparents choose to move closer to their family to provide support, which can affect their financial stability and increase social isolation (Findler & Taubman, 2016). Research shows grandparents often prioritise their family's needs over their own, risking physical and emotional health issues (Novak-Pavlic et al., 2022). As many take on custodial roles for their grandchildren, therapists need to be resourceful in connecting families to appropriate services that offer specialised support. This highlights the importance of including grandparents' perspectives in research to ensure all viewpoints of those involved with the child are heard.

The therapeutic relationship in EI is shaped by the complexity of family dynamics, which depend on shared responsibilities, often across generations, and are shaped by culture and social norms. Broadening research to include the perspectives of marginalised groups, such as LGBTQ+ parents, single parents and the extended whānau will help ensure equitable access to services. This review highlights areas where researchers have not yet explored, potentially offering valuable insights into how EI is accessed and engaged if investigated.

2.15 Transformed Parenting

When infants require EI, parents' experience of parenting is fundamentally altered. Transformed parenting theory, as outlined by Seideman and Kleine (1995), describes the social process parents go through when facing additional parenting challenges linked to having a child with a disability. Parents navigate a complex, non-linear journey involving stress, coping, chronic sorrow and adaptation. This theory integrates chronic sorrow theory, which explains the recurrent emotional responses to tragic circumstances, such as having a child with a developmental disability resulting from an early or traumatic birth that cannot be fully resolved (Vitale & Falco, 2014; Whittingham et al., 2013). Parents often grieve and lose the perception of the 'ideal child' (Granero-Molina et al., 2018); however, with chronic sorrow, these feelings may intensify over time. There can be a disconnect between

parenting expectations and the realities of raising a child with additional needs. While grief may resurface at times, such as on birthdays or special milestones, certain triggers, such as a therapist providing supportive equipment like a feeding seat or wheelchair, can also trigger these feelings. Healthcare professionals must recognise these responses as normal grief and identify parents who might be at risk of chronic sorrow. Therapists working in EI must be sensitive, connect parents with support groups and facilitate referrals to additional services when needed. Being aware of potential trigger points, even years post-diagnosis (Whittingham et al., 2013) and reassuring parents that these reactions are normal supports a non-pathologising approach (Dickinson et al., 2023; Elvrum et al., 2025). Part of this process involves parents eventually reframing their experiences, finding moments of happiness and resilience and seeking support to find solutions (Vitale & Falco, 2014). This cycle underpins transformed parenting, which is deeply rooted in the caregiver's lived experience.

2.16 Connection – Peer Support

Connecting families with peer support from other parents, families and communities can both facilitate and hinder engagement in EI. Sharing feelings and experiences with other parents can reduce isolation and loneliness (Ochandorena-Acha et al., 2022). It can support parents' mental health through shared connection (Treyvaud et al., 2019). Peer support can serve as a practical knowledge exchange that reinforces professionals' messages (Berg et al., 2023). Green et al. (2016) found that Aboriginal families (First Nations Peoples of Australia) wanted to connect with other Aboriginal families in support groups within their local area. While these authors reported that this was positive for families, they also noted concerns that respected elders offered conflicting advice, such as that the child 'will pick in their own time', even when parents suspect something is wrong. This peer-to-peer connection may add to ambiguity and erode trust in health professionals. This indicates that models of care are culturally misaligned and require greater understanding to ensure families do not have to contend with the tension this may cause. New models of care need to be investigated that truly are culturally aligned.

One such model is a peer-delivered EI model, 'Learning through Everyday Activities with Parents for Infants at risk of Cerebral Palsy' (LEAP-CP), which may offer a novel approach to EI (Benfer et al., 2023). This culturally adapted programme promotes parent-child interactions, targets environmental enrichment, supports caregiver mental health and addresses perceptions of the parenting role within a culturally responsive model of care. In a RCT comparing outcomes for families receiving LEAP-CP with those receiving equal-dose health advice in low-income countries with limited resources of trained professionals, LEAP-CP led to superior motor outcomes for ambulatory infants with CP (Benfer et al., 2024). This has now been adapted for First Nations Australian parents with infants at risk of CP, with a large RCT currently being conducted (Benfer et al., 2023). Connections through peer-to-peer and culturally adapted, peer-led models, such as kaiāwhina (Māori for 'assistant') models of EI, may help address barriers to equity and engagement related to cultural factors. This emphasises a potential area for research within the Aotearoa New Zealand context: how to put tino rangatiratanga (self-determination, sovereignty, autonomy) into practice in a tangible way. Such an approach could truly be a transformative way of practising, providing Kaupapa Māori EI services.

2.17 Systemic Barriers

Systemic factors vary globally and can influence access to EI services. In Aotearoa New Zealand, most health services are publicly funded. There are documented parents' experiences that the healthcare and disability system is difficult to navigate (McCarty et al., 2022; Williams et al., 2023) and fragmented (McCarty et al., 2022). Williams et al. (2023) found that families' experiences with healthcare services were "overwhelmingly complex, disconnected, and inefficient" (p. 5). While parents can be empowered to navigate the healthcare system (Elvrum et al., 2024; Gibbs et al., 2019) with the help of therapists, systematic changes driven by consumers' experiences are needed to identify and ameliorate these barriers to care.

Socioeconomic status, defined as the position of individuals or families in society based on occupation, income and education is recognised as an important risk factor

for many childhood-onset disabilities, including CP, ASD and GDD (Durkin & Yeargin-Allsopp, 2018). This literature review found higher rates of GDD (ID) and CP among children from lower socioeconomic backgrounds. For ASD, the review reported later diagnosis, limited access to care, lower identification accuracy and under-diagnosis in lower socioeconomic groups. Social concerns, such as providing food for the family, may be more pressing than EI (Little et al., 2015).

In the Aotearoa New Zealand context, there is a highlighted link between child poverty and disability, with disabled children disproportionately likely to live in low-income households (Wynd, 2015). Wynd found a poverty cycle, which is characterised for caregivers of children with childhood-onset disabilities by extra costs, reduced work opportunities and inadequate support for caregivers of children with childhood-onset disabilities, and this finding is supported by other international studies (Hurd et al., 2024; Wynd, 2015). Chronic poverty and early-life exposure to poverty, from prenatal to age 5 years, are linked to many poorer outcomes, including reduced cognitive and health outcomes (Ministry of Social Development, 2018). Service fragmentation, with poorly coordinated, inconsistent and inequitable access to help, is a barrier to care. Practical solutions offered by Wynd (2015) include comprehensive data collection to fully understand the problem, coordinated services and equitable funding to ensure that children can reach their potential.

This research highlights that having a childhood-onset disability has financial impacts on families who often already face greater financial strains. There may be a cumulative disadvantage in combining poverty with inadequate intervention, which affects neurodevelopmental outcomes and underscores systemic factors that likely influence engagement.

2.18 Geographical Factors

There is a paucity of evidence on the effects of geographical isolation and access to EI. Living in rural areas or small towns, away from the larger centres where services are often based, adds another layer of complexity. An integrative literature review

on experiences of rural mothers caring for a child with a chronic health condition included seven studies, mainly representing mothers from the United States of American and one Australian study. The review found that mothers face additional barriers, including transport and the need to travel long distances to attend clinics (Bristow et al., 2018). The need to travel affects not only parents but also the extended family. It led to time off work, wage loss and, at times, job loss. The parental experience described was one of constant stress, with mothers feeling like prisoners in their own homes (Bristow et al., 2018). This integrative review also found that rural children had more unmet needs and experienced higher rates of poverty.

In Aotearoa New Zealand, most services are based in the main centres. The New Zealand Cerebral Palsy Register (2022) found that 46% of those living with CP in the most socially deprived areas, as measured by the New Zealand Social Deprivation Index, were Māori. Some of the most socially deprived areas include rural and small-town areas, where accessing EI may be hampered by greater barriers. This finding highlights potential sources of inequity.

Telehealth is documented in the literature as an effective and complementary way of delivering EI for infants at risk of developmental delay, especially those who are geographically isolated. Fernandes et al. (2025) found that therapists can perform ongoing monitoring in an acceptable and feasible manner via telehealth. Harniess et al. (2025) contended that video conferencing increased efficiency and flexibility, reducing travel but also introducing new challenges for caregivers. These included increased cognitive load (multitasking), communication issues, additional tasks such as camera work (positioning the device and adjusting angles so the therapist could see the child) and heightened pressure to perform (Harniess et al., 2025). These factors may cause distraction, thereby affecting learning and engagement. The authors concluded that teleconferencing is useful as part of a hybrid model.

Telehealth and home visiting, as a hybrid model, may be part of the solution for more geographically isolated whānau and those who cannot attend clinics, such as

during a global pandemic. The literature highlights the need for research to determine the additional challenges that geographical isolation may pose for access to and engagement with EI services and how these can be mitigated.

2.19 The Influence of Culture and Experiences of Migrant Populations

Culture plays a significant role in shaping people's identities and influences how communities support and perceive disability. These factors can be both facilitative and enabling. Some studies identified culture-related barriers, including low awareness of disability, discrimination, shame and blame directed at mothers, which can lead to isolation as well as specific cultural restrictions on breastfeeding, stigma related to disability, superstitions about cures, limited access to health information and restricted social lives, all of which affect connection with EI services (Chandrasekaran et al., 2022; Dlamini et al., 2023; Harniess et al., 2024; Mwinbam et al., 2023). Facilitators included family belonging, community support, parents with higher education, access to information and healthcare (Chandrasekaran et al., 2022; Dlamini et al., 2023; Mwinbam et al., 2023). Conflicting advice from communities and health professionals can increase uncertainty. How these experiences influence access to EI in the Western context needs further exploration.

Many migrant and refugee families with children need to access EI. Migrant parents and caregivers face greater challenges navigating health and disability services, a phenomenon described as a double minority challenge (Arfa et al., 2020). Language barriers, differing values, goals and behaviours and stereotypical assumptions that lead to inequitable access are reported among migrant families of children with disabilities in Norway (Arfa et al., 2020). Harniess et al. (2024) documented themes of "fatalistic orientation" (p. 3074) and stigmatisation of disability within some cultures in immigrant communities in metropolitan London. Communicating through interpreters is reported as frustrating and can be unprofessional (Arfa et al., 2020). While there is gratitude for services, navigating the system and accessing help felt like a battle (Arfa et al., 2020). Families valued FCC and being involved

in decision-making. These families require additional support and a deeper understanding, and systemic issues affecting migrants' equitable access to services are identified as knowledge gaps. Considering how to support minority communities should be part of all other considerations to ensure equitable access for everyone needing EI services, revealing an additional gap in the research.

2.20 Conclusion

While existing literature provides substantial insight into EI practices, it remains limited in several critical ways. Much of the research is conducted in international contexts and may not account for the structural, cultural and geographic realities of Aotearoa New Zealand. In particular, there is limited understanding of how service delivery models are experienced within mixed urban–rural systems, and how these experiences are shaped by inequities in access, cultural context and health system structure. Furthermore, much of the literature assumes effective implementation of family-centred and coaching-based approaches, with less attention given to how these are enacted in practice or experienced by caregivers. This suggests a need to move beyond describing ideal models of care toward examining how EI is experienced, navigated and understood by families within specific contexts. This study addresses this gap by exploring caregiver and whānau experiences within a regional Aotearoa New Zealand setting.

2.21 Research Aims and Questions

This study explores the experiences of parents, caregivers and whānau of EI services, following positive screening for adverse neurodevelopmental outcomes, for infants born preterm or with health complications, during the first 2 years of life in the Waikato region.

2.21.1 Research Question

What are the experiences of parents, caregivers and whānau of EI services for infants born preterm or with health complications in Waikato, following identification as being at high likelihood of adverse neurodevelopmental outcomes such as CP, in their first 2 years of life?

2.21.2 Objectives

- To describe the experiences of parents, caregivers and whānau of EI services using a narrative inquiry.
- To identify the perceived key needs for EI* for their pēpi/infants, when identified at high likelihood of adverse neurodevelopmental outcomes using early detection tools.
- To explore how parents, caregivers and whānau access early therapy services in the first 2 years of life.
- To observe ways in which any barriers in service delivery might be ameliorated.
- To identify and communicate practice recommendations to service providers and policymakers.

*EI includes physiotherapy, occupational therapy, speech language therapy or conductive education.

Chapter III: Methodology

Tē rapu, tē kitea
What is not sought will not be found

3.1 Introduction

The literature review established the significance of the research and informed the formulation of the research aims and questions, exploring the experiences of parents, caregivers and whānau of EI services, following positive screening for adverse neurodevelopmental outcomes, for infants born preterm or with health complications, during the first 2 years of life in the Waikato region. The methodology provides the philosophical and theoretical frameworks that underpinned and guided this research, including the design, how it is conducted and interpreted (Guba & Lincoln, 1994). This chapter provides the rationale for conducting a narrative inquiry and the qualitative methodology underpinning the research, which is grounded in a pragmatist philosophical framework. Initially, I outline the research paradigm, followed by an explanation of why I have chosen narrative inquiry, including its suitability for this topic. The essential methods for conducting narrative inquiry are outlined in the methods chapter. Finally, I discuss rigour and reflexivity as they relate to this research, finishing with the conceptual framework.

3.2 Research Paradigm – Pragmatism

A paradigm is the belief system or worldview that underpins research, guiding the researcher and the research process (Guba & Lincoln, 1994). This research was conducted within a pragmatic paradigm. Pragmatism, as a philosophy, examines what works in practice, not just in theory. Ontology deals with how to determine whether things exist and the nature of reality (Creswell & Creswell, 2018). Within pragmatism, reality is viewed as constantly changing and being interpreted. This supports the idea that parents' and caregivers' lived realities exist because they involve real-life sequences, although these realities will differ across contexts, times and relationships. Epistemology is concerned with the nature of knowledge,

how it is generated and how it is justified and validated (Creswell & Creswell, 2018). Using a pragmatic paradigm, knowledge is gained in this study through interaction with parents and caregivers (the world), and the 'knowing' is action oriented. Pragmatism, according to Dolan et al. (2022), embraces observable facts and incorporates the importance of intangibles, such as grief. This means that outcomes or findings from research by a pragmatist researcher are considered valid only if they are useful to the participant, the researcher or the research consumer (Ormerod, 2020). Axiology considers the role of values in the research (Creswell & Creswell, 2018). The pragmatic axiological stance assumes that values are inseparable from inquiry and considers research useful if its outcomes are relevant, valuable and consequential, aligning with an impact focused approach. This demonstrates the ethical integrity of researching in a pragmatic way, as knowledge is not pursued for its own sake but is used for a beneficial or practical purpose.

The classical pragmatist movement has its origins in American sociological scholars in the 1800s, who challenged traditional empiricism by seeking to study the more subjective experience of a social world (Savin-Baden & Major, 2025). Charles Sanders Peirce (1839–1914), William James (1842–1910) and John Dewey (1859–1952) were major contributors to the development of this philosophy (Savin-Baden & Major, 2025). As these philosophers were prolific writers, several conceptions of pragmatism quickly developed (Ormerod, 2020). While Peirce, James and Dewey had different notions of truth, the essence of pragmatism in epistemology is that truth is what we get when we solve a problem or, in other words, what works (Ormerod, 2020). Truth is understood by pragmatists in practical actions to solve a problem due to a stressor and the value of experience (Rescher, 2005). Underpinned by fallibilism, all truths are provisional and no truth can be entirely proven (Dolan et al., 2022). Dewey redefined truth as the notion of 'warranted assertibility' (Rescher, 2005), meaning that one can claim a truth when a problem is solved. Using Dewey's understanding of truth, the inquiry starts with a problem (confusion and uncertainty) and ends with clarity that can be acted on. Fundamental to pragmatism is the notion that what is true today may not be true in 15 years' time; in other words, it is the truth for now (Rescher, 2005).

Building on these philosophical foundations and ideas, pragmatic research is driven by its aims, with a primary focus on the problem that needs to be addressed and the desired outcomes (Creswell & Poth, 2018). Pragmatism relies on human experience observed within natural contexts to develop knowledge and understand the world (Allemang et al., 2022). The goal is to create real-world impact, actionable knowledge and organisational change (Kelly & Cordeiro, 2020), which aligns with my research aims and objectives (Chapter 2, section 2.21) of generating findings to inform service delivery and improve EI systems.

Pragmatic research has an inherent focus on social justice and collaborative problem-solving, with the researcher seeking answers to questions that can be applied in practice. The pragmatist paradigm affords considerable flexibility, allowing the researcher to use the most appropriate methods to address the question (Savin-Baden & Major, 2025). The researcher, therefore, does not need to be overly concerned with adhering to established ways of doing things or set ideas, provided the researcher starts with the problem and ends with an actionable solution. This concept is applied in my data analysis, where narrative inquiry is paired with reflexive thematic analysis. In this way, pragmatism provides an ideal opportunity to bridge the gap between theory and practice (Dolan et al., 2022). This paradigm is best suited to my project where, as a clinician, the aim of the research was to be situated in real-life, practical answers to questions that can be clinically applied. This paradigm is emerging in healthcare as a research strategy and within the field of qualitative research (Allemang et al., 2022).

Pragmatism is often associated with mixed methods research. However, Caine et al. (2022), leading contemporary narrative inquirers, discussed how the study of narrative is deeply rooted in pragmatism, particularly Deweyan pragmatism. This will be discussed in greater detail in section 3.3.1, regarding its direct relationship to a narrative inquiry.

While the underpinning research is grounded in pragmatism, it should be acknowledged that other theoretical assumptions are also used, particularly in data

analysis where interpretivism and constructivism are employed. These worldviews complement pragmatism and are compatible with narrative inquiry. An interpretivist stance holds that reality is subjective, socially constructed and understood through individual experiences (Savin-Baden & Major, 2025). Constructivism holds that there are multiple realities; participants actively construct realities and make knowledge and its value is bound to time and context (Savin-Baden & Major, 2025; Yin, 2016). Using both assumptions allowed the analysis to reflect participants' perspectives while accounting for my own influence on the interpretation.

3.3 Qualitative Methodology

Qualitative methodologies emerged to conduct social research beyond the constraints of empirical and quantitative methods. Qualitative methodologies engage with participants in their natural settings. It aims to understand how people make sense of their experiences and ideas (Creswell & Poth, 2018; Denzin et al., 2024; Savin-Baden & Major, 2025). This approach is well suited to my study, as the aim is to understand the experiences of people who have encountered the phenomenon and how they make sense of these experiences within their contexts. In the health and disability sector, listening, interpretation, sense-making and subsequent findings can be used to transform how services are delivered, making them more accessible, equitable and tailored to the needs of individual service users (Allemang et al., 2022). Given the aim of the research, which is to document the experiences of parents and caregivers, qualitative methodologies are well suited for the study.

3.3.1 Narrative Inquiry

Several qualitative methodologies were considered when planning this research. Weighing their suitability and merits for addressing the research question, narrative inquiry within the tradition of Clandinin and Connelly (2000) was chosen. Throughout this thesis, the terms story and narrative will be used interchangeably, as they are synonymous in this context (Liamputtong, 2013). The foundation of this inquiry is that people live and tell stories of their unfolding lives and that is their

way of thinking about the experience (Clandinin, 2000). The researcher comes alongside people, listens to their stories and observes what the participants do. The intention is to understand and document their experience. From this understanding, new knowledge can be gained. This approach has developed its own terminology, making it distinct from other qualitative methodologies in how the researcher considers, collects and documents individuals' experiences and stories (Clandinin, 2023; Savin-Badin & Major, 2025).

Narrative inquiry is both a phenomenon and a method of study (Liamputtong, 2013). As a phenomenon, it is underpinned by narrative theory, which concerns how meaning and sense-making are constructed through narratives. Narrative theory, or narratology, explores how stories are constructed, how they function and how they shape understanding of the world (Bal & Boheemen, 2009). Narrative essentials examine how plot, character and perspectives interact to create meaning. This forms the basis for how stories are analysed or restoryed (discussed further in the methods chapter).

According to Clandinin (2023), the most frequently cited philosophical foundation of narrative inquiry is Dewey's theory of experience. John Dewey was introduced earlier in this chapter, section 3.2, when pragmatism was discussed. Dewey's theory asserts that learning and growth are continuous (unfolding) and occur through interactions with others and the environment. Experiences are connected and one experience influences the next, whether it is 'educative' or 'mis-educative' (Dewey, 1938/1997). As a result, experience accumulates over time.

> Any experience is mis-educative that has the effect of arresting or distorting the growth of further experience. An experience may be such as to engender callousness; it may produce lack of sensitivity and of responsiveness. Then the possibilities of having richer experience in the future are restricted. (Dewey, 1938/1997, p. 16)

When Dewey discusses experience in relation to education, he notes that a student will not be without experience but it may be the 'right' or 'wrong' type. Everyone has had an inspiring teacher or mentor who makes dry topics come alive. Such an experience can change a person's life path. The quality of the experience influences how and in which direction a person's growth occurs. Dewey (1938/1997) described "that every experience is a moving force" (p. 24). Dewey's theory of experience can be applied to the experiences of parents and caregivers in EI, where, from the NICU onward, readiness and openness to engagement in EI can be shaped by prior experiences. This relates to Dewey's first core principle of continuity of experience, or the "experiential continuum" (p. 18). Experiences do not exist in isolation but are connected to those that came before and influence those that follow.

The shaping of experience occurs through the interaction between the individual and the environment (i.e., the situation). Experience is influenced both by internal and external factors, which is the second core principle of experimental learning: interaction (Dewey, 1938/1997). The environment extends beyond time and place to include other people, the subject being discussed and the things the learner interacts with (i.e., toys, books, social media). In other words, the contexts. Learning also occurs within the social environment, where communication and shared experiences socially construct knowledge. Reflecting on the experience is crucial to understanding and incorporating it, creating new, meaningful knowledge that can be applied to new situations. This gives the experience its significance. The principles of continuity and interaction in experience are important to understand in the context of narrative qualitative inquiry, as participants' experiences will be influenced by previous experiences, both positive and negative. In this research, participants' experiences were influenced by many factors, such as the birth experience, previous birth experiences and NICU experience, as well as previous experiences with 'agencies', health and non-health. In this way, each experience builds on the next, influencing understanding.

In narrative inquiry, the focus is on participants' stories and experiences, their relationships with others in those stories and how they make sense of what happens in their lives. Narrative inquiry, as defined by Clandinin and Connelly (2000) is, in a deeper way,

> Narrative inquiry is a way of understanding experience. It is a collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in the same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling the stories of the experiences that made up people's lives, both individual and social. (p. 20)

One of the key principles of narrative inquiry is a highly contextual and relational methodology (Clandinin, 2023; Creswell & Poth, 2018). Narrative inquiry is ontologically transactional or relational. Attention is paid to stories alongside the impact of physical, social, cultural, familial, institutional, historical (time and place) and emotional factors, and how these shape the individual's experience (Caine et al., 2022; Clandinin, 2023; Creswell & Poth, 2018; Haydon & van der Riet, 2017). Experiences are created and lived over time (continuity), so an essential element of narrative inquiry is the temporal nature of experience (Clandinin, 2023). Continuity holds that experiences are continuous and unfolding, with one experience leading to the next. Rosiek & Clandinin (2019) describe experience as occuring within a continuous stream that generates new realtions, which in turn shape fututre experience (p. 41), therefore the researcher is within this stream. Therefore, the experience of participating in research will form part of the story, including recruitment, initial introductions and the interview locations. There are many aspects to consider when embarking on this methodology, especially for a novice researcher; however, the nature of this inquiry allows for the messiness and complexities of lives (Clandinin, 2023). These principles must be congruent with a narrative phenomenon and methods must be embedded in data collection, analysis and write-up, attending to the temporal, social and situated dimensions of experience.

Narrative inquiry aligns with the research question because it helps to understand complex social events, such as how people navigate challenges and adapt when a baby is born early or identified as at risk of adverse neurodevelopmental outcomes. It is suitable for giving voice to marginalised peoples (Caine et al., 2022), as it honours individuals' experiences and considers cultural, institutional, historical and social contexts. In my view, it aligns with the Te Ao Māori worldview, where storytelling is central to culture, creating shared meaning and consequently shaping identity. The researcher listens to participants' hopes, dreams and purposes, which is valuable when designing services. Narrative inquiry fosters research that promotes equity and justice in society (Caine et al., 2022). This approach offers considerable flexibility, allowing adaptation as new perspectives emerge, making it well-suited to a pragmatist philosophical paradigm. Additionally, it is a reflective approach that enables me, as a novice or student researcher, to reflect throughout the process (Clandinin, 2023), providing a foundation for learning and development.

3.4 Reflexivity

Reflexivity involves critically and introspectively reflecting on my role in the research, examining what, how and why certain actions were taken, and how these actions influence the research and knowledge production (Braun & Clarke, 2022a). Reflexivity accepts subjectivity, recognising that knowledge is rooted in context, influenced by the research process and inherently affected by the researcher. According to Braun and Clarke (2022b), reflexivity should commence at the start of the research and be maintained throughout.

I used Braun and Clarke's (2022a, pp. 16-18) template as a guide to deepen my thinking on reflexivity. My positionality and stance are integrated in section 3.5. Personal/social and disciplinary reflexivity have been addressed in my positionality statement. I have detailed my personal positioning from my formative years to the present, as my values and beliefs have evolved. Within the context of narrative inquiry, this positioning situates me within the research, as Clandinin (2023) stated,

"In narrative inquiry, I know that I am in the parade, part of the landscape about which I am writing" (p. 4). These experiences and subsequent assumptions have shaped and informed my research (Braun & Clarke, 2022a), as a mature individual with diverse life experiences that shape how I see the world. My positionality and stance statement reflect a selective disclosure of personal experiences, with some elements intentionally omitted to maintain personal privacy. Nonetheless, as part of the reflective process, I have thoughtfully considered these independently and with my supervisor. Ideology is embedded in how one sees the world (Braun & Clarke, 2022b).

Throughout the research process, a reflective journal was used. An example of journaling is provided in Appendix A, where I reflect on my practice interviews with a colleague who has a child with a congenital birth defect. Following the interview, I noticed my responses to the participant and my colleague, their narratives, the flow of the questions and body language. This helped shape another rewrite of the question template. The process of journaling for reflection and reflexivity continued throughout the research journey.

3.5 Researcher Background – Positionality and Stance

In narrative inquiry, special attention is paid to the researcher's positionality. The question must be asked, "Who am I in this narrative inquiry?" (Clandinin, 2023, p. 61). Positionality is essential because data are analysed through shared sense-making between the researcher and the participant (Clandinin, 2023). It is imperative to examine any bias and explore my strengths and limitations as a researcher. It also involves understanding and acknowledging personal factors that influence the research. As a narrative inquirer, I have provided a summary of influences from my personal and professional life to align with Dewey's theory of experience and narrative, which underpin this research.

I was raised in rural Waikato, Aotearoa New Zealand, in a traditional household during the 1970s, with my parents: my father, a farmer and inventor; and my mother, a nurse and homemaker. My initial political leanings to the right, stem from

the influence of my parents and paternal grandparents. My paternal grandmother advocated for social justice for rural women, and my paternal grandfather is from a well-known multigenerational Waikato farming family. My maternal grandparents were devoutly religious, but generosity and charity were core values in their lives. In mid-life, my father, embodying the 'Kiwi number 8 wire' mentality, invented fencing tools that eventually sold internationally. This was a practical solution to a real problem. My mother is incredibly nurturing and caring, with these qualities naturally interwoven in her personal and professional relationships. Grief has been part of our family's story through the loss of a sibling. This mix of complexity and contradictions in my upbringing is not unique; it shapes the richness and biases of my identity. My understanding of politics has been challenging to shift from the right; I acknowledge this influences my thoughts. However, I cannot tolerate injustice, particularly when it affects children, women and the elderly, which provokes the need for social justice. As an adult, I align more with centre-left politics and have adopted a feminist worldview.

I occupy privileged positions, such as being white, middle-class and able-bodied. I also occupy marginalised spaces as a gay cis woman with health issues. I understand what it is like to be a health service user and have experienced marginalisation because of this. However, my experience is from a white, middle-class female perspective, which also grants me privilege in these spaces. My life has included many experiences, such as becoming a mother of four, religious experiences, going through a divorce and being a solo parent. All these experiences, hardships and more have shaped my views and the way I see things.

Social justice is fundamental; however, as a physiotherapist with over 30 years' experience across various practice areas and as a solutions-focused individual, I tend towards a pragmatic worldview in both work and academic life. I deeply value people's stories, which enrich my life in many ways, but I am currently focused on tangible, clinically applicable outcomes from my research. My current research interests align with my work, as I specialise in early detection and EI for children with childhood-onset disabilities. This gives me a bias and a belief that EI is crucial

to these children's health and development. I also strongly believe that if we care for the health and well-being of parents, caregivers and the entire whānau, their children will achieve better outcomes. It is my opinion that health services often fall short of ideal expectations and that services can be limited. The advantage of researching in my clinical field is that I have a thorough understanding of technical jargon, terminology and early developmental intervention processes. The disadvantage is that I have some assumptions about the subject that may influence the interpretations. I seek to account for this through the strategies described in section 3.4. As a co-constructor of knowledge alongside the participants, is congruent with a narrative inquiry.

My postgraduate journey started in my 50s and has been a dream for most of my career. I am a novice researcher. Until I completed a postgraduate course in research methods, I had only a basic understanding of 'lived' experience and its potential to enhance clinical practice. When I was given the opportunity to undertake a thematic analysis as part of an assignment, I was immediately captivated. It was exciting to begin recognising similarities (or patterns) and the unique experiences. I am passionate about understanding the richness of people's experiences, especially when they face challenges such as having a child with a complex disability or health issues. As a clinician, I enjoy sitting back to truly listen to their stories and the messiness that comes with them. I chose qualitative research, conducted in a strengths-based way, because it aligns with my values, ethics and professional practice.

3.6 Conceptual Framework

A conceptual framework is a collection of broad yet related ideas and concepts that guide the study (Savin-Baden & Major, 2025). The purpose of the conceptual framework was to define the scope and direction of this study. It was developed from multiple theories and empirical data. No single theoretical framework was used because of the phenomenon's complexity. My conceptual framework was informed by the literature review and existing knowledge on this topic and was tailored specifically to this research project.

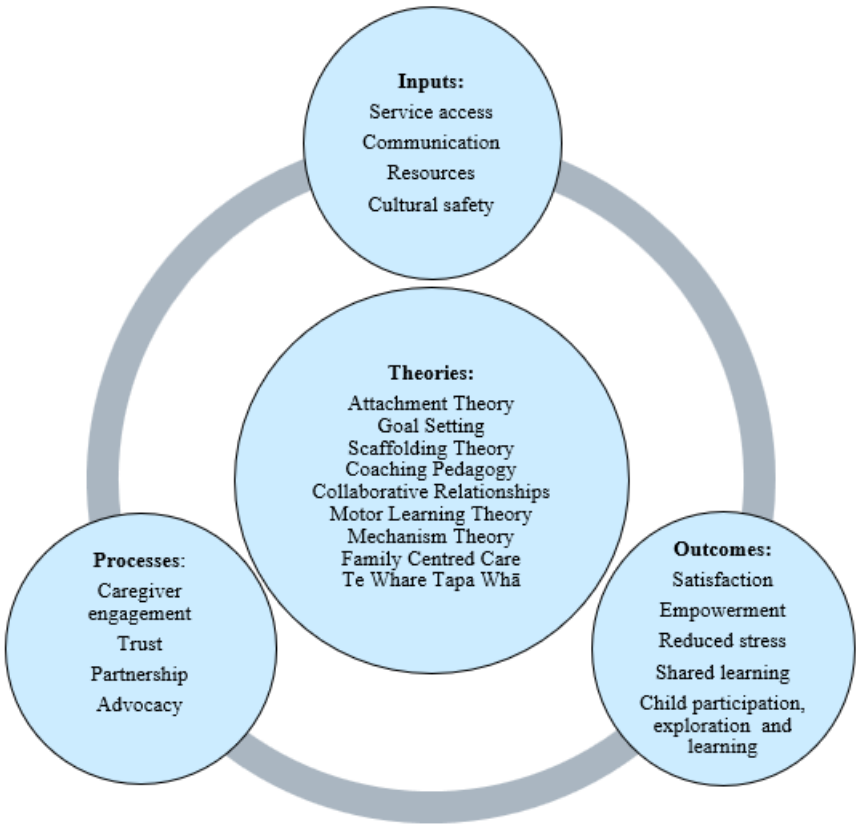
The conceptual framework recognises that experiences are shaped by a range of complex factors, creating a dynamic ecosystem. Its theoretical foundations include attachment theory, collaborative relationships, coaching pedagogy, scaffolding therapy, collaborative goal setting, motor learning theory, mechanism theory, family-centred care (Chapter 1, section 1.7) and the cultural framework, Te Whare Tapa Whā (Chapter 4, section 4.10). This framework has been significantly influenced by the work of Harniess et al. (2022, 2024). Research indicates that factors affecting caregiver experiences encompass access to health services (e.g., barriers like transport, geographic isolation, eligibility, professional expertise, regional differences); principles of family-centred care (e.g., whānau involvement, shared decision-making, autonomy); cultural responsiveness framework and prior studies on stress, resilience and advocacy for families. These factors are categorised as inputs, including service access, cultural safety, communication and resources. Processes involve caregiver engagement, trust and partnership with providers. Outcomes include caregiver satisfaction, empowerment, reduced stress and enhanced child participation, exploration and learning. All these elements are integrated within a conceptual framework (Figure 5). The diagram is circular rather than linear, illustrating how each component interacts and depends on others. It also symbolises a balance of ideas, with no hierarchy, depicting an ecosystem. This conceptual framework is central to this research and forms the core of this inquiry.

3.7 Summary of the Methodology

This chapter outlined the research paradigm and methodology, including the epistemological, ontological and theoretical foundations underpinning the research. I have detailed how I established rigour and included my positionality statement as part of reflexivity. Finally, I have integrated multiple ideas and theories to develop a conceptual framework to guide this research. In the next chapter, I detail the step-by-step methods used to conduct this study.

Figure 5.

Conceptual Framework for Early Intervention



Chapter IV: Data Collection Methods

Mā te rongo, ka mōhio

From listening comes knowledge

4.1 Introduction

This research aimed to document the experiences of parents, caregivers and extended whānau of EI services in Waikato, Aotearoa New Zealand. In this chapter, the research methods used in the study are outlined and justified, including the narrative research methods I applied in data collection and analysis. Methods describe the tools, techniques and procedures for collecting the data (Caelli et al., 2003). The chapter begins with a description of the study design. Next, I describe the population and introduce the participants. The application of narrative data collection methods in this study, including sampling and recruitment strategies, are outlined. Next, I detail the data generation process and management through the interviews, followed by the methods and stages of analysis. I conclude the chapter with ethical and cultural considerations for the study.

I use the first-person pronoun for the remainder of this thesis, identifying myself as an active participant in this research, congruent with the methods. The methods draw on the work of Connelly and Clandinin (2000) and Braun and Clarke (2006, 2022a, 2022b).

4.2 Study Design

This is a retrospective observational study, using qualitative narrative inquiry and semi-structured interviews to document the experiences and stories of parents, caregivers and extended whānau (families) using EI services when identified through early detection tools as having a high likelihood of an adverse neurodevelopmental outcome or the need for greater developmental surveillance, in the Waikato region. The initial intention was to recruit 12 individual or whānau/family groups.

4.3 Setting and Context – The Waikato Region and Early Intervention Services

This study takes place in the Waikato region of Aotearoa New Zealand. The current section provides information on the general population, including social deprivation. The Waikato region is the fourth-largest region in Aotearoa New Zealand, with a population of nearly 500,000 (almost 10% of New Zealand's total population) (Stats NZ–Tatauranga Aotearoa, n.d.). The main centre is Hamilton City, which serves a large rural community. Within this population, an estimated 128,800 are Māori, accounting for 25.2% of the Waikato's population (Stats NZ–Tatauranga Aotearoa, n.d.). While 66.5% of the Waikato region identify as New Zealand European, the region has a large and diverse mix of ethnicities, including 5.8% Pacific Peoples (Cook Island Māori, Samoan, Tongan, Niuean, Tokelauan, Fijian and other Pacific Peoples); 5.2% Indian; 2.8% South East Asian; and 2.7% Chinese (Stats NZ–Tatauranga Aotearoa, n.d.).

Many residents of the Waikato region experience considerable financial hardship, especially those living in isolated rural areas, where accessing services can be more challenging. The New Zealand index of socioeconomic deprivation uses variables across eight census dimensions, including communication, income, employment, qualifications, home ownership, support, living space and dwelling condition, to provide a socioeconomic deprivation decile of the small geographical area in which people usually live (Stats NZ–Tatauranga Aotearoa, n.d). The higher the deprivation decile, the more socioeconomically deprived the area. The 2023 New Zealand Consensus data showed that Waikato residents experienced greater social deprivation than residents of other areas of Aotearoa New Zealand, with Māori experiencing even greater deprivation (Stats NZ–Tatauranga Aotearoa, n.d.). This issue is important to discuss, as it affects the health and well-being of children living in higher-deprivation areas.

Health New Zealand-Te Whatu Ora Waikato and Disability Support Services (DSS) provide publicly funded health services for this region. Pre-school EI services for children with developmental differences are provided through the fully publicly

funded Child Development Centre (CDC) at Waikato Hospital and through small community providers using a mixed funding model (government and attendee-funded), including Wana Tamariki (previously known as Conductive Education Waikato) and McKenzie Centre, where families have a choice of services. CDC provides assessment, monitoring and therapy in clinics, homes and early education centres (ECEs). There are several providers of intensive EI models, both within and outside the region, that families can privately fund. In addition, the Little Miracles Trust provides fortnightly playgroups, run by a peer support group, with monthly paediatric physiotherapy support. Psychological support for parents and caregivers is provided through the True Colours Children's Health Trust, Maternal Mental Health services, and several not-for-profit, non-governmental organisations that provide culturally based services. Participants' children have received services from one or more of the agencies listed above.

4.4 Participants and Sampling

Participants invited to take part in the study were parents, whānau, caregivers and their extended families (grandparents, aunties, uncles, close family friends) who had experience with EI services in the Waikato and were willing to share their stories. Their infants must have been eligible for Waikato Hospital's early detection service at CDC between 2017 and 2024. Infants must have met the criteria to receive the GMA in the NICU or within the first 3 months of life. The participants' children were at least 2 years old (CA) at the time of the interview and living in the Waikato region. Children over 2 years of age would have received two full years of EI to capture experiences over this period. Participants represented a range of ethnicities, including Māori and non-Māori. Te Puna Oranga Māori Consultation Research Review Committee requested that all efforts be made to recruit up to 50% of the sample as Māori, as this is a priority population, due to health inequities experienced in this group.

4.4.1 Inclusion and Exclusion Criteria

The inclusion criteria include parents, caregivers and extended family of infants who were eligible for a 3-month GMA, either having had a term (writhing) GMA

due to identified detectable newborn risk factors or subsequently identified after the writhing age due to postnatal neurological concerns, and who met Health New Zealand Te Whatu Ora Waikato's entry criteria for a -month GMA. For infants to receive a term GMA at Waikato, they must meet one of the following criteria:

- Born at <32 weeks or weighed <1500g
- Neonatal Encephalopathy (Higher Severity – Sarnat 2 or 3)
- Concern by neonatal staff regarding feeding, growth or development.
- Live within the Waikato region

To be eligible for this study, infants' 3-month GMA results were absent or abnormal fidgety movements. An absent or abnormal result indicates a higher likelihood of adverse neurodevelopmental outcomes. Alternatively, infants may have had a suboptimal Motor Optimality Score-Revised (MOS-R) of 24 or below, which warranted increased surveillance and support for the child and their whānau. Additionally, infants might have presented with a suboptimal Hammersmith Infant Neurological Examination (HINE) score below 72. (Fehlings et al., 2024). Finally, infants with a normal 3-month GMA result but who exhibited motor difficulties requiring follow-up by the intervention team were eligible.

The exclusion criteria included parents, caregivers and extended family of infants identified as having a lower likelihood of adverse neurodevelopmental outcomes and not requiring follow-up by the intervention team. Infants who subsequently received a diagnosis of a genetic or severe cardiac condition requiring surgery or received Accident Compensation Corporation funding in the first 2 years of life and who are non-English speaking were also excluded. Further exclusions include past or current patients of the lead investigator.

4.4.2 Sampling

As qualitative research aims to gain in-depth understanding of the topic, it relies on people who can give rich accounts of their experiences (Liamputtong, 2013). Sampling is focused on 'what' rather than 'how much'. The sampling in this study was purposeful or purposive, aiming to reflect the diversity of the population

(Barbour, 2001). It involved deliberately selecting individuals who had experience of having a child identified as at risk and who participated in EI services. Although the sample was purposive, maximum variation sampling was also employed to gather data from a heterogeneous sample spanning a range of contexts, opinions and views, making it well suited to this research (Creswell & Poth, 2018; Liamputtong, 2013; Lincoln & Guba, 1994).

4.4.3 Sample Size

When considering sample size, I kept in mind that it would not be representative of the population, nor could statistical comparisons be made (Liamputtong, 2013). As a qualitative study, the focus was on collecting extensive detail around the experiences of a few people, including the 'outliers' (Barbour, 2001; Creswell & Poth, 2018). There is no set formula for deciding the number of participants (Malterud et al., 2016). In narrative inquiry, often one or two participants are used but a larger sample can be used to develop a collective story (Creswell & Poth, 2018). The latter has been adopted for this narrative study.

Saturation is the indicator that a large enough sample has been reached and refers to "the point in data collection when no additional issues or insights are identified and data begin to repeat so that further data collection is redundant, signifying that an adequate sample size is reached" (Hennink & Kaiser, 2022, p. 2). The concept of saturation originated in grounded theory, particularly in the work of Glaser and Strauss (Creswell & Poth, 2018). Given my choice of narrative inquiry, the concept of saturation did not align. However, as a novice researcher, I felt it was important to have some theoretical guidance for the sample size.

Malterud et al. (2016) proposed the concept of information power to determine sample size. The theory is that the broader the aim, the larger the required sample size, and the narrower the aim, the smaller the required sample size. Considering this guideline, the specificity of experiences will also influence the sample size. Using the concepts outlined by these authors, information power was used as the aim of this study was relatively narrow; that is, to document the experiences of

whānau, parents and caregivers of EI services within the Waikato, which justified a smaller sample. Secondly, the specificity of the sample was dense because I used purposive sampling to recruit participants with experiences relevant to my aims, which favoured a smaller sample. Lastly, the quality of the dialogue or stories in the interviews was strong, favouring a smaller sample. Twelve participants were deemed sufficient to provide information power within the context of a Master's project.

4.4.4 Recruitment

Several recruitment strategies were used to identify individuals who met the eligibility criteria. Potential participants were identified from service record systems by key clinicians at the CDC (public provider) and through advertising at McKenzie Centre and Wana Tamariki (community providers). At the start of recruitment, after obtaining locality and ethics approval, clinicians at CDC, McKenzie Centre and Wana Tamariki were emailed to request assistance with recruitment (Appendix B). The email included the recruitment flyer (Appendix C), participant information sheet (PIS) (Appendix D) and consent form (Appendix E). Follow-up phone calls and meetings with clinicians were scheduled to introduce them to the project, enhance their understanding and increase awareness.

Clinicians at CDC assisted me, as the lead investigator, with recruitment by utilising existing databases that track infants who have undergone GMA and other early detection assessments. CDC maintains a secure database of all infants from 2017 onwards who have received early screening. Community providers identified participants from current caseloads. Once identified as eligible in the database, clinicians initially acted as intermediaries to identify and approach potential participants, aiming to minimise the risk of coercion. If parents, caregivers and whānau expressed interest, clinicians offered a research flyer and the PIS and obtained verbal consent to share their contact details. The PIS outlined the aims of the research; my background as the investigator; participants' rights, including the right to withdraw; risks; support options for any harm caused by participation; benefits; the complaints process and available cultural supports. I then received the

names and, with their consent, contacted the interested persons to discuss the project. I then rechecked whether the interested person's child met the inclusion criteria. Details about the time requirements, venue, rights and the option to withdraw were provided verbally. A 1-week cool-off period was allowed, enabling interested persons to discuss participation with whānau, seek advice and consider their involvement. After this period, I contacted the interested person, and if they agreed to participate, we arranged a time and place for the interview. Recruitment took place between October 2025 and February 2026.

4.5 Data Collection

Data collection and interviews were planned with many aspects in mind, including sampling, the timing and location of interviews. The interview type align with a pragmatic philosophical approach and took into account specific cultural and family dynamics. Lastly, the interviews were restoryed to be consistent with narrative inquiry.

4.5.1 Fieldwork

Fieldwork is the process by which researchers collect data in natural settings (Savin-Baden & Major, 2025). The research setting is part of the data, not a passive backdrop and is highly influential (Savin-Baden & Major, 2025). Savin-Baden and Major suggest "Since the research site is indeed part of the meaning, a critical element of what is under study, it should be the most logical choice for the research being undertaken." (p. 334). The timing and location were carefully considered, guided by the participants' preferences. This required me to be aware of the participants' context, which is particularly relevant for a narrative inquirer (Clandinin, 2023). The location was important because the participant needed to feel relaxed and safe and the venue needed to be easily accessible. Multiple sites and options were offered, including the participant's home, university, hospital clinic rooms and virtual options. Allowing participants to choose their location encouraged honesty due to fostering feelings of safety. The participant's home was considered the most suitable and convenient option, especially because it reduced the need for childcare, lowered travel costs, levelled power dynamics and was

culturally aligned, with as many extended family/whānau as possible included in the interview. Furthermore, since the topic might have evoked unresolved trauma and difficult feelings, the venue needed to be private. It was also recognised that some participants preferred to keep their homes confidential. In such cases, alternative venues, including the University of Waikato and CDC, were provided. While face-to-face interviews were ideal for enriching the context and background of the data, I used videoconferencing when face-to-face interviews were not feasible. One interview was scheduled at a remote location but due to extreme weather and a civil defence emergency, the face-to-face interview was moved to a virtual format. This enriched the data by demonstrating the vulnerability of some isolated communities.

Savin-Baden and Major (2025) discussed how space (sites) can influence the researcher; an unfamiliar place can help avoid assumptions that a familiar setting might promote. Disadvantages of using multiple sites include the risk of superficiality, as unfamiliarity may reduce the researcher's attention (Savin-Baden & Major, 2025). Additionally, as a novice researcher, I had to quickly adapt to different spaces and process large amounts of information through all my senses. This was partly offset by my clinical experience across various settings.

4.5.2 Sources of Data Collection

4.5.2.1 Interviews

Interviews are the most common method for qualitative researchers to gather data, aiming to replicate a natural conversation (Savin-Baden & Major, 2025). The interview style aligned with the chosen philosophical and methodological stance. Among various interview types, I chose an in-depth, semi-structured interview. This provided significant flexibility; while following an interview protocol with open-ended questions, I could deviate from the guide as the participant discussed what was important to them. I interviewed each participant only once, which minimised participants' time requirements and enabled me to focus them on the specific topics relevant to my research aims. The narrative inquiry yielded detailed rather than brief stories, offering a rich, deep understanding (Liamputtong, 2013).

It also allowed for comparison of themes and narrative threads. One drawback was that the 60-minute interview might not have been sufficient for participants to express all their opinions and views on the topic.

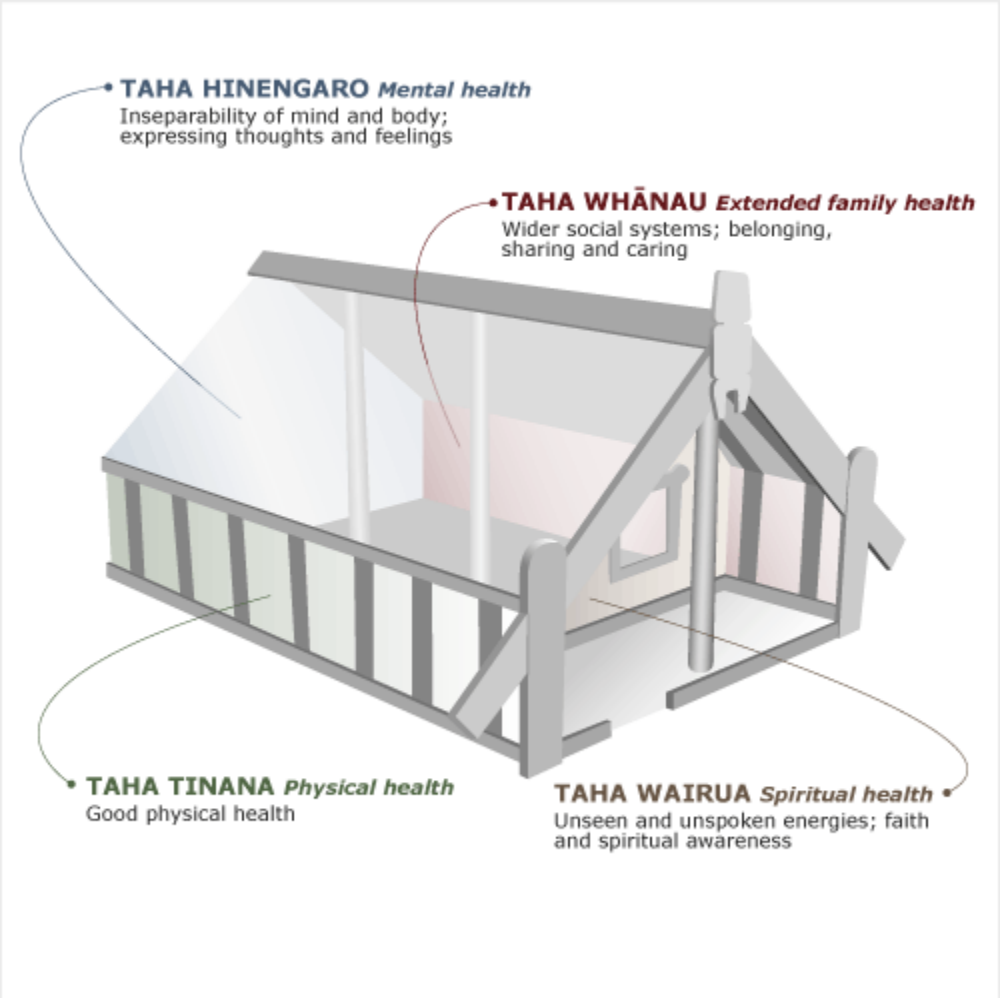
The participants were interviewed about their experiences and perspectives using semi-structured interviews either individually or in small whānau groups. They were questioned about their perspectives and experiences of EI, including when they first saw a therapist, what supported them in engaging and accessing EI, what was important to them and how it affected their hope and spirituality. I loosely adhered to the strengths-based interview agenda (appendix F) and was guided by what the participant found most meaningful in their experience of the topic under study.

Semi-structured interviews using the contemporary Māori health framework, Te Whare Tapa Whā (Durie, 1994), served as a culturally compatible basis for designing the open-ended interview questionnaire (appendix F) in order to answer the research questions. This holistic health model (Figure 6) uses a whare (Māori house) supported by four pillars that encompass the person's physical well-being (Taha tinana), social well-being (Taha whānau), mental and emotional well-being (Taha hinengaro) and spiritual well-being (Taha wairua). Adopting this model as a framework for the questions ensured that aspects of participants' experiences were considered in a strength-based, culturally sensitive way. This approach was chosen to fulfil the Te Tiriti o Waitangi obligations as a researcher and was endorsed by the cultural advisors.

The interview protocol was checked by the cultural advisor and tested with a colleague, with questions adapted accordingly. The reflective statement on this process is provided in Appendix A. The interview was led by me, as lead investigator. I am an experienced interviewer through my clinical role. Māori participants were offered the option of a Māori interviewer to co-lead the interview. One parent opted for this alternative. Each interview was digitally audio-recorded and stored on a secure platform.

Figure 6.

Te Whare Tapa Whā



Source: Mason Durie, *Whaiora: Maori health development*. Oxford University Press, 1998, pp. 68–74 is reproduced with permission from Te Ara – The Encyclopedia of New Zealand. All rights reserved. See appendix T.

To acknowledge the collective experiences of whānau, interviews were offered as either individual or whānau interviews (Simpson et al., 2025). This aligned with a kaupapa Māori-informed (collaborative, family-centred) research approach. Whānau groups can be viewed as small focus groups or collectives of two or more

people, recognising collective care systems (Simpson et al., 2025), in which multiple individuals form support and care networks.

4.5.2.2 Demographic Data Collection via Questionnaire

A short questionnaire (Appendix F) was used to collect participants' characteristics and describe the background of the participants and the children. The information was kept brief, including the participant's age bracket, ethnicity, relationship to the child, whether they live in Hamilton city or in a rural area, the child's age and sex, a general diagnosis, EI services, the child's age at first engagement and the frequency of EI. The demographic information was kept broad to ensure participant anonymity, given that the study was limited to one region. The demographic questionnaire provides the reader with the participants' background and helps situate the social and cultural contexts for interpreting their experiences, potentially helping readers apply the research to broader contexts (Creswell & Poth, 2018). Further this information enhanced rigour, providing credibility and transparency by showing who was in the study and who was not. Adopting maximum variation, the questionnaire helped highlight the diversity in the sample.

4.5.2.3 Artifacts, Fieldnotes and Journaling

Sharing photographs of their child, if participants wished, was encouraged as a prompt for memory and conversations about their child. However, these were viewed only during the interview and were not collected or used in the re-presentation. The conversations regarding the photographs were documented as part of the fieldnotes and journaling process. During interviews, the participants talked about photos on the walls of their homes rather than shared photographs from other sources.

Fieldnotes were taken as part of data collection to add depth to the data. I recorded behaviour, surroundings and events during the interview, in accordance with a narrative inquiry. These fieldnotes included the date, time and location of the interview, as well as observations. Notes taken during the interview were written up in detail soon after the interview ended to ensure accuracy. Journaling, memos

and fieldnotes all served as an audit trail, adding rigour by providing evidence of why decisions were made throughout the research process.

4.6 Analysis

Data analysis is one of the most important stages of the qualitative research process and involves analysing data iteratively to make sense of it and provide meaning (Savin-Baden & Major, 2025). As Carl Leggo (2011) posited, "interpretation addresses the basic question of so what." (p. 1). Data analysis should answer the research question and aims, offer interpretations and be grounded in what is known in the existing literature (Yin, 2016). The analytic decisions in this study were guided by both the principles of reflexive thematic analysis and my own interpretive judgement as the researcher. Codes and themes/threads were developed iteratively, with careful attention to maintaining the integrity of participants' narratives while identifying patterns across accounts.

The data were handled in two ways to prepare it for analysis. The audio recordings were initially transcribed verbatim. Both an artificial intelligence (AI) transcriber in Microsoft Word and my review and rewriting for accuracy were used. There was a continuous process of rereading, relistening and rewriting to familiarise myself with and immerse myself in the narrative accounts (Yin, 2016).

Following transcription, the text was restoryed by arranging the texts into a coherent, tentative narrative account as a 'whole' chronologically in which events occurred, re-speaking the voices of the participants (Clandinin, 2023). Restorying in narrative is the retelling of the participants' stories, arranged to have a beginning, middle and end to form a plot (Creswell & Poth, 2018). This process considered contexts such as culture, situation and the significance of experiences. Fieldnotes and observations were added to the text to provide further richness and depth to the data.

The texts were then shared with participants and adapted or edited as part of the collaborative, co-authoring stage of a narrative inquiry. Two participants requested

that additional information be added to the narratives for clarity. Credibility was established when the participant confirmed that their final narrative accurately represented their story. The stories are not shared in this thesis because of their personal significance and to ensure confidentiality.

While narrative inquiry provides a rich framework for understanding lived experience, it does not, in isolation, offer a structured approach to identifying patterns across multiple accounts (Saldaña, 2021). To address this issue, reflexive thematic analysis (RTA) (Braun & Clarke, 2022a, 2022b) was used alongside narrative methods to support systematic identification of patterns across narratives while maintaining attention to context, temporality and relational meaning (Clandinin, 2023). This combination was deliberately chosen to balance depth of individual experience with cross-case analytical insight, ensuring that both individual narratives and shared patterns of experience could be meaningfully interpreted. Saldaña (2021) noted that there are diverse methods for analysing narratives, including thematic analysis. This method has been used in similar research, where RTA was used in a narrative inquiry to understand senior intensive care nurses' experiences working with graduate nurses (Whittam et al., 2021). While RTA may not be used in every narrative inquiry, there is justification for its use within this research (see Chapter 3, section 3.3).

Clandinin (2023) used the term 'narrative threads' to describe 'themes' that appear throughout texts. These narrative threads are found through reading and rereading the texts to find the meanings and significance of experience. While Connelly and Clandinin (2002) did not mention coding, other researchers do support coding if attention is paid to maintaining the integrity of the story and it is especially useful for novice researchers (Lewis, 2019; Saldaña, 2021). Saldaña (2021) discussed how narrative coding is justified for exploring intrapersonal and interpersonal participant experiences, which is why I chose to use coding in my data analysis.

As a novice researcher, I needed a framework for thematic analysis to interpret the data systematically. Braun and Clark's (2022b) RTA was used to guide the

identification, analysis and reporting of 'threads' (themes) (Whittam et al., 2021). Braun and Clarke (2006) defined RTA as "a method of identifying, analysing and reporting patterns (themes) within the data" (p. 79). They argued that thematic analysis is a foundational skill for qualitative researchers and, as this is my inaugural study, this approach could be justified. I was guided by Braun and Clarke's (2019) who emphasise that the importance of being explicit, thoughtful and deliberate how the researcher applies method and theory (p. 595). To assist in the analytic process, I read scholarly articles on more contemporary versions of RTA (Braun & Clarke, 2019, 2022a) and used a working example by Byrne et al. (2019) to improve my understanding. RTA was also utilised because I was unable to engage a second person to complete the analysis as a sole researcher. Braun and Clark stated (2022b), "A single coder is normal – and good – practice in reflexive TA" (p. 55).

RTA is an interpretative data analysis method that aligns with my objectives. The authors describe the six-step process as a family of methods rather than a single method (Braun & Clarke, 2022a). These key principles include being explicit about how I analysed the data, the role of the researcher in knowledge production and the assumptions that informed the analysis (Braun & Clarke, 2006), thereby adding rigour.

The theoretical assumptions that underpinned the data analysis in this study were interpretivism and constructivism (Byrne, 2022), as discussed in section 3.2. Using both assumptions allowed the analysis to reflect participants' perspectives while accounting for my own influence on the interpretation. An experiential, rather than a critical, orientation was adopted as the aim was to emphasise meaning and what was meaningful in the participants' experience. I adopted a predominantly inductive or data-driven approach. A combination of latent and semantic coding was utilised. Semantic codes are identified through the explicit or surface meanings of the data and are more descriptive (Braun & Clarke, 2022b; Byrne, 2022). Latent codes are more interpretive, attempting to identify hidden meanings in the data (Braun & Clarke, 2022b; Byrne, 2022). Common experiences and divergent meanings were

explored (Braun & Clarke, 2006), allowing me to see the more obvious aspects and look below the surface of the description, deepening my understanding of the narrative. The process was iterative, moving back and forth through the stages, allowing me to see new interpretations (Braun & Clarke, 2022b). The qualitative data analysis software (QDAS) NVivo 15 was utilised to manage large volumes of data, support analysis and facilitate thread sorting.

4.6.1 Data Analysis Process – Reflexive Thematic Analysis

In phase one of RTA, or familiarisation, I initially examined the narrative accounts as a 'whole' to gain an understanding of the text and form initial threads (Braun & Clarke, 2006; Savin-Baden & Major, 2025). Generative artificial intelligence was not used in the coding process or theme development, as sense-making is a critical human process (Jowsey et al., 2025). The method I adopted encouraged reflexivity, subjectivity and creativity (Braun & Clarke, 2019). Within the phase, I sought to operationalise Braun and Clarke's (2022b) juxtaposition of immersing myself in the data and distancing myself through critical engagement. The restorying provided the opportunity to really immerse myself in the data. While stepping back and looking at the narrative provided a 'birds-eye view' or a distancing from the data. A summary of this process was documented on A3 paper (appendix H).

Phase two is generating initial codes. This should be a systematic review of the entire data set, with care. A code is a researcher's interpretation of the narrative threads across the dataset (Byrne, 2022). The code can be descriptive or interpretative. Tracking code iterations is useful for showing evolution, providing transparency and serving as an audit trail. I attempted not to be too granular in coding to avoid misinterpretation of the data. A document of codes (appendix I) was then generated, including the code name, a description of the code and quotes/examples from the data to illustrate the code's meaning (Creswell & Poth, 2018). Supervision was conducted with a cultural advisor and research supervisor to discuss excerpts of the narratives. Consensus was not the end goal, rather a richer understanding of the data, in keeping with RTA key ideals (Braun & Clarke, 2019; Byrne, 2022).

Phase three involved generating initial threads. Themes or categories are broad units of information formed by aggregating different codes to convey a shared idea (Crewell & Poth, 2018). For some threads, sub-threads and minor threads, in vivo coding was utilised, embedding participants' exact words and phrases as labels (Manning, 2017) to capture authentic, emic perspectives from caregivers, celebrate their voices and reduce my bias. A visual representation in the form of a thematic map was produced (Appendix J) (Braun & Clark, 2006). This phase starts to formulate relationships between threads and sub-threads.

Phase four required the reviewing and refinement of theme threads and consideration of their credibility. Through a two-level process of refinement, the result of step four is having a good idea of what the threads are, how they fit together and the story they tell (Braun & Clarke, 2006) (Appendix K). Phase five required defining and naming the themes (Appendix L). Phase six was to produce the report. Even as the final report was written, I remained open to changing the threads. I went back through a few times to revisit phases. This section has provided a detailed summary of the data analysis process and the considerations that informed my decision about methods and processes.

4.7 Rigour

Rigour pertains to the quality of qualitative inquiry and how consumers can assess the trustworthiness of qualitative research (Liamputtong, 2013). Given the inherent subjectivity and socially constructed realities in qualitative research, the concepts of validity and reliability, as congruent with the positivist approach of quantitative research, cannot be applied (Liamputtong, 2013). Padgett (2008) sums rigour up as "the trustworthiness of the research study depends on whether the research is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the respondent" (p. 184, cited in Liamputtong, 2013, p. 28).

Lincoln and Guba (1995) offered a framework for defining rigour and evaluating the strengths of qualitative research. These are credibility, dependability, transferability and confirmability. This provides a common language for qualitative researchers to describe how each element is addressed within the research. Furthermore, rigour is addressed internally by ensuring that the researcher's work aligns with the chosen approach. "Investigators need then to ensure rigor by adhering to principles that are congruent with the assumptions of the approach they are using" (Caelli et al., 2003, p. 8). Therefore, applying this principle to the study, the investigator and participants are co-constructors of new knowledge.

Narrative inquiry, by design, focuses on the individual rather than the general. As a result, this research cannot make claims about frequency or prevalence, and the co-constructed nature of the narrative process means the findings reflect what participants chose to share and what I, as a researcher, chose to amplify in the findings and conclusions. Using RTA partially addressed this issue by identifying threads and patterns across the accounts. However, because attention was paid to individuals' experiences as a commitment to methodological congruence, this limitation related to the chosen methodology is not completely resolved.

4.7.1 Credibility (Truth value)

Credibility is comparable to validity in quantitative research and, for some, is considered the most important aspect of rigour. Credibility is linked to authenticity and indicates whether the research can be trusted (Liamputtong, 2013). Credibility queries whether participants' descriptions of their experiences and explanations of those experiences fit (Liamputtong, 2013). Assurance is provided to the reader that the data have been collected and interpreted accurately, and that the findings and conclusions accurately reflect the population that participated in the research (Yin, 2016).

Credibility has been addressed in this research through purposive sampling, with participants selected for their experience relevant to the research question, as defined by the inclusion and exclusion criteria in the methods section. In-depth

individual and whānau interviews were undertaken, providing rich data. Thick description was used after the interviews to account for contextual elements during the narrative restorying. Tracey (2010) presented thick description as one of the most important means of achieving credibility. Member checking was utilised by providing participants with the opportunity to read the narrative and edit as needed. The narratives included quotes, and participants had the opportunity to add or redact, co-constructing the final narrative.

4.7.3 Transferability (Applicability)

Transferability or applicability is comparable to generalisability in quantitative research (Lincoln & Guba, 1994). Can the consumer of the research transfer findings to other similar individuals, groups and situations? This criterion was achieved through maximum variation sampling, provision of demographic data and a thick description of the research setting (Liamputtong, 2013).

4.7.3 Confirmability (Neutrality)

Confirmability is ensured by linking findings back to the data and incorporating quotes throughout the write-up (Liamputtong, 2013). Journals, note-taking and an audit trail were used to enhance understanding. Audit trail included codes (phase two, appendix I) and photos of each RTA phase in this report. To address my interests and motivations that may influence the research, positionality and stance statements have been provided (see Chapter 3, sections 3.4 and 3.5).

4.7.4 Dependability (Consistency)

Dependability relates to the consistency and reliability of the research (Liamputtong, 2013). It was supported by an audit trail maintained throughout the process, including decisions about coding. As the sole investigator, I had regular supervision with an experienced qualitative researcher throughout. This process included my supervisor and co-interviewer/cultural advisor reviewing sections of narratives. Clear documentation was kept throughout the research process.

Triangulation is the principle of using at least three methods to confirm or verify a finding or data (Yin, 2016). Data triangulation was achieved through multiple sources, including note-taking. Researcher triangulation and peer review were employed, with three investigators from diverse backgrounds offering distinct perspectives rather than serving as a verification process, including one with a Te Ao Māori worldview, who reviewed sections of the data. Theory triangulation involved examining the data through various theoretical perspectives.

Crystallisation differs from triangulation and involves using multiple data sources, researchers and numerous theoretical frameworks and lenses with the goal of fostering a more open, complex, in-depth understanding of the problem (Tracey, 2010). Multiple data sources (participants) from varying backgrounds participated.

Sarah Tracey (2010) provided an eight-point conceptual model of the key markers of quality in qualitative research. It is informed by the work of contemporary researchers such as Lincoln, Guba, Denzin and Creswell (Tracy, 2010). This pedagogical model is ideal for a novice researcher to develop their skills. I used this model to evaluate and guide my practices and methods in this study (Appendix M).

Rigour has been a key focus throughout this research. Creswell and Poth (2018) advised employing at least two strategies to maintain rigour. I have implemented more than two strategies to ensure rigour has been thoroughly addressed.

4.8 Ethics

Ethical approval for the research was granted by the University of Waikato Ethics Committee (Appendix N). Health New Zealand, Te Whatu Ora Waikato required locality approval, which was applied for and granted on 29 September 2025 (RD025040) (Appendix O). As part of Health New Zealand approval, an application for cultural approval for this research was submitted to Health New Zealand – Te Whatu Ora Waikato's Te Puna Oranga Māori Consultation Research Review Committee, which endorsed the study on 7 May 2025 (Appendix P). Ethical Approval from the Health and Disability Ethics Committee (HDEC) screening form

was completed on 22 May 2025; HDEC approval was not required, as Master's-level research is exempt.

Protection, respect and reciprocity for participants were prioritised throughout the research process, including in the examination of power dynamics. To minimise the risk of coercion, I did not contact potential participants directly. Paediatric physiotherapists, occupational therapists, visiting neurodevelopmental therapist (VNT), speech language therapists and conductors acted as intermediaries to identify potential families and caregivers from existing databases and caseloads and to approach them accordingly. To safeguard therapeutic relationships, any parents and carers known to me through my clinical role were excluded. Once potential participants were identified, they received verbal information from the therapist over the phone. They were also provided with a flyer (Appendix C), a PIS (Appendix D) and a consent form (Appendix E) to ensure autonomy and informed decision-making.

Interviews were offered at a location most convenient to the participant. All participants were offered the option to have a support person and/or to conduct interviews as part of an extended family/friend group (whānau interviews). A researcher safety protocol was developed to protect me, the interviewer, when conducting interviews at home alone (Appendix Q). The risk was considered low.

To protect participants' privacy, all data were de-identified and participants selected a pseudonym. The representation of participant data in the final report ensured that specific cases could not be identified.

4.9 Vulnerable Population

A great deal of consideration was given to this population's vulnerability. Participants were vulnerable as all have an infant who has had an unexpected health journey at birth, either due to premature delivery or health complications. Even if they are well at birth, subsequently having an infant identified as at 'risk' is stressful and traumatic (Morgan et al., 2023). Numerous negative experiences can occur

throughout this journey, leading to a sense of loss and grief that need to be acknowledged (Adcock et al., 2021; Falke, 2024). It was understood that by participating in this research, parents and caregivers may discuss painful memories and experience unresolved trauma or chronic sorrow (as discussed in Chapter 2). However, without involving this cohort, the study could not have taken place and deep gratitude was expressed to all who participated.

Trauma-informed care (TIC), a framework for supporting individuals impacted by trauma, such as having a premature or sick baby, is at the heart of this research. The main foundation is to give participants a sense of control and agency. TIC originates from substance abuse and mental health theories but has been translated into practice across many areas of health, including child health, to address trauma in babies, their caregivers and health staff (Sanders & Hall, 2018). The key concepts listed below (Figure 7) are practical ways to implement this approach and illustrate how it was applied throughout the research journey. Included are key principles of TIC: safety, trustworthiness and transparency, peer support, collaboration, empowerment, voice and choice (Falke, 2024).

Strategies to mitigate stress and re-traumatisation included acknowledging the stress of having a baby born early or with health concerns at the start of the interview. From the outset, participants were clearly informed that the interview would be suspended if needed. Providing positive, supportive interview environments, gradually introducing topics and using a support person or conducting the interview as a whānau/extended family group, were viewed as protective. Positive environments were established using a strengths-based semi-structured interview. Furthermore, by encouraging the use of support people, participants could draw on family networks. I, the lead investigator, am an experienced clinician who currently works with vulnerable families and have a range of communication and coaching skills that were utilised throughout the interview process.

Information on support services, including True Colours Trust, primary health providers and general practitioners, was available. Access to mental health lines (1737) was offered if needed, with a follow-up call in 1 week.

There were three occasions when participants became upset and tearful as they recalled their stories. Space was held for these family members to sit with them as they processed their emotions, validating their experience. There was a balance between staying with this place and rushing or moving on with the interview. I listened to the cues, as participants were open about what they needed. The choice was to discontinue the interview. All wanted to continue sharing their important stories. For most participants, this interview was the first time they had shared their experiences, and they reported that, while hard, it was validating and sense-making. These families were followed up with texts as a check-in. As the interviewer, I utilised supervision because I found it was emotionally challenging.

Figure 7.

Adaptation of Models of Trauma-Informed Care (Falk, 2024; Sanders-Hall, 2018)

Realising the impact of trauma on people (past experiences)	• Acknowledging at the outset the stressful nature of having a pēpi at risk. • Taking time to allow for participants to sit with feelings, without rushing into the interview questions (trust). • Acknowledge the value of the participants' experience (voice, empowerment). • Acknowledge that the researchers have their own trauma that will also inform their experience throughout the research process (peer support).
Recognising the signs and symptoms of trauma in the participants and the researchers, and caring for them	• Providing a safe environment – home-based with a support person and/or whānau members (safety). • Provision of an interviewer who is Māori for Māori whānau (collaboration, peer support). • During the interview, being aware of body language and the types of language/voice used. • Acknowledging that it may be difficult for the researchers. Provision of time to reflect after the interview (peer support). • Regular professional supervision.
Resisting re-traumatisation	• Relationship building is essential at the beginning to foster safety and trust. • Careful consent that participants are fully aware of what they are participating in and why (transparency). • Carefully worded questions, ensuring they are strengths-based (safety). • Participants have full autonomy to withdraw at any time or to decline to answer questions (choice). • The provision of information about support services (e.g., True Colours or other counselling services), if required.

4.10 Cultural Considerations

Researchers need to consider the cultural context in which the research takes place and account for the tremendous cultural diversity of Aotearoa New Zealand (National Ethics Advisory Committee, 2019). Māori are the Indigenous peoples of Aotearoa New Zealand. Due to multiple complex sets of circumstances, including colonialisation, Māori have inequities in health outcomes and access to quality health care (Curtis et al., 2019). It is, therefore, imperative that researchers demonstrate responsiveness to Te Tiriti o Waitangi (National Ethics Advisory Committee, 2019) in both ethical and legal terms.

The three principles derived from te Tiriti o Waitangi—rangatiratanga (partnership), whaiwahi (participation) and kaitiakitanga (protection)—need to be acknowledged and responded to through the research process (Wilson et al., 2021; Wyeth et al., 2010). Cultural responsiveness within research ensures that the research addresses challenges to Māori health and well-being (equity); findings are translated into gains for Māori health and well-being (active protection); tino rangatiratanga (self-determination) is promoted; Māori models of care are included in the design (options); there is partnering with Māori and Māori have autonomy throughout the process (HRC Te Ara Tika the Ministry of Health, 2019; National Ethics Advisory Committee, 2019). Each of these aspects has been addressed, from consultation through to write-up, with feedback to the involved communities.

Consultation is a key component of research involving Māori participants in Aotearoa New Zealand (Wyeth et al., 2010). As a pākehā (non-Māori New Zealander), I acknowledged that I needed cultural support throughout the research process. This research sought to be explicit in its partnership with Māori throughout the process to ensure the study adhered to tikanga principles, optimised Māori participation, and demonstrated the reciprocity and authenticity of the findings. Cultural consultation was sought from a local Māori researcher and educator in March 2025, who has links to both Health New Zealand – Te Whatu Ora Waikato and the University of Waikato. The advisor was able to critically review my intended study and offer key insights into how it could be conducted in a way that

truly partners with Māori. The advisor pointed out that there are points of connection throughout the research journey for partnering with Māori. This process connected me with a Māori researcher (PhD candidate) who agreed to serve as a co-interviewer, cultural advisor and assist with supervision during data analysis. This gave Māori participants the choice of having an interviewer who is Māori and portions of data were analysed with the support of this researcher to ensure the authenticity, that participants were not misrepresented and that it reflected Māori values. One participant was interviewed with a Māori co-interviewer.

The foundation of this research was a strengths-based, rather than a deficit-based, lens to foster empowerment (tino rangatiratanga) and a solutions-focused approach, providing congruence with the pragmatist theoretical underpinnings. Strengths-based also aligns with a FCC approach (Rosenbaum, 2021). A strengths approach involves identifying strengths, celebrating resilience and protective factors, capacities and resources, and actions that are a 'power-with' rather than a 'power-over' approach to others (McCashen & Anglicare, 2005, p. 19). The strength-based lens was overlaid with interpretative and constructivist theoretical assumptions. Narrative inquiry aligns with a strengths-based approach framed in this manner. This was the justification for using Te Whare Tapa Whā (Durie, 1994) as a framework for interviewing. Each pillar is represented in the interview protocol (see section 4.5.2 and Appendix F), facilitating reflection in each area wholistically (Figure 6) (Durie, 1994).

Many Māori values and concepts are deliberately incorporated into this research. Some concepts included were Kia tupato, a cautious approach to research. Engaging in consultation with Māori at the initial stages of planning ensured this approach. Another concept was mana, or respect, power and authority. The participants' mana was respected throughout the research by providing consultation time points across the entire project for input from Māori, from initial inception/planning through participation, analysis, interpretation and validation. Consultation was sought as needed throughout the research journey. A further concept, tapu (protection of the sacred personhood of all participants), was applied by acknowledging individual

voices, member checking to ensure authenticity and taking care when bringing them together as a collective understanding/creation of knowledge/understanding. Care was taken when integrating Māori and non-Māori experiences, considering the uniqueness of individuals and their cultures.

Tikanga refers to customs and traditional values. The hui process (meeting, gathering) was used for the interview, a culturally based and relational way of engaging with Indigenous peoples and their families, ensuring tikanga is addressed. (Wilson et al., 2021). A further way tikanga was ensured was by establishing trust (he kanohi i kitea) by meeting face to face where practicable, the provision of kai (food-home baking), whakawhanaungatanga/relationship building throughout, use of te reo Māori (Māori language), koha (gift), karakia/mihi (incarnation or prayer) and Poroporaki/whakamutunga (closing session). Ngā mihi (thank you) cards explaining the research findings and their application were sent to participants to ensure the findings were communicated authentically and tangibly, as a practical demonstration of reciprocity (Appendix S). Attention was paid to cultural responsiveness throughout the research journey, ensuring that the research was conducted 'with' rather than 'to' the participants.

This research also recognised that there may be specific cultural needs of different ethnic groups. For instance, Shama Ethnic Women's Trust or K'aute Pasifika Trust Waikato were identified as supports for consultation if participants were from cultures that required special considerations. This was assessed on a case-by-case basis; however, no participants required these supports.

4.11 Summary of the Methods

This chapter has outlined and justified the research methods and data collection used in this study, explaining the decisions made throughout. The population central to the research was introduced, including the inclusion and exclusion criteria. Ethical and cultural considerations were discussed, including a trauma-informed approach used to support safe research with vulnerable populations, power

dynamics and cultural sensitivities. In the next section, I will discuss the findings generated from the data analysis.

Chapter V: Findings

Ko tō hoe, ko taku hoe, ka tere te waka e
With your paddle and my paddle, the waka will travel

5.1 Introduction

In Chapter 4, the processes related to data collection and analysis were described and rationalised. In this chapter, the focus shifts to presenting the findings from the demographic questionnaire and the qualitative data analysis. The narrative summaries were treated as whole texts to form tentative narrative threads in the first part of the analysis through repeated reading. A secondary analysis used RTA (Braun & Clarke, 2022b) to identify detailed patterns in the data and establish threads and minor threads, as part of sense-making. This was an iterative process, weaving together similarities, tensions and differences within the narrative accounts (Clandinin, 2023). Initially, the characteristics of the participants and their children are described. This is followed by a description of the overall understanding of parents' and caregivers' experiences of EI in the first 2 years, captured in one essential thread, "On the journey with us", which resonated throughout the accounts. This thread was complemented by three minor threads—"uncertain beginnings", "we lacked nothing", and "it takes time"—and eight sub-threads that provided additional depth to each minor thread. Interpretation of findings is presented in Chapter 6.

5.2 Demographic Characteristics of Participants and Their Children

Thirteen parents and whānau participated in semi-structured interviews representing nine children (see Tables 2 and 3). Two interviews were conducted and recorded online (Teams and WhatsApp), and the rest were conducted face-to-face in the families' homes. The interviews lasted between 37 and 52 minutes. One whānau interview involved the mother, father, grandmother and great-grandmother; there was one mother-father dyad, and the remaining interviews were with individual participants (father $n = 1$, grandmother $n = 1$, mother $n = 5$). Participants represented a range of ethnicities: Māori, New Zealand European, Pacific Peoples, Indian and Chinese. Most participants lived within Hamilton city limits ($n = 8$); five lived in rural areas or smaller towns outside the main centre.

Of the nine children represented, five were male. Not all children had an absent fidgety result on their 3-month GMA, but they were identified as at risk due to brain changes on term-equivalent MRI, lower scores on the MOS-R, HINE or other developmental assessments and, therefore, met the eligibility criteria. They had a range of developmental differences, including GDD, CP, gross motor delay and CP-like (awaiting further diagnostic testing). Severity ranged from non-ambulatory to fully ambulatory. All children had additional developmental and medical concerns, including communication, feeding, epilepsy and vision, with communication differences being the most common coexisting concern ($n = 6$). Parents mostly reported seeing a therapist between 6 weeks and 3 months, with one recalling seeing a therapist in the NICU and two recalling seeing a therapist between 3 and 6 months. All these infants would have been seen at least at the 3-month (CA) visit, as they all had a GMA per the study inclusion criteria.

All infants received diagnostic or EI/therapy services from the CDC, either centre-based (physiotherapy) or via the visiting, home-based therapy service (VNT) and/or speech language therapy. Some started in the centre-based setting and were then transferred to visiting therapy. Other services accessed in combination included a developmental play group (Little Miracles Trust) and Wana Tamariki (Conductive Education). Some families also arranged private therapy opportunities locally and overseas. Frequency of therapy ranged from weekly to six times weekly, with most children receiving therapy fortnightly or more often ($n = 7$).

Table 2.

Demographic Characteristics of Participants.

Number of participants	*n* = 13
Relationship to child	
mothers	*n* = 7
fathers	*n* = 3
grandparents	*n* = 3
Age range (years)	
26-35	*n* = 4
34-45	*n* = 4
46-55	*n* = 2
55+	*n* = 3
Ethnicity	
Māori	*n* = 3
New Zealand European	*n* = 7
Pacific Peoples	*n* = 1
Indian	*n* = 1
Chinese	*n* = 1
Dwelling	
Large city (Hamilton, Aotearoa New Zealand)	*n* = 8
Small town	*n* = 4
Rural	*n* = 1

Table 3.

Characteristics of Children.

Number of children	*n* = 9
Gender	
male	*n* = 5
female	*n* = 4
General Movements Assessment Outcome	
Absent Fidgety	*n* = 5
Normal Fidgety	*n* = 4
Diagnosis (Primary)	
GDD	*n* = 2
CP (GMFCS) – total	*n* = 6
I	*n* = 1
II	*n* = 3
IV	*n* = 1
Gross motor delay	*n* = 1
CP-like GMFCS II (awaiting MRI)	*n* = 1
Other co-existing concerns	
Communication	n = 6
Feeding	*n* = 2
Epilepsy	*n* = 1
Vision	*n* = 3
Age of child at interview (years)	
2 -5	n = 6
6- 8	n = 3
Age first seen by therapist (PT, OT, SLT, VNT) *	
NICU-term (CA)	*n* = 1
Term -6 weeks (CA)	*n* = 2
7 -12 weeks (CA)	*n* = 4
13 weeks – 6 months (CA)	*n* = 2
Frequency of therapy	
Weekly	*n* = 3
Fortnightly- 3 weekly	*n* = 4
Monthly	*n* = 1
6 Weekly	*n* = 1

VNT-Visiting Neurodevelopmental Therapy/visiting therapy, PT – Physiotherapy, OT – Occupational therapy, SLT – Speech language therapy, CE – Conductive Education, CA = corrected age, GMFCS = Gross Motor Classification Scale, *as recalled by parents

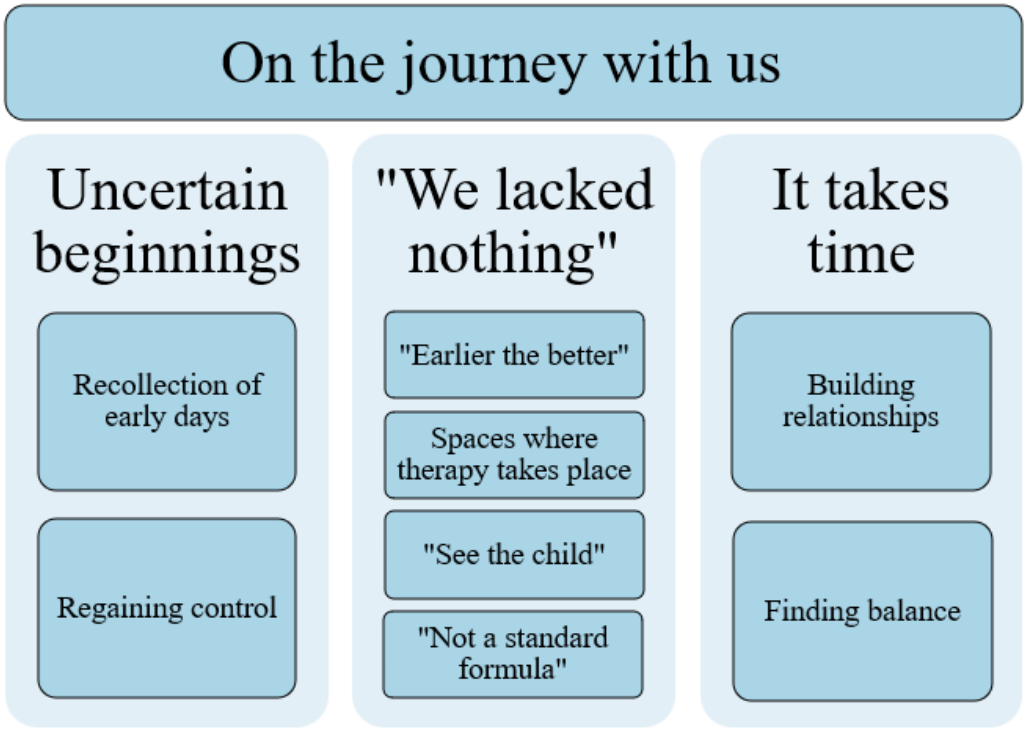
5.3 Interview Findings – Setting the Scene

Participants frequently began their accounts with detailed experiences in NICU, which formed the foundation of their narratives. Retelling these beginnings set the scene for

their experience with EI services. Parents described a turbulent time, moving from very challenging, emotional and uncertain beginnings to a place of equilibrium and balance, drawing on many nuanced sources of strength. This was not a linear path, but it was approached with resilience and hope. A summary of the overarching threads, minor threads and sub threads is depicted in Figure 8.

Figure 8.

Overarching Threads, Minor Threads and Sub Threads.



5.4 Overarching Thread – "On the journey with us"

"On the journey with us" describes the many people, not only health professionals, who supported parents and carers throughout the EI journey from the NICU to 2 years of age. Supports included parental dyads, whānau and grandparents; health professionals, including the therapy team; friends; peers; faith communities; early education educators (day care/childcare) and virtual supports such as social media.

> *I'm just grateful for Brad and Hannah [mother and father]. They've done a wonderful job with all the help right from the beginning, right from day one. They've been really marvellous*. (Cherie, Grandmother)

The participants discussed how these relationships met their physical, emotional and spiritual needs, strengthening them and supporting resilience. These supports were individualised and evolved over time. Therapists became 'like family', forming an important part of their support networks.

> *She [physiotherapist] made us feel comfortable and like she'd come in and we just all felt comfortable. Sort of like she was family kind of thing. You know, so it was just, oh [the physiotherapist] is here, come on in, you know. "Do you want a coffee?" ... and it just felt like she was on this journey with us and she made things a lot clearer for us along the way, so it actually felt good having her next to us and that support*. (Faith, Mother)

In this study, for parental dyads (mother-father), the participants' predominant experience was working together and supporting one another. There were descriptions of the child 'tying them together' and of relationships remaining strong throughout. They described pulling together for the family's good, which supported their hope for the future. Sarah (Mother) commented, "*Just the kids, really, and just sticking together and doing it. It's not a forever thing, you know, it's going to be some hard patches, but we'll eventually get there*". Marcus (Father) and Faith (Mother) described the strength and unity they found within their whānau using the metaphor of a waka (boat): "*We are on our own waka*".

The notion that parents often balance each other in stressful situations was discussed by several parents. Anahera described how her husband supported her mental and emotional health by thinking pragmatically and optimistically in response to the stressful situation of their child receiving an early diagnosis of CP through the early detection programme. Anahera (Mother) described how her strong relationship and a different perspective helped her cope, "*He's [husband] just like, well, we'll just figure it out as we go along, and let's put a plan in place; whereas I'm like, worst case scenario off the bat. This is overwhelming, this is too much*".

Fathers featured prominently in this study and their experiences differed from those of mothers. They often took a supportive role, including providing financial and emotional

support and caring for other children in the family. Fathers also took active roles in therapy and were described as "*very hands-on*" (Faith, Mother). Sarah (Mother) commented, "*And dad was obviously at home with the kids, with my other two*".

Fathers often experienced separation from their infants during the NICU stay and had to play catch-up on bonding with their new baby once they were discharged home. One dad had a traumatic experience when he visited the NICU which was frightening, and he never went back. This affected the support he could give his partner in the NICU. Another grandmother described how difficult it was for her own son (the father) being separated by many hours from the hospital as he needed to return to work. These traumatic experiences induced worry for these fathers.

> *It was a hard time for Brad* [father] *because he had to leave at the worst times sometimes. And it was probably more difficult for him to deal with because he wasn't seeing the everyday thing. And the imagination can play havoc in that place*. (Cherie, Grandmother)

Whānau and extended family were on the journey with the parents and caregivers. In Te Ao (the knowledge, understandings and practices of Māori people), the backbone of culture is whānau and the understanding that it takes a village to raise a child. All participants drew strength from their family support, but for Māori participants the significance of whānau support was discussed in detail. Anahera's whānau had considered moving closer to therapy options but this would mean being disconnected from their iwi who provided important natural supports.

> *So, if you ever are struggling, there is always a way to tap into something, which is really good. My child gets a lot of that, it's hard to explain. Within Māori culture, it is a community. Whereas I find, I guess, Pākehā culture steps away from that a lot. They're very individual people. …whenever you kind of want to experience something or you need assistance with anything, that's how you tap in. You talk to certain people and they're all within the same family and you can do all of that. Like, it is really big*. (Anahera, Mother)

Nearly every participant described how grandparents supported their EI journey; and, in one instance, the grandparent was the primary caregiver. Grandparents took on many practical roles, including providing meals, caring for siblings, offering respite and providing emotional support to their own children.

> *Yes, Cherie* [grandmother] *probably spent the most time with me. She took care of all the practical parking and feeding me and everything, because Brad* [father] *had to go back to work. So, Cherie did a lot of the hard yards*. (Hannah, Mother)

Grandparents were actively involved in therapy and were described as more patient in achieving some goals, especially when activities were difficult. Activities were often taught to grandparents by the parents, using written programmes provided by therapists, which helped maintain consistency. Ani (Father) noted, "*Our* [physiotherapist] *gave us a suggestion, gave her more tummy time, but she did not like it. At that time, her grandparents taught her. I think they have more patience*".

Having the support of family, both practically and emotionally, offered vital respite, with parents describing how it has boosted their capacity in their parenting roles. "*Just having the family around us, helping when I got overwhelmed*" (Lily, Mother).

Parents reported that some grandparents were in paid employment, geographically separated (either in Aotearoa New Zealand or overseas), had other caregiving roles (caring for other family members with disabilities) or were becoming older and more frail and therefore unable to provide hands-on assistance. "*Well, mum* [grandmother], *she works quite a lot. So, it's a whole week she's at work type of thing. She* [looks after] *my brother, he's autistic and epileptic, so he's full on himself*" (Sarah, Mother).

Two participants had grandparents who returned to their home countries after their work visas had expired. This meant less practical support and a disconnection from these relationships. For Ana, whose baby was born 3 months early, it meant her mother could stay only a few more months after NICU discharge. Ana resigned from her job at the end of her parental leave, as she did not have the necessary family support.

> *I mean, I couldn't just manage the work and the baby, so I just quit. So, by quitting my job helped me to take care of my baby. Because we had to choose something that time, because I didn't have she* [grandmother], *as* [she] *was allowed only 6 months stay, but she was already for 2 months*. (Ana, Mother)

For some participants, it was not just whānau who offered essential support; counsellors also provided psychological and emotional assistance, especially in the early days in the NICU. In some cases, this support continued through the first 2 years. Counsellors supported them when difficult news was delivered, such as a diagnosis indicating a high likelihood of CP. "*And she* [the counsellor] *was there for a lot of my child's hard stuff*" (Lily, Mother).

Families of medically fragile infants in Aotearoa New Zealand can receive carer support. These carers provide respite for the parents and support parents in carrying out the developmental programmes suggested by therapists.

> [The play ideas were] *pretty doable. With all the kids were in school at that point. So, I had pretty much the whole day. Yeah, just one-on-one with her or with her carer. She'd do a lot of it too*. (Lily, Mother)

All participants expressed gratitude to the health professionals who cared for and supported their child from the NICU through the first 2 years. Special bonds formed with doctors, nurses and therapists. The parents and caregivers expressed gratitude for lifesaving medical interventions and for being prepared for a successful discharge home. These relationships become like family, comfortable and collaborative. "*My wife and I, even the grandparents, we're very happy to have the therapist. Our child's therapist. All of them are very good*" (Ani, Father).

Most participants utilised early childhood centres (ECC) to support their child's development, usually after the first birthday. Families found that ECC supported their children's physical, communication and learning goals. "*The best thing that we did was sending him to daycare … This is a win-win situation. It's not just a one-man job to make a child speak*" (Ana, Mother).

Social media, such as joining closed Facebook community pages or setting up private pages with friends and family, was seen as an important way to connect, reduce isolation, share information and learn.

> *I'm part of a few of the tube feeding Facebook groups, the cerebral palsy group, the NICU group … Generally, if I have questions about the feeds and about just stuff that she does sometimes that seems weird, I'll post a question up and people will give me advice or tell me their stories about how they've handled it, which is amazing*. (Lily, Mother)

Parents and caregivers attributed their child's progress to the support they received throughout the first 2 years.

> *I think that without ... all the different teams that we had involved with my child, she wouldn't be where she is now. When she was in the NICU, we were told that she would never walk, that she would never talk and she can do both because we had those people involved pushing her every day. It made a massive difference*. (Lily, Mother)

Being 'on the journey with us' was woven through the stories shared in this research and continues to resonate through the minor threads detailed below.

5.4.1 Uncertain Beginnings

Parents and carers described the uncertainty they felt, particularly during NICU admission and in the early post-discharge period. This minor thread—uncertain beginnings—is supported by two sub threads, 'recollections of early days' and 'regaining control'.

Parents and carers provided vivid accounts of conversations with medical staff in the NICU. Many recalled being given 'worst-case' scenarios about their infants' developmental outcomes. In some cases, this was clarifying; in others, it was frightening and distressing, with information that was ambiguous, not pitched at the right literacy level or delivered without adequate support. Marcus' experience was that he did not know whether his child would survive. He felt fear and anger for many

months until the visiting therapist explained, in terms he and his wife could understand, what was going on with their son. "*We knew he had a stroke, but they were trying to tell us that he had bugs in his brain eating at it. And then once it's gone, that's it, he's dead, sort of thing*" (Marcus, Father).

For some parents, these conversations led to a desire to prove the prognostic predictions wrong; for others, it led to confusion, especially when their child's presentation did not align with the prognosis. Bobbi (Mother) commented, "*Life's still going to be great, and you know, and I felt like we had to prove to the world it's still going to be great*". Other parents recalled being given information in a way that they could process and understand.

> *And they're kind of timely as well. I don't think they flooded us with anything that we didn't unnecessarily need to know. But they drip feed it to us, give us the time to process it, and they welcomed questions as well*. (Hannah, Mother)

Early experiences for some parents led to putting up their guard, as it did for Bobbi. She described "*becoming defensive*" when a label was "*put on my child*". Some of these conversations were described as delivered from a deficit lens.

> *Again, like going back to the hospital, whenever they would sort of mention the possibility of cerebral palsy, it was always with a, 'we're really sorry … it's not looking good, it' s probably cerebral palsy' … it always came with this, like, just negativity around it, you know? And like, I didn't know anything about cerebral palsy, you know, and then that's kind of your first, like, learning of it is that this is something that comes with a negative association, which I don't think it needs to be*. (Bobbi, Mother)

Parents talked about medical complexity, often leaving the NICU with their babies requiring oxygen supplementation and feeding tubes, as well as medications. This meant learning new skills prior to being discharged, with some parents feeling confident with care, while others recalled that going home with their medically fragile infant was frightening.

> *It's a big change coming home with a severely primed baby who's on like oxygen and feeding pumps and all the medical stuff … You panic. I stayed awake so many nights watching her, making sure she's still breathing*. (Lily, Mother)

Parents recalled having to juggle many aspects of their infant's health journey, especially when their infant presented with medical complexity. For many parents and carers, an early diagnosis of a developmental disability did not alleviate this uncertainty, as the prognosis was not always clear. Anahera knew her child would have CP but did not know what the disability would look like as he grew older, leaving her feeling that the future was unpredictable.

> *One of the first appointments was that she* [visiting therapist] *was just here to observe. Then we were going to implement some things to help him strengthen and recreate those pathways for him to, in the best-case scenario,* [he will] *get full use of everything. Worst case scenario, still be semi-mobile or whether he will eventually need to stay in a wheelchair kind of scenario. So that was probably the most overwhelming was that he's definitely got cerebral palsy. We just need to see to what degree he has it and how we can work with it*. (Anahera, Mother)

5.4.1.1 Recollection of Early Days

The early days were characterised by parents and caregivers, on many occasions, as 'a blur'. Recollections of the initial meeting with the therapist and early assessments were often described as vague. Only one parent remembered being seen in the NICU by a therapist for a neuromotor assessment (GMA). None met their visiting therapy team before NICU discharge. Rose (Grandmother) described that while she saw the therapist a lot, she was unable to recall when the visits started, "*No, to be honest, I just ... It's a blur, but I know that we've spent so much time together, our visiting physiotherapist*".

Some parents did not understand why a therapist needed to visit or what the therapist's role was, at times confusing therapists with nurses and doctors. "*Lot of confusion, yeah, why she's here. Why the physiotherapist? ... we were a little bit puzzled, but our physiotherapist was awesome*" (Marcus, Father). Although initially confused, the therapist did not take long to build a relationship and provide clarity.

Other participants had a clearer understanding of therapist roles and were expecting a visit, recalling that the GMA would be conducted. These were described as honest, informative conversations that provided condition-specific advice. While this information was difficult to process, understanding why these assessments were being conducted helped clarify their necessity.

> *I do remember that, and I remember talking to us a lot … about cerebral palsy and what that kind of practically looked like. So, it's pretty full-on term, but once you actually understand it, then it's something … But yeah, I do remember the test, but it's about being informed about why they're doing it*. (Hannah, Mother)

In the early days, waiting for the GMA results was another period of uncertainty. Ana (Mother) described feeling tense, anxious and restless while waiting for the results, although her husband provided emotional support:

> *Waiting and thinking like what it will be, how it will be? Obviously, the waiting. I'm someone who always get tensed or anxious in the waiting time for a doctor result. But my husband is very calm. He is very practical. He* [said], *"like it should be fine, nothing to worry". But still, I hear from an expert like you, I will be a little restless*.

For one mother, the abnormal GMA assessment result was a shock and unexpected. As parents, they were optimistic that the 'worst-case scenario' they had been told about by NICU doctors would not occur. Bobbi (Mother) saw her baby moving all his limbs, so she thought the GMA result would be normal:

> *I wasn't worried about the movement's assessment … I was watching him on the video being like, oh yeah, now he's wiggly. And because I'm a real deep researcher, I've done my own training, you know, and I was like, nah, he's doing it. He's doing the movements. Like it's all sweet kind of thing. And so, it was a bit of a shock to get the call back … I think I was just expecting best-case*

scenario because we're optimists and, he'd kind of knocked expectations before. But then when it came back, it was like, oh, okay.

Overall, most participants have a hazy recollection of the early assessment process, often mixing up the neuromotor assessments (GMA, HINE, developmental assessments) and describing them under an umbrella term of assessment, using terms such as watching, coding, scoring, observing or taking videos.

> *It was when we were in child development centre and we did all those code things on different places of her body. And I think it was like her arms, legs, hips, like if she could roll over, and all those types of things*. (Sarah, Mother)

If a diagnosis was given, it was done so by the paediatrician. No participants reported experiences in which the diagnostic process disrupted the establishment of the therapeutic relationship.

5.4.1.2 Regaining Control

As part of the uncertain beginnings, there is a relinquishing and eventual regaining of control as a parent, which was threaded throughout the participants' stories. The NICU experience requires parents to trust the medical professionals with their infants. Bobbi talked about the necessity of surrendering control to the doctors and nurses in the NICU for her child's survival. This meant doing what the health professionals said. It came at a cost to parental confidence, which took time to reestablish. In addition, there was a narrative thread in this excerpt about fear of doing something wrong or hurting her child.

> *We went from an extreme emergency situation in hospital where literally all you can do is trust the doctors completely, to then being back in normal life. One specific example, in hospital while* [my baby] *was on life support I was sitting next to him and gave his chubby baby leg a comforting rub. And a nurse came and told me not to touch him as it was important his brain wasn't stimulated at all during the initial treatment he was receiving. And obviously, you want the absolute best for your baby and have no knowledge of how any of this treatment works, so you just have to trust, and do what they say. And then once you're*

> *back in the real world, the confidence gradually grows back. There's a transition period between the stage where the doctors are the ones who understand the treatment and we as the parents are totally new to it all, and then the stage where we are the ones who know everything about our child's specific type of cerebral palsy and how that affects his specific daily life and the doctors are still super knowledgeable but our knowledge has also grown*. (Bobbi, Mother)

Autonomy is re-established once parents and carers have gained knowledge and confidence. They report becoming the experts on their own child. As Anahera's story in the previous section (5.4.1 Uncertain Beginnings) described, a therapy plan gave parents and carers an understanding of what they could do for their child, supporting the regaining of control.

5.4.2 "We Lacked Nothing"

Most parents reported receiving therapy and found that their infants' EI needs were well supported by providers after hospital discharge. In addition to this minor thread, four sub threads provide further insight into the experiences, "earlier the better", spaces where therapy takes place, "see the child" and "not a standard formula". EI was described, for the most part, as responsive, collaborative and supportive, delivered by skilled and knowledgeable therapists who partnered with them on their infants' EI journey. Rose (Grandmother) reported, "*He never lacked anything because of these visits … I can't see anything that could have been changed from what we had done*".

While this was the general narrative, in some cases it was difficult for parents to know what to expect from services and whether they had received what they were supposed to. Hannah (Mother) remarked, "*I certainly don't feel like we're lacking in anything that we desperately could have needed, but it's a little bit hard to know on the physio side of things, if you don't get it, you don't know*".

One narrative thread, distinct from the majority, describes Ana's inability to access the therapy her child needed through Aotearoa New Zealand's public health system; therefore, therapy was sought privately in Aotearoa New Zealand and abroad. Ana was referred to CDC physiotherapy, where her son received assessments and some

intervention, which she was grateful for but described as insufficient. Even when attempting to engage with private providers, there were barriers, including a lengthy waitlist and difficulty scheduling regular sessions. Ana felt she had no choice but to take her child overseas, where she did not encounter the same barriers, to get what he needed. The therapy this family received was hands-on (traditional), multidisciplinary (speech language therapy, physiotherapy, occupational therapy) and intensive (5 days a week) in the family's country of origin. Mother and child were separated from the father and there were financial implications, but staying with extended family offered an advantage. They had choice and flexibility, and the therapy was located close to where they stayed. "*So that's when physiotherapists were like, he needs physiotherapy more. But the services here* [Aotearoa New Zealand] *are a little different. They don't give any one-on-one for babies or children*" (Ana, Mother).

5.4.2.1 "Earlier the Better"

Earlier the better refers to the minor thread that parents and caregivers valued engaging in EI services early to begin habilitation. Referrals to EI services were reported as seamless. "*The CDC system was helpful; everything was done from the hospital through the CDC. We didn't need to approach anyone, … the doctors referred him to the CDC*" (Ana, Mother).

There were inconsistencies in the timing of the first community appointment. For most families, the first appointment with a therapist occurred within the first 3 months (CA), which was considered early enough. Others did not have a clear understanding of what the expectation might be. When the first appointment was at the 3-month (CA) GMA assessment, after having such close support in the NICU, waiting several months to be seen felt like a long time.

> *I think it was about right. I think possibly thought, well, maybe they could follow this up a little bit earlier. You know, after having such an intensive and long NICU stay … but to go from such hands-on experience and then to come home with nothing for quite a long time, like a few months, is quite a long time.* (Hannah, Mother)

Neuroplasticity was discussed in various ways, both directly and indirectly, throughout the conversations with participants. The understanding was that the earlier therapy begins, the better. Therapy was recalled as an investment in the child's future, providing support when learning is easier and reducing the need to relearn when learning is more difficult.

> *I felt like the, because it was quite early for us, being that he is a premmie, it was good to get it in early. I think if you left it too late, it would just be harder. It would be harder on the baby or the child to relearn those pathways if you didn't start them as they were picking it up. That's sort of what I think. The earlier the better*. (Anahera, Mother)

The knowledge parents and carers had gained over the first few years of their EI journey helped motivate engagement.

5.4.2.2 Spaces Where Therapy Takes Place

This minor thread discusses the environments in which EI took place. All participants discussed the parents' and caregivers' experiences of where therapy occurred during the first 2 years. The concept of 'space' described included our space, enough space, safe space and the child's space. While the participants had EI in different 'spaces' (clinic, home, early learning centres), the preferred place of therapy in the first year was home. Reasons identified included convenience; fewer challenges carrying medical equipment, such as oxygen bottles; the child being relaxed at home, so they show more of their skills; the ability to see the home environment to adapt, if necessary; reduced travel time and easier parking at the main centre.

> *What I found having them* [therapists] *come to the house was a lot less stressful than trying to pack up all her equipment and then drive to the hospital and find parking because there's never any parking. And yeah, having to get her out of the car and then to make sure that nobody got snagged on her tubes. It's almost like you need to put her in a bubble*. (Lily, Mother)

For participants living in geographically isolated areas, the visiting service was an enabler, reducing the need to travel.

> *I know that's why our therapist was always very happy to come up* [rural location] *and play at home, which is, you know, it's their own space. It's how they really are, and they're relaxed; and even taking our child down and meeting her* [therapist] *at the* [local hospital], *which isn't a big deal for us. She would have said it's still not quite the same as seeing her as her in her own space ... I think you get so much more out of it face-to-face*. (Hannah, Mother)

At times, EI was supported by a hybrid model utilising telehealth and home visiting, though there were some technical challenges.

> *Because it was COVID, our first meeting with her was supposed to be Zoom, and the Wi-Fi at the hospital was so bad that we were sitting out in the car park on phones and stuff and ...* [we ended up] *just going inside with our child and seeing her face-to-face.* (Brad, Father)

Inequity in the services available was identified following discharge from visiting therapy for rural families. Some rural families were excluded from certain services, even when they were willing to travel. Anahera found that even with individualised disability funding available to employ private therapy, there was no one in the region with the necessary expertise. For Anahera, when her son was transferred to centre-based services, she found they had "*less assistance, less help, less enthusiasm*", and she tried to keep her original therapist who lived locally. "*So much so I tried to keep her for as long as I could. "Do you do private?" She said "no". Yeah, I tried to do everything I could just to keep her but no, once we handed over, that was it. I was pretty sad*" (Anahera, Mother)

The rural families in this study needed to travel more; yet the travel reimbursement systems were not streamlined and they had fewer choices of EI providers. When they travelled to the main centres for appointments, they took time off work and had to fit in with the therapists' schedules. "*Well, the expense, after you have to travel, you have to take a day off work. You know, it gets expensive*" (Cherie, Grandmother).

While home was perceived as better, it was not necessarily easy. There was tension between the ease of being at home and the intrusion of having someone in one's own space. Inviting therapists into 'their space' created vulnerability and fear of judgement. Lily described doing what she must for her child and said home was "*the lesser of two evils*". Having a stranger come into their home was reported as a big deal and four participants felt as if they were under a spotlight. There are many adjustments for new parents, and home visiting adds pressure. Bobbi's (Mother) story exemplifies many of these narratives:

> *Definitely, there is pressure that goes with it, but I think it's like when people come to your house, I do remember a few times feeling like, is this an assessment of him or me, you know, as a mum? Do I need to clean the house before these people come? You know, all that kind of stuff. And you know, you're a new mum, I'm just getting to grips with breastfeeding, and then I've got people rocking up. Opening your safe space up and letting people in is a big deal*. (Bobbi- mother)

Sufficient space was an aspect of EI provision identified by two parents. Rose thought home therapy worked because she had enough space. In contrast, Ana thought centre-based intervention was better, as the child would be able to get into a routine, have more space and access to specialised toys and equipment.

ECE was another 'space' where therapy took place, often in conjunction with home visits. This supported continuity in implementing play and developmental programmes for parents and their caregivers. A collaborative approach was reported, with frequent communication between the parents and the therapist to support success. This practice helped the child integrate skills into other contexts and provided an additional level of support for the child and their parents.

> *Sometimes when* [our child] *is not going to kindy, she'll come and do it here. Otherwise, she'll message me, "would you rather at home or at kindy this time?". And we'll do kindy and then the next session we'll do at home, so that we get to catch up with her and talk with her and find out*. (Faith, Mum)

Ana sent her child to preschool to make up for the lack of therapy services. By this time, her child's main needs were speech language therapy and play skills, so ECE supported her goals. In addition, it provided her child with opportunities to develop his social skills.

> *All the doctors, even used to tell to put him in the daycare because see here we don't have the therapies* [in Aotearoa New Zealand] *like in back my* [country of origin], *like we can't take him to therapist but the only thing what we could do is the daycare where a child can go learn something, even if it's the smallest thing of you know what to do, how to play with other child. So that is the best thing we did. And we have put him till now full time all the days, all the 5 days*. (Ana, Mother)

5.4.2.3 "See the Child"

Parents and caregivers experienced that the therapist saw the child, not the disability and valued the therapist's efforts to build a strong relationship with the child. The therapist's child-centred, strengths-focused outlook was important for the participants in this study. Bobbi (Mother) did not want the therapist to see her child as a project:

> *Yeah, and so I was grateful that* [the visiting therapist] *saw him rather than what should be … I just think like seeing the child and the person, the human being, is so important … not seeing our child as a project, but as a person and the family as a family rather than, yeah, sort of a project. Like all our therapists that we've had have been awesome, but I think it's more than just being good at the job … like it's, yeah, I think the way they see the child is really important*. (Bobbi, Mother)

Continuity of care with the therapist helped ensure the child's achievements were recognised and celebrated. Lily found that those on the journey with them celebrated her child's successes, no matter how small the gains. Her child had many setbacks throughout her first year due to medical complexity, so understanding her child's 'story' was essential. New people did not understand how much progress Lily's child had made, whereas those who had seen the progress did. These small milestones were significant for Lily.

> *It made it a lot easier, being able to just have them in our space and be like, my child's made this milestone this week, and then them celebrating that with me instead of like a new person every now and then you'll be like, "Oh, my child did this", and they'll be like, "Okay". But every time there's a new person, they didn't exactly like … make it into a big thing, whereas people that have seen her from the start, they did, because they knew where she'd come from*. (Lily, Mother)

Parents reported that the therapist provided interventions at the child's pace and frequently emphasised not 'pushing' or 'forcing' the child. This helped the child be at ease with the therapist. Many parents described these experiences as EI being child-centred and honouring both parents' and the child's responses to interventions.

> *Just letting our child do her thing, she* [therapist] *didn't push her, she was there* [to] *kind of to support our child and see how she's going. It wasn't, "we're here to do this, get up and we've got to do this and we've got to assess it". And our child had enough, she was like, "no, that's fine'. And then she'll pull something out and distract her away from the point* [where] *it's getting a bit overwhelming because I'm getting touched too much and it's just wait, "I can't do that, so don't force me". Yeah, she's just been really comfortable with our therapist*. (Sarah, Mother)

5.4.2.4 "Not a Standard Formula"

Parents and caregivers described that the therapist listened to them, saw them as experts on their child, recognised that they know their child's needs best and acknowledged the family's unique needs. Anahera (Mother) described the bespoke approach to EI, which was valuable. "*It wasn't standard formula and I think and that's, it was personal to every family which is probably what was beneficial the most*".

The therapist's highly relational, encouraging and positive approach to therapy supported these parents' and caregivers' hope for the future. Bobbi describes how, early on, her therapist told her that her child could achieve anything, although they might

need to adapt how things were done. Bobbi (Mother) also noted that knowledgeable therapists supported these outcomes:

> *So, I think probably the thing that's taken time, but also that having* [our visiting therapist] *early on was good for, was just like we learned pretty early on, nothing is out of reach. We just have to figure out his way, you know, and be okay with it looking different*.

The parents' and caregivers' experience of EI was collaborative, with many instances of joint decision-making reported. This collaborative practice was fostered by providing choice, feedback, clear communication and information sharing. Collaborative practice helped keep "*everyone on the same page*" (Faith, Mother), where "*it was two-way. It wasn't just one*" (Rose, Grandmother).

Parents and carers experienced a non-judgemental approach to therapy. Therapists understood the many aspects of life and supported integrating activities into daily life, without pressuring them to do specific things. This fostered openness and trust, deepening collaboration between parents and their therapists.

> *We all tried to put in as much* [practice], *but there were times where it was unavoidable. We just couldn't do it. But we did what we could in between the times that we could, but we always used to, whatever is suggested, we're going to run with it. Because at the end of the day, yeah, it's about him. It's how we as the carers take it on board what's being suggested, never like it was said "you need to!* (Rose, Grandmother)

In contrast, the pressure sometimes came from within the parents, who wanted to invest in their child's future and achieve the best outcomes. Faith said she felt "*gutted*" if her son resisted some of the exercises the physiotherapist provided. She did not want to feel that they, as parents, had failed him. "*I don't want to feel like we've failed him when he's older and he could have had more*" (Faith, Mother).

While parents and caregivers were seen as experts on their own child, they discussed relying on the therapist to identify needs and guide them in the next steps. Anahera's

infant presented with hemiplegia. Without the therapist's expertise, she may not have realised this was not typical for her child's age, delaying timely, specific interventions such as upper-limb therapies (Baby CIMT). "*If we hadn't had that intervention, we wouldn't even think about doing that. We just, oh, he's left-handed. We'll just go with the left hand*" (Anahera, Mother).

Others found that the therapist confirmed what they had noticed about their child. Therapists provided extensive education about the condition, including specific, understandable information.

> *So, she was able to sort of tell us things, so that was great support we were* [given] *that made us feel a lot better knowing what we can do to help his condition, rather than just treat him like a normal baby and because I only know so much*. (Faith, Mother)

Ani, whose child has non-ambulant CP, was grateful for the expertise guiding him and his wife on the next steps. Ani talked about how he would not have been able to know what to do to support his child without EI. This advice supported all areas of life such as eating, sleeping, moving and personal care.

> *I would thank them. For the help* [they gave us] *us for the last 5 years and give us a lot of support. If* [we] *haven't got them a lot of things, we don't know how to do this. Even how to choose the car seat, the first time how to choose the car seat, how to let her sleep, how to bathe her*. (Ani, Father)

Parents and caregivers reported numerous instances in which the therapist used coaching practices. Marcus and Faith expressed their gratitude for the therapist's time in teaching them as parents.

> *All of them have put into our son, and put into us and teaching us to teach him … I wouldn't change the way things have been going with the therapy and all of that, because they're doing what they can to help us, help him as well*. (Faith, Mother)

Therapy and play suggestions were reported as achievable, 'doable' as they were routine-based, goal-directed and realistic, scaffolding the child in their next developmental steps. "*Well, I feel like what's being suggested it's workable and it can be included in your routine*" (Rose, Grandmother). Goals were based on what was important to the family and tailored to the child's identified needs. "*We did goal setting in regard with ... like feeding and movement. They were to do certain movements and we had like exercises to do at home to try and strengthen her as well*" (Lily, Mother).

For parents and caregivers, implementing the therapy ideas was easier in the early years. As children got older, it became harder to get them to engage. Some parents met the challenge by being creative; for example, doing exercises at the park or utilising ECE supports. For Anahera (Mother) it became so hard as her son got older that they no longer do any therapy, which worried her:

> *The early years were the easiest, obviously, because that's the years, they're learning and they're developing. So, you're investing that time. ... Whereas as a baby he would sit there and you'd play with him and he would learn all of that stuff and he'd be quite happy and it wasn't as prominent the limp in the earlier years because obviously he was just learning to walk and all of that. But yeah, now it's more difficult. He won't do any of it. It is hard*.

When the next goal or 'mission' was set in the child's developmental journey, parents had resources to refer to, including videos, written programmes, diagrams, texts and emails. These were used as visual prompts and were often kept documenting their journey which helped track progress and celebrate success. These resources were shared with other whānau and support people to support continuity.

> *We know what the next mission is for the next 3 weeks so do and it's just if you forget little things like how you could make kind of make it easier if something's not working you can always go back to it and it's printed in front of you so you can't really if you're your phone breaks or whatever, you know, you've still got the hard copy. Or you can give it to Nan, and then Nan's at her house doing the same thing. So, it's pretty good*. (Sarah, Mother)

The play ideas often did not require specialised equipment to implement. In Sarah's (Mother) story, both the therapist and the caregiver creatively used what was already in the home to achieve the goal:

> *It was easy, it wasn't to do with equipment, it was just floor time. Pillows, like things that you'd have in every home. Fluffy rug that she can't hurt herself and we'll lay that out with a couple of pillows from that room … and it was quite easy to set up and have our child's little area*.

At times, specialised equipment was needed to support the child. This equipment included feeding and mobility seats, standing frames, wheelchairs, walking frames, car seats and bathing equipment. Ani's child had a lot of equipment and he was grateful for the time the therapist took to find the right solution, even as they worked through some challenges.

> *The equipment was very good. The physio and OT* [occupational therapist], *they're very kind, very thoughtful. They gave us a lot of types to try, yeah. And like standing frame, we already tried, like the third one, which one suitable for our child and became the best one*. (Ani, Father)

There were many instances in which parents discussed the therapist taking on additional roles, often coordinating services for parents and caregivers. This included making and following up referrals and clarifying medical information. For parents and caregivers, this 'key working' role was seen as going the extra mile.

> *Like she's* [physiotherapist] *the middle person. And you know, we're grateful because otherwise we wouldn't know what we're doing. We wouldn't know how to explain things to the paediatrician. They know in their medical term how to explain it better than us. So, it has been great support, they've been awesome*. (Faith, Mother)

5.4.3 It Takes Time

Through their narratives, parents and caregivers described how they changed as a result of their experiences of having a child with developmental differences. These changes

took time and eventually led to adaptation, acceptance and new perspectives. As a sub thread of 'it takes time', parents discussed how it took time to build relationships and find a balance. Parents had not been prepared for what they had gone through with having a baby born early or having a difficult birth but, through their experiences and the support of those on the journey with them, they gained strength. Anahera (Mother) learnt many things from her child, including how to slow down:

> *So, my child taught me a lot and I'm probably really grateful that it made me slow down and reevaluate things because I was, you know, just racing through life before then. Yeah, so I guess that's probably what I'm grateful for is the slowness that came with it and the less caring about other things that weren't important*.

Taking time was threaded throughout the narrative as the parents and caregivers recalled their journeys, including relationship-building and reaching equilibrium.

5.4.3.1 To Build Relationships

This minor thread describes how building relationships takes time for the child, parents and caregivers. Parents and caregivers noted that offering accommodating, flexible services facilitated the building of these connections. Parents appreciated the ability to reschedule appointments if needed, which facilitated the integration of all the services the child was involved with. Sarah (Mother) said, "*All those different types of things up the hospital, eye tests and things. So just making sure everything fits so we can all kind of get it done and not miss anything*". One mother suggested the therapist could be explicit that rescheduling was acceptable to reduce feelings of guilt.

Ani described how his child needed a gradual introduction to new situations. The service was adapted to suit her individualised needs, to allow for the gradual building of a relationship, the child's capacity and to suit her temperament, enabling future experiences to be more positive.

> *Yeah, I think it's the right time because when our child was small, she needed time to get used to the new stuff, like the new people, a new place. She took maybe 3 or 4 months to accept our* [visiting physiotherapist]. *And when we went*

> *to conductive education, the first conductor took maybe 3 or 4 months and our child got a good relationship with her. But when she was growing up, that would be much better. Going to the older class, I'm very surprised even the first time we do not need to stay over there*. (Ani, Father)

Consistency also helped parents and caregivers build a trusting relationship with the therapist. Faith and Marcus found changing therapists disruptive, and it took time to build a relationship with a new therapist. While they understood the change was unavoidable, they wondered how the new physiotherapist would view them, as they were so comfortable with the original therapist who had walked them through the first part of their EI journey. They feared that a change of physiotherapist or a change in service would interrupt their child's progress. The importance of taking time to build relationships is illustrated in the excerpt below. Once the relationship with the new therapist was re-established, this was viewed as positive.

> *Probably the challenge, my most challenging thing that annoyed me of the therapy, and I couldn't change it and it did upset me. Like the wife had calmed me down a bit, as we got so attached to our first physiotherapist and then they swapped. That took me a long time to actually get used to the next person ... Bring* [the first physiotherapist] *back*. (Marcus, Father)

> *For me, it was more the personalities adjusting to, you know, because we're not your A-class people, you know what I mean? Like, we were worried, like, oh, "are we gonna adjust to* [second physiotherapist]*? Is it gonna be all right?" Are we, you know, cause we, and our child had gotten so used to* [first physiotherapist]*, so it was a big change ... But now,* [second physiotherapist] *has explained to us, we can go to the* [private provider] *and all of that stuff, but that means we cut her out. And I said, no, I don't want to do that because our child has adjusted to* [second physiotherapist]. *So have we. And too much change for our child might slow him down and set him back ... So, it has its challenges, changing, but it also has good outcomes if you let it*. (Faith, Mother)

The concept of therapists' personalities was a key element in building relationships with parents and caregivers. 'Gelling', the therapist's 'personality', being the 'right fit', or

feeling 'comfortable' with the therapist, was viewed as essential to building trust. Although almost all participants reported that their therapists were the right fit, they wondered whether, without the right support, their experience could have been entirely different.

> [Our visiting therapist] *was just amazing and like, to this day, I still feel like I could trust her, you know? But I think if we had have had somebody that we didn't gel with, it could have been an entirely different experience. So yeah, like for us, it was a positive.* (Bobbi, Mother)

One parent described a situation in which a therapeutic relationship could not be established, compounded by living rurally. Travelling to services is time-consuming, and, as Hannah (Mother) described, if there is no clear understanding of the need for the appointment, the experience can feel like a waste of time and lead to disengagement:

> *I think sometimes you just have a better relationship with some specialists than others. But yeah, at the time it's like, I don't really know what she should have been doing, why it was necessary. And like, it was quite a big draw in our time to go visit her* [speech language therapist] *and I remember going to visit her in the* [larger centre] *and just going, well, that was kind of a waste of half of a day*.

5.4.3.2 To Find Balance

Many parents and caregivers described reaching a state of acceptance, balance and equilibrium over time. They noted that this process takes time, and even once this point is reached, many unpredictable events in life can disrupt this balance. Balance was achieved by ensuring life did not revolve around therapy or focusing on the child's developmental differences. For some, reaching equilibrium meant returning to the workforce or study, and for one grandparent who had made many sacrifices to look after her grandchild, it meant starting to put herself first. For others, as in Ana's (Mother) case, it meant letting go to support her mental health, "*My mind can't keep revolving around that because if I keep thinking like what he is doing, if he's doing this, then I'll get into depression*".

Bobbi (Mother) talked about balancing physical progress with the importance of "*just being a kid*":

> *But for us, we kind of just, we just want to keep it a normal, regular life, you know, but do everything that we can for our boy to feel confident and to thrive and to, yeah, just to feel like his life is exciting, you know, and big, his world's going to be big*.

For Marcus and Faith, having their son has positively impacted their whole family. They have not arrived at this place straight away, given the beginning of their story.

> *I look at that as a gift for my kids that they obviously needed in life … it's changed it for the better. Hasn't changed it in any negative way. And I know it's just made us a more open family, more open with the kids. …he's like a big blessing to our house*. (Faith, Mother)

Ani and his wife had hoped things would be different, but they have now accepted and are looking forward to their child's next stage. This has taken years to reach. "*Yeah, I understand the doctors, but we think maybe good luck, she will be okay, but of the 5 years, so we already accept that*" (Ani, Father).

5.5 Conclusion

These accounts reflect the rich experiences shared by parents and caregivers. Many experiences were common, while others were unique, highlighting the complexity of families' journeys. While multiple threads were identified, the most significant finding was the centrality of relational, evolving support systems, captured in the overarching thread "On the journey with us". Supporting threads provide insight into how this experience is shaped over time, beginning with uncertainty, progressing through engagement with services and evolving toward adaptation and balance. This suggests that caregiver experiences are shaped both by service provision and how relationships, communication and support unfold over time, highlighting the complexity of EI beyond clinical provision and reflecting a broader ecosystem of relational and contextual influences.

In Chapter 6, the data analysis will be presented in relation to the research questions and objectives. The perspectives revealed through this research will be considered alongside current literature and theoretical frameworks. In doing so, the chapter will demonstrate how these findings may inform practice, policy and future research.

Chapter VI: Discussion

Na te whakarongo me te titiro ka puta mai te korero
Through looking and listening we gain wisdom

6.1 Introduction

This research aimed to explore the experiences of parents, caregivers and whānau of EI services for infants born preterm or with health challenges in Waikato, following identification as being at high likelihood of adverse neurodevelopmental outcomes such as CP, in their first 2 years of life. Parents and their whānau generously shared their feelings and experiences regarding EI from the NICU onwards, as documented in Chapter 5.

This chapter will first summarise the findings and, based on the data, provide answers to four of the five research aims posed at the outset. The fifth research aim concerns the identification and communication of service and policy recommendations and will be addressed in the final chapter. The findings will then be linked to current research, theories and models of practice as supporting evidence for triangulation, including extending knowledge and making original contributions. I will discuss how they relate to early practices. The study's strengths and limitations are considered.

Throughout this discussion, the interplay between the temporality (time), sociality (social influences and people) and spatiality (space, environment) perspectives (Haydon & van der Riet, 2017) are considered and documented to explore parents' and caregivers' experiences, their perceived key needs, access and any barriers or inequities identified through the stories.

6.2 Parents', Whānau and Caregivers' Experiences; How They Accessed Services; Perceived Needs and Identified Barriers

The first aim was to describe the experiences of parents, caregivers and whānau of service using a narrative inquiry. Study participants' past experiences shaped their stories, influencing how they see the past, present and future and aligning with the temporality of narrative inquiry, which allows for social change (Haydon & van der Riet, 2016). Participants who experienced deficit framing of disability in the NICU

expressed a need for strengths-based, positive approaches from therapy services. Participants who experienced uncertainty desired consistent service with minimal disruption. Those who received poor or ambiguous communication emphasised the need for clear communication. These early experiences begin to make sense as life unfolds, influencing the formation of attitudes about what is needed and about purpose, as described by Dewey's first principle of 'continuity' (Caine et al., 2022). This provided a frame of reference for what mattered to parents and caregivers, guiding them as they moved forward on their EI journey. Sense-making is always evolving in relation to the larger narrative (social, cultural and institutional) and is deeply rooted in this larger context, such as political and health systems (Dewey's second principle of 'interaction').

The early days were difficult for the parents and caregivers as they experienced uncertainty, ambiguity and a loss of control. Their infants were medically complex, and they had to process difficult prognostic information. Participants had mixed recollections of the timing and specific purpose of the neuromotor assessments. When information, therapist roles, communication and processes were clear, it fostered trust and confidence; in contrast, times that lacked clarity, contributed to worry and uncertainty.

The parents in this study described how they formed strong, therapeutic relationships with their community therapists, despite uncertainty and the key role that social networks, in addition to therapy providers, played in facilitating engagement with EI. These social contexts supported their physical, emotional, spiritual and mental health. The supports are nuanced, dynamic and need dependent. Trusting, collaborative and empowering parent-therapist relationships developed over time, with the therapist often becoming like family. In addition, the relationship was strengthened by the therapist assuming key roles as a link to the hospital.

Parents and caregivers eventually reached a place of acceptance and equilibrium, though they continue to face challenges. In many cases, their EI experiences helped equip them to meet these challenges with resilience and hope.

The second aim was to identify perceived key needs for early EI for their infants. While parents identified some key needs for their infants, they also identified many needs that facilitated their own engagement in EI. They needed therapists to 'see the child', not the disability, and to understand the broader family context. In addition, parents and caregivers wanted therapists to work at the child's pace and have non-judgmental approaches to therapy. A pressure-free, non-judgmental approach and having a consistent therapist were facilitators of the parent-therapist relationship. They needed the therapists to provide condition-specific advice and assist with providing links to other health professionals. In addition, caregivers found therapists to be a valuable source of accurate, appropriately tailored information that accounted for literacy level. Caregivers relied on therapists' expertise to deepen their understanding of their child's presentation and receive guidance on next steps.

Parents and caregivers received EI that met their needs, for the majority, with therapists who focused on the parent-child relationship and used goal-directed, family- and child-centred approaches. There was a great deal of congruence between practice recommendations and what parents received, indicating acceptability. Individualised and flexible programmes were provided, empowering parents through coaching models of care to deliver motor, sensory and play programmes. The therapy ideas were feasible, routine-based and salient, and did not require specialised equipment. As the children got older, therapy ideas became more difficult to implement, prompting parents to find creative ways to support their child's developmental goals. Parents and caregivers valued autonomy and choice but also relied on the skilled therapist to advise on next steps and provide specialised equipment. They attributed their child's developmental and functional success to the support they received from this early therapy.

The third aim was to explore how parents, caregivers and whānau access early therapy services in the first 2 years of life. This study found inconsistencies in service delivery and in the timing of first contact, including minimal contact with neonatal therapists and no prior contact with the community-based therapy team prior to discharge, reflecting broader structural challenges in service delivery. In the early days post NICU discharge, access to clinic and community services was facilitated by a seamless referral pathway after discharge. Access to specific services, such as physiotherapy and speech language therapy, for one participant was limited and did not meet their needs. This

raises questions about service access for children who have clearly been identified as 'at risk' of CP or with a diagnosis of CP, and for those children who are identified as having early biomarkers for non-CP outcomes. These children may have inequitable access.

The study explored parents' experiences of the spaces where EI was accessed, including hospital clinics, home visiting, telehealth, early childhood providers and community providers such as Wana Tamariki (Conductive Education). Home was considered the most acceptable, though it came with some constraints such as parents' feelings of vulnerability and the need for sensitivity when entering 'our space'.

The fourth aim was to observe how barriers to service delivery might be mitigated. A change of therapist can disrupt the relationship and impede the formation of a therapeutic relationship. The study found that families living in small towns and rural areas faced barriers to accessing EI, including fewer choices, needing to make more compromises and a greater need to travel. Other barriers included having to travel to appointments when infants were still medically fragile, parking and technological barriers when using telehealth. Home visiting reduced inequity for rural families, enabling them to access the same care as those in larger centres, but they did not have a choice of provider. As introduced above, home-based services can be a barrier. It has been identified that there may not be enough space; most importantly, the home is the family's safe space, and parents and caregivers may not wish to invite therapists into it. This will be discussed in greater length in section 6.7. Lastly, barriers to accessing services may be influenced by the initial service to which children are referred, such as clinic-based physiotherapy or home-based services, with the observation that parents who had home-based services found them more acceptable.

This section has provided an overview of the findings related to the objectives and aims of the experiences of parents, caregivers and whānau of EI services for infants in Waikato who were identified as at high likelihood of adverse neurodevelopmental outcomes. Further discussion regarding interpretation, meaning and in-depth analysis, beginning with the importance of nuanced relationships, is offered in the succeeding section.

6.3 The Importance of Nuanced Relationships

The study specifically asked about support networks (family, friends, community, therapists) and how those relationships have made a difference for participants in the EI journey, providing an opportunity to discuss these relationships in detail and capture participants' thoughts, informed by Te Whare Tapa Whā (Durie, 1994). Parents and carers discussed how having a child with a developmental difference entails an additional care burden, requiring individualised support networks to ensure physical and mental well-being. These networks supported parents and carers in delivering interventions, consistent with previous Aotearoa New Zealand-specific and international research (Massey et al., 2025; Williams et al., 2024); however, my research extends this finding to entail a greater network of supports including online peer support and ECE providers.

Parents, mothers and fathers supported each other throughout the journey, with roles encompassing emotional and practical support, as well as direct (involved in therapy) and indirect (financial provision, care of siblings), mirroring research in other contexts (Harniess et al., 2022). The participants in this study did not experience relationship breakdown, as reported in other studies (Baraldi et al., 2020); instead, pulled together and supported one another. The whānau collective, as the wider context, including grandparents, strengthened the overall resilience of the whānau, extending existing findings on the experiences of whānau of preterm infants (Adcock et al., 2021, 2022; Massey et al., 2025). This highlights that the EI provider ought to consider the interconnections within the family collective and find ways to strengthen these relationships.

Sociality includes the role of culture expressed throughout the narratives. Both Māori and non-Māori participants conveyed the pivotal role whānau has in their EI journey in similar ways. For Māori, infants are the centre of whānau, and parents are closely supported by the extended whānau (Adcock et al., 2022); therefore, it is not surprising that whānau features strongly in the narratives of Māori participants. The stories in my study discussed the importance of collectives and how they support the overall well-being of the child and parent. When parents consider moving closer to medical and therapy services, it creates a tension between the importance of whānau, connection to iwi (tribe) and whenua (land), and providing for the 'needs' of the child with a

disability. This is an example of inequity in healthcare services for infants and their families, which is likely compounding unjust, inequitable health outcomes and experiences for Māori across Aotearoa New Zealand (Paine et al., 2022; Sorhage et al., 2022). A tailored child disability service that is equitable and cultivates emotional, mental and physical well-being was the key recommendation from co-design workshops involving Māori and non-Māori families of children with CP and health professionals (Williams et al., 2024). The visiting therapy service offers a solution to reduce inequity by providing services where the whānau lives, where natural supports are embedded, enabling a holistic approach to care. Providing EI in this way reflects tino rangatiratanga (self-determination, sovereignty, autonomy) and partnership. In this way, the visiting therapy service strengthens these vital relationships.

An emergent finding from the narratives is the role of migrant parents' extended families (grandparents). Although this was not the primary focus of this study, it offers insights for policy recommendations. Two migrant families in the study had grandparents on a 'parent and grandparent visitor visa' who provided essential support but were required to leave the country after 6 months under Aotearoa New Zealand immigration law (New Zealand Immigration, 2026). I have observed this situation anecdotally in practice many times. The support provided by the grandparents aligned with cultural values and preferences, possibly reducing the need for government-funded carer support (Raghupathy et al., 2025). Being required to leave Aotearoa New Zealand places an additional burden of care on the parent, without their preferred natural supports. As Aotearoa New Zealand welcomes migrants to support the workforce and economy, this situation may arise more frequently, and extending stays would have many positive effects for these families.

The key finding in my study is the importance of whānau collectives within the context of EI provision and the nuanced, evolving nature of these relationships. The participants in my study came from diverse cultural, social and family contexts, as well as diverse understandings of health information, which emphasised the need for individualised approaches. As parents and caregivers grew in the capacity and knowledge of their child, what they needed from EI changed. There was an adjustment to the therapeutic approach over time. Parents needed time to form these relationships.

The ‘collaborative relationship-focused occupational therapy’ model of practice (Restall & Egan, 2021) provides a framework for how therapists can strengthen these collectives and extend beyond a family-centred approach. This model of practice highlights the importance of the individual and the collective, describes the nuanced nature of these collaborative relationships and makes it an ideal model for therapists to consider when working in the field of EI. Contextually, the therapist attends to individual and collective priorities and aspirations. Temporarily, this model recognises the time required to build a new relationship and that it changes over time. The evolving relationship makes space for parents and caregivers to change over time, with the therapist adjusting their approach to meet changing needs.

Restall and Egan (2021) argued that working in partnership with individuals, whānau, groups, communities and populations promotes participation, justice and equity. This way of practising supports respect, power-sharing and collaboration and, most importantly, safe relationships. Safe relationships are crucial, as these parents have experienced such an unsafe time, having a baby born early or unwell. Furthermore, this approach supports cultural safety by enabling therapists to build relationships with parents and their collectives from diverse cultures and backgrounds. It promotes emotional safety, respecting cultural and spiritual beliefs, and how these contexts impact choices and engagement in EI. Consistent with Harniess et al.’s (2025) findings, therapy cannot be imposed on families and must respect individual preferences; my study adds the perspective that understanding the benefits of therapy is built through these safe relationships.

The current study’s finding is that parents and caregivers need a judgment-free approach to the therapeutic relationship. A collaborative, relationship-based model recognises that the therapist is part of the relational context of therapy, thereby bringing themselves into the relationship. Critical reflection on attitudes and beliefs that may conflict with the goals and preferences of parents and caregivers is essential, as personal attitudes and beliefs may create barriers to engagement. This highlights that critical reflection is foundational, with the therapist being self-aware “of their own social positionality and the privileges and disadvantages accorded by their social identities including, but not limited to, race, sexuality, gender, and ability” (Restall & Egan, 2021, p. 223). For therapists, including occupational therapists, to truly journey with parents,

caregivers and communities, adopting a collaborative, relationship-based practice provides a framework to support their safe practice within the highly relational context of EI. My data demonstrated that non-judgmental relationships were critical and helped parents trust and feel safe. Parents experiencing financial hardship and social challenges are at greater risk of having children with a developmental disability (Wynd, 2015) and are less likely to engage with services. Therefore, being non-judgemental is a key attribute of therapists working within these communities to ensure that families access EI services.

6.4 Early Communication Practices

Parents' experiences of uncertainty and stress in the acute setting and at early discharge, while understandable, appear to have been intensified by the communication they received about their infant's prognosis while still in the NICU. Parents experienced a lack of support while receiving distressing information, insufficient time to reflect on it, information not tailored to their health literacy level, information framed with a deficit bias, impairment focus and a lack of appropriate follow-up resources following these conversations.

There was limited contact with neonatal therapy, constituting a missed opportunity to educate parents about therapy roles and expectations for ongoing follow-up. Church et al. (2024) found that difficult and worst-case scenario prognostic information is often disclosed by medical staff in the acute setting who have minimal experience of the life course of people with disabilities, and that the way the information is delivered can be traumatising for families. This situation perpetuates negative discourses around disability, impairment-focused thinking and reinforces ableist attitudes (Church et al., 2024) and can erode trust in health professionals' and parental mental well-being suffers (Fortune et al., 2024; Håkstad et al., 2016). This contrasts with recommendations that prognostic information should be delivered in a way that is sensitive and honest, conveys hope and encouragement, and is supported by reliable web-based parent resources (Cameron et al., 2025; Church et al., 2025). There are now excellent tools to help professionals learn to have difficult conversations empathetically and compassionately (Novak et al., 2019). Gibbs et al. (2019) found that contact with the neonatal therapist during inpatient care improved parents' understanding of the therapist's role. In contrast, when NICU presence is inconsistent, there are fewer

opportunities to provide consistent messaging and to educate on therapy roles. This has been found to be especially important for those at greater social risk (Harniess et al., 2022). Consistent, individualised communication is critical, as it builds trust, provides reassurance and reduces parental stress and anxiety (Hadders-Algra, 2021). The experiences of the participants in my research establish that literacy levels and understanding of difficult medical information are overlooked in the provision of important information, reflecting that FCC is not prioritised in this way on many occasions, especially within the NICU, a situation that requires urgent attention.

6.5 Initial Contacts with Therapy Services

In almost all situations, initial contact with therapy services was delayed until discharge home. The absence of a dedicated neonatal therapy service at Waikato Hospital highlights a resource-constrained gap in service provision. It represents a missed opportunity to provide neuroprotective and neurorestorative strategies that improve neurodevelopmental outcomes for infants (Inder et al., 2023) and to strengthen the vital parent-infant relationship (Fortune et al., 2024; Purdy et al., 2015). This gives regional specific data on the impact of not having this essential service, also reported by Atkins et al. (2026), who found that neonatal neurodevelopmental therapy across all regions of Aotearoa New Zealand is well below international standards (British Association of Perinatal Medicine, 2022).

The timing of the first appointment after NICU discharge varied among participants, but all participants believed that early is best. This narrative is consistent with current evidence that EI supports neuroplasticity during the period of rapid brain maturation in the first 1,000 days; thereby improving developmental outcomes (Kolb et al., 2017; Damiano, 2026). Although considered best practice, the literature provides no definition of what constitutes early or standard timing for post-discharge therapy follow-up visits and the timing provided varies (Litt et al., 2024), creating ambiguity in practice recommendations. Following recommendations that improve parent and infant outcomes by supporting parents' confidence and the parent-infant bond (Orton et al., 2024), the first appointment should ideally occur within the first few weeks post-discharge. Again, multiple factors may affect the timing of the initial visit, including competing service pressures, waitlists and delays in visiting to geographically remote

areas. Therapists have many factors to consider when working without clear guidelines, including family preferences.

6.6 Readiness to Engage in Early Intervention

Readiness for engagement varied. Some participants reported that the visits were unexpected, while others described them as a 'double-edged sword', acknowledging their necessity even as this marked the end of what was perceived as a typical parenting experience post-discharge. Readiness for engagement has been explored in the research, with cited obstacles including the NICU experience's focus on day-to-day needs rather than the future (Gibbs et al., 2019) and the dualistic tension between wanting to recover and bond as parents and wanting to do what is best for the child (Harniess et al., 2024). Alternative ways to meet this need while respecting this precious newborn stage, where bonding and recovery are so important, include telephone screening, offering a choice of an early appointment, identifying the most at-risk families through MDT meeting attendance, using telehealth as the first appointment, meeting the family in the NICU, and working closely with the MDT to coordinate or reduce the number of visits.

In most cases in the Waikato context, early assessments and therapy were delivered in parallel by the same therapist. The study findings indicate that early neuromotor assessments did not disrupt the establishment of the parent-therapist relationship, as no discourses suggested otherwise. That said, the early assessment process was challenging for parents, often marked by confusion. In this study, therapists were often a valuable source of condition-specific information, helping parents untangle medical information and alleviate misunderstandings. When an infant is very young, early movement difficulties are often difficult to recognise, as they can appear typical. This can create a mismatch between the prognostic information provided and the observed movement, further confusing parents. These findings are replicated in other qualitative research, adding strength to the argument that the information provided does not always meet parents' needs (Harniess et al., 2024). Addressing parents' knowledge gaps has been shown to reduce confusion (Church et al., 2024). Furthermore, therapists help prepare parents for assessments and receiving a diagnosis by providing clear, accessible information (Fortune et al., 2022).

A sense of regaining control and increased knowledge among parents when a clear diagnosis was provided was linked to being proactive and solution-focused, which facilitated and motivated readiness to engage in EI. When an infant is given a diagnosis of CP or a high probability of an adverse neurodevelopmental outcome, grieving the loss of dreams is always present. Yet research points to this often being a turning point in their journey (Cameron et al., 2024; Harniess et al., 2024), as was replicated in my study. This was a time of taking back control (Morgan et al., 2023) and is linked to transformed parenting theory, in which parents and caregivers adapt to new parenting practices (Seidman & Kleine., 1995). However, not every parent experienced this turning point. Some participants waited years for diagnostic tests, leaving the situation unresolved, while others, receiving a CP diagnosis without prognostic information, experienced chronic stress and uncertainty. This delay in diagnosis is unacceptable and contrary to best practice, which states that parents both desire and need a timely diagnosis (Williams et al., 2021). The introduction of improved diagnostic processes may provide earlier and more accurate prognostic information, thereby supporting parents' mental well-being and readiness to engage in EI (Einspieler et al., 2019; Luke et al., 2025).

Coaching practices were valued by the participants, but crucially only once they understood what therapy was for. Harniess et al. (2024) described readiness to engage in therapy; my data suggest that readiness to engage is built through the coaching relationship, not prior to it. This strengthens the importance of these early therapeutic relationships.

6.7 'Spaces' Where Early Intervention Takes Place

One of the significant findings concerned parents' and caregivers' experiences of the spaces in which therapy takes place. Home offered many benefits, including meeting 'where families are at', seeing the whole picture, the generalisability of activities, reduced travel and increased comfort, supporting the implementation of best-practice guidelines for EI for infants under 2 years with or at high likelihood of CP (Morgan et al., 2021). In addition, home visiting has been shown to reach higher-risk or isolated families (Lovitz & Easterbrooks, 2025).

Participants living in rural and geographically isolated areas in this study found the visiting service to be an enabler that reduced the need to travel and allowed families to access the same service as urban families. As Māori are more likely to live rurally or in small urban communities away from the main centres (Stats NZ, 2024), this is likely to have a greater impact by reducing inequities in the services Māori receive, thereby improving developmental outcomes. As outlined in Chapter 2, there is a paucity of evidence in experiences of EI services for this cohort, which provides some original contributions to the benefits of visiting therapy, particularly in reducing inequities. Although the cost to the health system of home-visiting services may be higher than that of centre-based services due to the time-intensive nature of travel, the overall cost on health and society of not providing equitable services, given the long-term health implications, is greater.

Telehealth was used in a hybrid model in this study; however, its use was limited and accompanied by technical issues, as noted in the literature (Harniess et al., 2025). To supplement home visiting, scaling up virtual support or telehealth options to improve healthcare may also reduce inequity for rural families (Williams et al., 2023). Telehealth has been demonstrated to be a feasible and satisfactory way to complement care in this cohort but must be used in conjunction with in-person visits (Fernandes et al., 2025; Harniess et al., 2025).

While home-based services offered many benefits, a tension existed between delivering what was best for the child and the parents' opening of 'safe spaces' or 'our spaces' to providers. To my knowledge, this finding has not been discussed in detail in the literature previously. Little et al. (2015) found that some vulnerable families decline services due to social concerns, particularly when they have had previous contact with child protection social services. While the above may contribute to cancellations and non-engagement among some families, my research findings suggest this is more nuanced and complex. Some of the babies were born during the COVID-19 pandemic, which may account for the need to protect safe spaces. Some of the experiences prior to the pandemic may be related to protective psychological parental responses aimed at maintaining a sense of normality or equilibrium. Following such an unsafe, emotionally traumatising period, it is reasonable to want to create a 'bubble' of safety around the home, as a parental response. Furthermore, given the high levels of depression and

anxiety related to these unsafe births, this response may be related to postnatal depression and post-traumatic stress disorder; therefore, the psychological well-being of parents needs to be prioritised (Røhder et al., 2025; Ropero-Padilla et al., 2025).

Another hypothesis is that personal preferences, generational effects (Mannheim, 1952) and different personalities make face-to-face connections psychologically challenging; a parent noted that her introversion made interactions difficult. This highlights once more the complex and nuanced nature of relationships, which demands significant insight to build effective therapeutic relationships. Furthermore, it highlights that knowledge generated may not translate to subsequent generations of parents, whose needs are shaped by their context and the societal norms in which they parent (Caine et al., 2022). While apprehension about home visiting cannot be entirely eliminated, focusing on early relationships, both in the NICU and beyond, may help foster reassurance and a sense of safety (Ropero-Padilla et al., 2025). Providing alternative spaces close to home, such as Plunket rooms and community spaces; utilising online platforms, such as telehealth and providing choice may ameliorate some of these barriers. It is necessary to note that the sample represents the perspectives of families who engaged with EI and continued with EI services. Those who declined or disengaged may have experienced the home-visiting dynamic very differently and are absent from this analysis. This study enhances understanding of how parents perceive home visiting and might offer a hypothesis into why families decline services.

ECE featured strongly in this study as a space where therapy took place, as a setting to promote social connections and play and as an adjunct to home-based therapy to support the practice of skills in different contexts. While there is a paucity of evidence on how ECE can support EI for this cohort of under 2-year-olds, one study reported that the ECE provider appreciated visits from EI therapists and learned to incorporate therapy goals into routines (Gibbs et al., 2019). Despite the lack of research in this area, the core principles of effective EI could be supported by ECE providers, such as environmental enrichment (Novak et al., 2017; Morgan et al., 2017), task-specific practice, responsive relationship-based care (Hadders-Algra et al., 2021) and coordinated multidisciplinary care (Morgan et al., 2021). ECE provides an opportunity to offer rich, varied sensory-motor settings that foster consistency of care and may increase the activity dose by embedding developmental goals into play routines.

6.8 Work at My Pace

Many therapy practices that parents and caregivers experienced in this study exemplified contemporary approaches that focus on enhancing their capabilities through coaching. Play ideas were routine-based, varied, individualised and targeted at the right level, with parents and caregivers as active participants, demonstrating the feasibility and acceptability of implementing evidence-informed practices (Church et al., 2024; Poulsen et al., 2026). Developmental and play ideas were often co-created through the reciprocal relationship between the caregiver and therapist.

A new finding my research contributes is that parents and caregivers in this study valued the therapist working at the child's pace. Discourses such as 'not pushing', 'wasn't a lot of pressure', 'it was never I have to' and 'working at my child's pace' in the context of therapy were attended to in the analysis. On the surface, this may indicate that parents saw the therapist as not distressing the child and that therapy was fun (Morgan et al., 2021). An alternative approach, if the child was pushed, may result in giving up on therapeutic supports, further trauma for both parent and child and possible disengagement from services. However, with more hidden sense-making, parents may be saying the therapist worked at a pace that allowed them to understand without being overloaded. These experiences may have been shaped by time in the NICU, impacting parenting styles. Parents who have had emotional trauma during their time in the neonatal unit may adopt an overprotective parenting style or develop vulnerable child syndrome, where parents hold a distorted view of the medical fragility of their infant (Green & Solnit, 1964; Shaw et al., 2013). The therapist plays a key role in empowering, motivating, educating and encouraging the parent in safe handling and therapeutic practices, thereby building parents' self-efficacy (Øberg et al., 2023). This cannot be done without careful consideration of the caregivers' and child's responses, to ensure that trust continues to be built, providing another example of this nuanced relationship in which the therapist is attuned to the caregivers' and child's cues.

6.9 The Skilful Therapist

The recognition that parents and caregivers are experts on their own child and that they are listened to and understood was a key need identified by participants in this study; however, they also relied on the skilful therapist to support the 'next steps' and provide fresh ideas for implementing them. Parents and caregivers depended on the therapist to

know what to look for when a developmental difference was not overtly apparent to them or to affirm what they had noticed themselves. This trusted advice was supplemented by other evidence-based materials (written and online) to facilitate recall and knowledge sharing with support networks. It encouraged efficacy, competence and increased their knowledge. These experiences of EI practices extend existing knowledge, in which the sharing of expertise and teaching the parent 'how to teach their child' through coaching, partnering and collaborative practices are accepted therapeutic practices (Akhbari Ziegler & Hadders-Algra, 2020; Poulsen et al., 2026). Øberg et al. (2023) found that interacting with a skilful therapist diminishes fear, allowing parents to "fulfil their role with a sense of autonomy, confidence, and enthusiasm" (p. 9). Within the context of the visiting service, this practice is supported.

This study confirms many key elements of Lord and colleagues' (2018) model of triadic interactions among the child, parent/caregiver and therapist, including empowerment, motivation and reciprocal relationships that build trust, focuses on the parent and enables them to cope. However, this study extends these models beyond just the parent-therapist or parent-child-therapist dyadic or triadic relationships to encapsulate the polyadic nature of these relationships. While an MDT may describe the 'professionals' involved, it does not account for the para-supports highlighted in this study. These extended whānau, friends, peer networks, ECE teachers and carer supports have been highlighted as essential contributors to successful engagement in EI. Recognising these supports reframes EI engagement to include these relationships and is an essential mechanism of care.

Over time, parents grew in their parenting roles and their relationships with their child and the therapist changed. As they became more autonomous and empowered, they relied less on the skilful therapist. The relationship becomes more collaborative as the parent and caregiver gain knowledge and can focus more on what is important for the child and the family (the collective) as a whole. While there is an abundance of evidence supporting this contemporary therapeutic practice in EI of partnering and co-designing therapy, my study adds weight to the body of research and its relevance within the specific context of Aotearoa New Zealand.

6.10 Parental Autonomy and Therapists as a 'Champion'

On many occasions the therapist acted in a keyworker capacity and was regarded as a necessary link between the family and the hospital. This therapist role is less emphasised in the literature, particularly with respect to therapists providing EI, thereby advancing the knowledge regarding therapist roles. Adcock et al. (2022) used the term 'champion' to describe how a health professional, in particular nurses in the NICU, provides compassionate, FCC in a culturally sensitive way. In many ways, the therapists in this study acted as champions for families.

Careful consideration is required when therapists take on a champion role. Firstly, taking on a keyworker role is an enabler, rather than taking over from caregivers' own roles in self-advocacy and autonomy. Therapists have a role in empowering parents and increasing their capacity to navigate the healthcare system themselves with their support (Øberg et al., 2023; Poulsen et al., 2026). However, parents and caregivers experience the healthcare system in Aotearoa New Zealand as complex and difficult to navigate (Williams et al., 2023), so supporting service navigation could be the therapist's role, given their knowledge and connections with hospital-based services and, on many occasions, the family's trust. There needs to be consideration of the increased burden on the therapist taking on this role and the time commitments, without a clear definition of the role, given the resource constraints of health services. Some disability funding services provide navigator, connector or advocacy services that could be utilised by parents and caregivers; however, this requires having another professional in their lives, which adds to the complexity. The therapist, as a keyworker, is viewed by families as 'going the extra mile' but requires further understanding.

6.11 Structural Inequities

For one participant whose child had a subsequent non-CP outcome of GDD, the publicly available service did not meet their needs. They eventually engaged their child in intensive, traditional hands-on therapy. While this case stands alone as one person's account, it is presented as a hypothesis rather than conclusive findings. This narrative suggests a structural inequity between the centre-based CDC service and the visiting therapy service, with less frequent monitoring in the centre-based service than in the more frequent in-home visits. In addition, referral pathways for children with non-CP outcomes are less clear because developmental outcomes cannot be accurately

predicted (Luke et al., 2025). Early detection tools have only emerging evidence of accuracy, potentially leaving children without condition-specific EI. While these points are speculative and exploratory, it is essential to discuss them, as many preterm infants and those who have difficult births will go on to have a non-CP outcome, highlighting institutional influences on the ability to access EI and a lack of evidence for this cohort of infants.

6.12 Disruptions – Managing Transitions

For the participants in this study, transitions represented a time of disruption, whether due to a change of therapist, a change of EI provider or a transition to an ECE provider. Fear and grief were associated with this time, with trust being eroded, and potential identified for disengagement from services. Parents feared it would affect their child's developmental progress and found that new people did not understand the journey to that point, reducing opportunities to celebrate successes. These emotional reactions may have been associated with unresolved trauma, loss of familiar and safe people and a loss of control, informed by previous experience of traumatic and difficult NICU journeys (Morgan et al., 2023).

My study found that transitions meant establishing a completely new therapeutic relationship, requiring work and adjustment from already tired caregivers. Being the 'right fit' was important to ensure an optimal relationship. The literature examining the impact of transitions on therapeutic relationships found that managing these transitions well is vital to ensure that trust is not eroded and communication channels are not broken down (Gibbs et al., 2019; Massey et al., 2025). Managing these transitions to minimise the impact of this disruption should be planned carefully by maintaining continuity of therapy goals and communication preferences, and, if possible, introducing the new therapist prior to the transition to aid relationship-building (Gibbs et al., 2019; Massey et al., 2025). My research adds to the understanding that this is a new relationship and, therefore, should be approached accordingly, giving the family time to adjust.

6.13 A New Unfolding Dream

Over time, adjustment, equilibrium and acceptance followed among the parents, caregivers and their whānau in this study. Through their journeys, they learnt about

their child's condition and how it had affected them, both individually and collectively, which was empowering. EI providers played a pivotal role in supporting this learning process across the first 2 years. Authors used different terms for this period, including "a new reality" (Gibbs et al., 2019, p. 265) and "a new beginning" (Harniess et al., 2024, p. 3073), and described a balancing of family priorities as part of transformed parenting. A combination of early diagnosis and responsive EI is associated with acceptance (Morgan et al., 2023), and these data provide further evidence of this. The literature suggests a balance among therapy, structured play and simply being a child (Church et al., 2024). Acquiring new knowledge is associated with this adjustment (Harniess et al., 2024), as is a period of acceptance that encourages new dreams and a vision for their child's future, one that can be different yet equally fulfilling (Church et al., 2024). There is consensus in the literature and in my research that parents and carers have tremendous capacity and resilience when the right supports are in place.

While parents and caregivers of children with developmental differences share many experiences with those of parents and caregivers of children with more typical development, they face additional challenges that shape their parenting experience. This begins at birth, with a disrupted transition to parenthood (Harniess et al., 2024) and evolves throughout the lifecycle. Transformed parenting does not mean there are no more challenges along the journey; rather, an acceptance of future unpredictability and an adjustment of expectations (Seideman & Kleine, 1995). Participants showed evidence of 'chronic sorrow' (Vitale & Falco, 2014; Whittingham et al., 2013), with some parents recalling stories with tears. However, on every occasion their stories were conveyed with a hope for a great future for them and their child.

This study was likely a trigger point for these parents, which is a normal response, and the research was conducted sensitively, offering additional support if needed. Harniess et al.'s (2024) conceptual model explains this process and how sense unfolds over time. Acceptance is unfolding and cyclical, and it is too simplistic to think of acceptance and balance as a place of arrival along a journey. Rather, acceptance is a place that is revisited many times. A narrative from my study by Bobbi (Mother) exemplifies this acceptance and how parenting and its evolution for parents and caregivers over time are transformed: "*I … just totally come to peace that life can be really different and look*

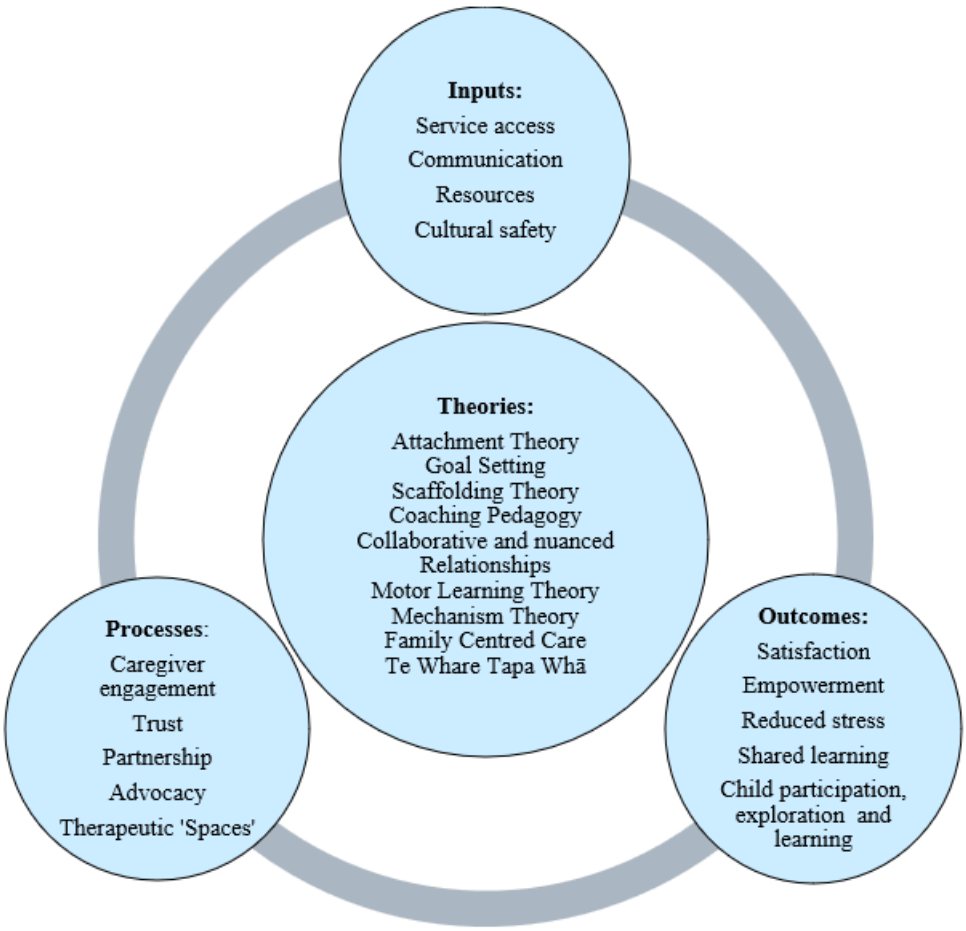
really different and still be just phenomenal, you know. But that takes time. Like, I didn't arrive at that straight away".

6.14 Conceptual Framework Revisited

The conceptual framework presented in Chapter 3, informed by the literature and current EI theories, has been reconceptualised to incorporate key learnings. EI engagement occurs within a dynamic and complex ecosystem but the takeaways extend beyond the initial concept, placing even greater emphasis on relationships and contexts. These relationships form the foundation for successful engagement, service provision and the implementation of family-centred practice. Unlike Lord et al.'s (2018) model, which centres on the parent-child-therapist triadic relationship, this study reconceptualises the framework, situating EI within a broader polyadic network and considers key relationships, such as extended whānau and communities, peers, care support providers, counsellors and early education providers (see Figure 9). The context addresses the environment or spaces in which EI takes place. This reframing has practical implications, as engagement in EI cannot be evaluated by the number of appointments the families have or by the 'doing of therapy', but by the quality of these relationships and how they are integrated into the therapeutic practices

Figure 9.

Re-conceptualised Framework



6.15 Study Strengths

There were many strengths to this study, including the methodology that underpinned the research. Using a narrative inquiry honoured the participants' stories by presenting them back to them in an accessible way. These narratives contributed to sense-making for both the participants and me as a researcher, allowing greater engagement with their stories during member checking. This was important, as the participants' lives have higher care burdens and are very busy due to having a child with a disability. Re-presenting the stories in this way was essential for accessibility, ensuring that the process was authentic and that the narrative was accurate, ensuring a co-construction of knowledge with participants. Furthermore, underpinned by trauma-informed care, a

strengths-based approach and Te Whare Tapa Whā, the process honoured and supported participants as they shared their experiences.

Cultural support was sought from the outset and throughout the research process to maintain an ongoing partnership with Māori and to honour the principles of Te Tiriti o Waitangi. This approach ensured adherence to tikanga principles, maximised Māori participation and ensured the reciprocity and authenticity of the findings. Every Māori participant was offered a second Māori interviewer. Supervision provided opportunities to discuss findings and share additional insights to prevent misrepresentation.

The use of a qualitative approach, employing RTA, allowed me to examine both common and individual experiences and to take a more nuanced perspective. This is a relevant approach given the complexity of the health, disability and social contexts of the parents, caregivers, whānau and their children. Healthcare needs to address individual needs and preferences; therefore, this approach represented many perspectives. Pragmatic outcomes resulted from this process, with implications for practice and policy. This approach also ensured that the analysis was undertaken reflexively and the process has been documented to enhance transparency. Detailed contextual demographic data for the study participants and their children (Tables 2 and 3) are provided, as the findings are transferable to broader contexts beyond the Waikato region.

A further strength of the study was its inclusion of mothers, fathers and grandparents. Fathers' perspectives provided additional insights that enriched the data. Parent dyads and whānau interviews strengthened recall of events and facilitated bouncing ideas off each other. I would have liked to have had more interviews conducted in this way.

An additional strength was that the study recruited the target number of participants, drawn from diverse backgrounds and ethnicities, providing rich experiences and perspectives. To my knowledge, this is the first study in New Zealand to examine experiences of EI, and the results align with international research while offering new knowledge.

6.16 Study Limitations

This qualitative sample reflects only the experiences and opinions of the 13 participants and does not claim to represent all experiences. Qualitative research is not 'representative' of all those who have engaged in EI services, as all experiences are subjective and situated within individual cultural, social and temporal contexts. Even an individual's experience can be influenced by emotional and personal factors related to the timing of the interview, highlighting its subjectivity. While I attempted to maximise variation through purposive sampling, it captures only the opinions of those who have engaged in EI, not those who choose not to utilise EI services. This is important to highlight because parents and caregivers choose to undertake EI and there may be many reasons why they do not, which could be explored in future research. Some infants are 'lost' to follow-up, so their opinions are not represented in this study. Furthermore, participants in this study received a substantial amount of EI, and although one participant lacked publicly funded EI, they had the resources to access private services. This may have biased the results, as most of the experiences reported were positive.

There is variability in the provision of EI services from the NICU to the community across Aotearoa New Zealand, and a further limitation is that the study was conducted in only one region, the Waikato. This restricted the evaluation to a specific service and may limit its applicability to other settings. That said, the main objectives of this study were specific to the region and focused on evaluating the experiences of caregivers who were part of the Waikato early detection service, which has not been evaluated since its inception in 2017. While the study attempted to recruit from community-based EI providers within the Waikato region, McKenzie Centre and Wana Tamariki (Conductive Education), only one participant was recruited from a community provider; therefore, the experiences of these families are minimally represented in this study.

A limited number of Māori participants (n = 3) were recruited, and only three families lived in small townships or geographically isolated areas. I had hoped to recruit a larger cohort from both groups, and Te Puna Oranga had requested best efforts to achieve up to 50% Māori. Unfortunately, because I relied on others to recruit, I was unable to control who was approached or who would be willing to take part. Nevertheless, these

participants provided in-depth stories that offered valuable insights into how the service could be developed. Furthermore, only parents and caregivers who spoke English were recruited. The sample included two migrant families for whom English was a second language, yielding interesting exploratory findings. However, the experiences of families who do not speak English may differ significantly and offer additional key insights. Other non-traditional family structures were not recruited to this study.

To maintain the therapeutic relationship with past and present families I have worked with, I was unable to recruit from some regions within the Waikato. These regions are among the more socially deprived areas of the Waikato and have large Māori communities. These whānau stories are not reflected in this study. This is a limitation of conducting a study within the field and context in which the researcher is actively working.

The children of participants in this study had varied presentations, with only one child eventually having no disability as they grew older. Most of the children were ambulatory (GMFCS I-III), with only two non-ambulant. Many participants' children had other outcomes, including language, learning, visual and medical concerns, and therefore broadly represent the concerns this population might present with. Given advances in medical treatments within the NICU, fewer children are now experiencing more severe forms of disability associated with premature and challenging births, which explains why recruitment did not capture more participants with children in this category. However, the experiences of parents and caregivers of children with non-ambulatory presentations (GMFCS IV-V) may differ.

As the sample included children from 2017 onwards, recalling the first 2 years was sometimes difficult, and some events described might have occurred when the child was older than 2 years. Despite this limitation, parents' and caregivers' recollections did not appear to depend on the child's age at the time of the interview, as some participants with older children remembered events vividly, as if they were transported back to that time. This recollection was highly individual.

6.17 Conclusion

This chapter has provided answers to the research aims outlined at the outset of the study, along with discussions and links to current evidence-based practice and theories. The conceptual framework was revisited, with a focus on how the dynamic ecosystem, informed by theories, relies on nuanced and evolving relationships as a foundation for service provision. The study's strengths and limitations were discussed to conclude this chapter. To provide pragmatic outcomes, which underpinned this research, the next chapter offers policy and practice recommendations, as well as ideas for further research. To conclude this thesis, these ideas and findings are summarised.

Chapter VII: Recommendations, Future Research and Conclusions

Ko te manu kai mātauranga, nōna te ao
The bird who partakes of knowledge owns the world

This final chapter outlines the implications for policy and practice, addressing the final aim of identifying and communicating practice recommendations to service providers and policymakers, drawing on research into the experiences of parents, caregivers and their whānau with EI. From here, I provide suggestions for future research and, as a final word, summarise the thesis' key findings and conclusions.

7.1 Implications for Policy and Practice

This study has highlighted practice and policy implications, many of which do not require increased health funding or staffing. Some are aspirational and would require significant financial investments, structural and policy changes at the local and governmental levels.

This study highlights the essential role of the visiting therapy service in ensuring therapy is provided in the child's most familiar environment. This service reduces many barriers to accessing support for infants and their families and offers numerous benefits, as previously noted. When rural families are transferred out of the visiting service, they experience inequities. Extending the visiting therapy service until children are at school age for rural and geographically isolated families is likely to reduce inequities and travel burdens. As this is likely to impact Māori whānau and vulnerable families, it may have an impact on the health outcomes for these groups, who have greater inequities in developmental outcomes. Structural issues and a lack of funding need to be addressed to ensure that services are family-centred and delivered in the place that is best for the child and their whānau.

This research emphasises the need for service providers (CDC' therapy team) to review discharge planning and the first 3 months post-discharge policies at Waikato

Hospital, where inconsistencies were identified. Identifying and meeting with families prior to discharge, by the community team, will support early relationship-building and clarify roles and expectations. This could occur during bedside meetings or discharge planning meetings. Additionally, service providers need to review referral pathways and recognise that medically complex infants, such as those on home oxygen, are better supported through the community team or via telehealth options, such as phone calls, video conferencing and parents sending developmental videos of their infant via secure systems, which could help reduce barriers to attending hospital-based services. The timing of the first appointment should be considered carefully by visiting therapists and health professionals; while an early appointment within the first few weeks of discharge may be ideal, it might not suit all parents. Offering a choice, by screening phone calls and involving the MDT will support this approach.

The lack of neonatal therapy requires investment in this critical early service, not only in Waikato but across the motu (country). This is beyond the scope of my research but needs continual highlighting to health funders at a national level. Lobbying by national groups such as The New Zealand Child and Youth Clinical Network should be pursued.

Embedding a collaborative relationship-focused practice, where therapists are encouraged to reflect critically on their practice in forums such as professional supervision and peer reviews, will continue to foster safe, therapeutic relationships that promote equity, self-determination and justice. Therapists should be encouraged to regularly examine their own positionality, recognising their role in the therapeutic relationship. In addition, given the importance of coaching practices within EI spaces, it is recommended that therapists receive formal training in this practice.

The study emphasises the role of the therapist as a ‘champion’ or key worker, assisting in navigating services. This role needs further exploration and definition

to ensure that it is provided in an equitable and sustainable way for whānau and services.

The information provided to parents and caregivers and the way it is communicated by health professionals in the NICU remain inconsistent. Health professionals may feel ill-equipped to deliver 'bad' news but many resources are available to support them, including the SPIKES framework (Novak et al., 2019) and video training such as "Early conversations: A message from parents for health professionals" (Cerebral Palsy Alliance, 2025). Resource packs that include both hard-copy and web-based materials are recommended, such as the Cerebral Palsy Society's (2025) '*Cerebral Palsy – Hōkai Nukurangi: The Early Years Kete*'. Doctors, paediatricians and neonatologists who communicate these prognosis and diagnoses should be utilising these freely available resources.

Continual service development must be prioritised as further evidence on targeted assessments for early diagnosis, prognosis and interventions for infants becomes available. This will begin to address some of the shortfalls in service delivery for children with non-CP outcomes. Doing so will require managers at Health New Zealand, Te Whatu Ora Waikato to invest in staff training and development. This will include the expanded use of motor optimality scores, such as the General Movement Optimality Score-Revised (3-month MOS-R), HINE and the introduction of the Baby Observational Selective Control AppRaisal (BabyOSCAR) for identifying CP, including severity and topography (Sukal-Moulton et al., 2024); the Hand Assessment for Infants (HAI) (Ryll et al., 2021) and the Social Attention and Communication Surveillance-Revised (SACS-R) tool for detecting children with early signs of autism (Athalye-Jape et al., 2025). Knowledge translation into practice will ensure that families receive early diagnosis and targeted EI.

This study highlights the importance of ECE providers and the potential impact of this service on the developmental outcomes of the infants represented in this study. It is suggested to strengthen relationships with ECE providers who offer alternative

spaces for evidence-based developmental support by embedding developmental goals into play routines. Providing early childhood educators with training and coordinated, individualised care plans will support infants and their caregivers in achieving their developmental goals.

Although an incidental finding, and not part of the original research objective, the unique needs of migrant families are evident, providing an additional policy recommendation. Extending the length of parent and grandparent visas on compassionate grounds is likely to have a multilevel effect—directly on the parents' well-being and reducing the need for government-funded support. This research insight may be combined with other findings in the health and disability sector to add weight to the argument, given the exploratory nature of this finding.

7.2 Future Research

Kia whakatōmuri te haere whakamua
I walk backwards into the future with my eyes fixed on my past

This study has highlighted areas for future research. Rural families remain underrepresented in research, and more targeted studies are needed to better support them in the first 2 years and beyond. Exploring how rural families could be better supported, including the possible use of the peer-delivered (Kaiwhina) model of care to increase the amount of face-to-face support families receive, by adapting the 'Learning through Everyday Activities with Parents for Infants at risk of Cerebral Palsy: LEAP-CP' (Benfer et al., 2023) EI model to the cultural needs of whānau in the Aotearoa New Zealand context is necessary.

Further research is needed to understand why parents and caregivers decline EI services or do not engage, including through multiple cancellations and loss to follow-up. This study found that home visiting was convenient but not easy for many caregivers. One parent wondered whether it was "*a Māori thing*" that made them hesitant to engage in home visiting at first. This is a complex and nuanced topic that requires further exploration. There may be indications of

intergenerational trauma and institutionalised racism; however, without further investigation and in-depth exploration, meaning cannot be assumed. Cancellations and 'did not attend' are costly for health service providers, and the short- and long-term costs to children and their families of not receiving these services are high. Identifying the barriers may facilitate the tailoring of services and greater engagement and implementation of evidence-based practices.

This research did not explicitly delve into the cross-cultural experiences of migrant families. The inclusion of two migrant participants offered some insight; however, minimal significance can be extrapolated from these individual experiences. Partnering with migrant and non-English speaking families to explore their experiences with EI and the barriers and enablers to engagement with EI is an important yet under-researched area in Aotearoa New Zealand. Furthermore, other marginalised whānau, such as those that identify as LGBTQ+, are not represented in the research with this cohort of children internationally. Finally, exploring how ECE providers and therapists can collaborate to support infants and their families in Aotearoa New Zealand is another identified research area.

7.3 Conclusions

Insights from the narrative accounts provided by parents, caregivers and their whānau regarding their experiences of EI highlight the important, changing and nuanced relational needs required to support them through the first 2 years and beyond. From uncertain beginnings to building safe, collaborative, non-judgemental coaching relationships, the families, as part of their unfolding lives, came to a place of transformed parenting, empowered and resourced with knowledge and hope. Parents and caregivers continue to contend with deficit-based discourses from medical professionals, which have long-lasting effects, including readiness to engage in EI and inequities related to the choice of where they live, which is likely to impact Māori more significantly. In addition, access to therapy is likely to be influenced by clarity of whether the infant is likely to have a CP or non-CP outcome, highlighting the need for improved pathways for intervention. This

study found that extending the visiting therapy service and using telehealth in a hybrid model are likely to reduce these inequities.

'Spaces' where EI took place were discussed in detail. Home-based therapy was deemed most convenient in the first 2-years but it must account for individual and collective preferences. Providing flexibility and choice is needed to mitigate barriers. ECE is an unexplored, possibly underutilised but valuable space for the provision of EI, warranting further investigation into how health and education partner to support these infants. Therapists working as 'champions' were an additional, novel finding, with concepts of being facilitative and encouragement of autonomy explored. Pairing a narrative inquiry with Te Whare Tapa Whā as a methodology enabled the parents', caregivers' and their whānau stories to be shared authentically with a strengths-based framing. The knowledge gained adds to existing insights into EI within the Aotearoa New Zealand context.

Collectively, these findings reframe EI not only as a therapy and health service provided to families and caregivers, but as a relational ecosystem that must be understood, delivered and funded as such within the family's unique cultural and ecological contexts. The quality of the service cannot be measured by the amount of therapy provided; it reflects whether the conditions for trust, cultural safety and whānau participation are genuinely present.

References

Åberg, K. B., Dahlberg, K., Størvold, G. V., Støen, R., & Adde, L. (2025). Doing everything we can to help our high-risk newborns: A qualitative, lifeworld-led study of what early risk assessment for Cerebral Palsy means to parents. *Journal of Clinical Medicine*, *14*(8), 2740. https://doi.org/10.3390/jcm14082740

Adcock, A., Cram, F., Edmonds, L., & Lawton, B. (2021). He tamariki kokoti tau: Families of Indigenous infants talk about their experiences of preterm birth and neonatal intensive care. *International Journal of Environmental Research and Public Health*, *18*(18), 9835. https://doi.org/10.3390/ijerph18189835

Adcock, A., Cram, F., Edmonds, L., & Lawton, B. (2022). He tamariki kokoti tau: Whānau of preterm Māori infants (pēpi) reflect on their journeys from birth to first birthday. *Journal of the Royal Society of New Zealand*, *52*(sup1), 57–74. https://doi.org/10.1080/03036758.2022.2090390

Akhbari Ziegler, S., Dirks, T., & Hadders-Algra, M. (2019). Coaching in early physical therapy intervention: The COPCA program as an example of translation of theory into practice. *Disability and Rehabilitation 41*(15), 1846-1854. https://doi.org/10.1080/09638288.2018.1448468

Akhbari Ziegler, S., & Hadders-Algra, M. (2020). Coaching approaches in early intervention and paediatric rehabilitation. *Developmental Medicine & Child Neurology*, *62*(5), 569–574. https://doi.org/10.1111/dmcn.14493

Alexander, C., Amery, N., Salt, A., Morgan, C., Spittle, A., Ware, R. S., Elliott, C., & Valentine, J. (2024). Inter-rater reliability and agreement of the General Movement Assessment and Motor Optimality Score-Revised in a large population-based sample. *Early Human Development*, *193*, 106019. https://doi.org/10.1016/j.earlhumdev.2024.106019

Allemang, B., Sitter, K., & Dimitropoulos, G. (2022). Pragmatism as a paradigm for patient-oriented research. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, *25*(1), 38–47. https://doi.org/10.1111/hex.13384

Appleton, R. E., & Gupta, R. (2019). Cerebral palsy: Not always what it seems. *Archives of Disease in Childhood*, *104*(8), 809–814. https://doi.org/10.1136/archdischild-2018-315633

Arfa, S., Solvang, P. K., Berg, B., & Jahnsen, R. (2020). Disabled and immigrant, a double minority challenge: A qualitative study about the experiences of immigrant parents of children with disabilities navigating health and rehabilitation services in Norway. *BMC Health Services Research*, *20*(1). https://doi.org/10.1186/s12913-020-5004-2

Athalye-Jape, G., Pillar, S., Saminathan, S., Wu, K., Sherrard, S., Dudman, E., & Sharp, M. (2025). Evaluation of the acceptability and feasibility of the Social Attention and Communication Surveillance-Revised (SACS-R) tool for early identification of Autism in preterm infants: The identify and act study. *Children (Basel)*, *12*(9). https://doi.org/10.3390/children12091130

Atkins, D., Kanagasabai, P., Battin, M., Desha, L., & Graham, F. (2026). Allied health provision of therapy in the neonatal units in New Zealand: A cross-sectional survey. *Journal of Paediatrics and Child Health*, 532–541. https://doi.org/10.1111/jpc.70279

Back, S. A., & Miller, S. P. (2014). Brain injury in premature neonates: A primary cerebral dysmaturation disorder? *Annals of Neurology 75*(4), 469-486. https://doi.org/10.1002/ana.24132

Badawi, N., Felix, J. F., Kurinczuk, J. J., Dixon, G., Watson, L., Keogh, J. M., Valentine, J., & Stanley, F. J. (2005). Cerebral palsy following term newborn encephalopathy: A population-based study. *Developmental Medicine & Child Neurology*, *47*(5), 293–298. https://doi.org/10.1017/s0012162205000575

Bal, M., & van Boheemen, C. (2009). *Narratology: Introduction to the theory of narrative*. University of Toronto Press.

Ballantyne, M., Benzies, K. M., McDonald, S., Magill-Evans, J., & Tough, S. (2016). Risk of developmental delay: Comparison of late preterm and full term Canadian infants at age 12 months. *Early Human Development*, *101*, 27–32. https://doi.org/10.1016/j.earlhumdev.2016.04.004

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, *89*(8), 1618–1624. https://doi.org/10.1016/j.apmr.2007.12.034

Baraldi, E., Allodi, M. W., Smedler, A.-C., Westrup, B., Löwing, K., & Ådén, U. (2020). Parents' experiences of the first year at home with an infant born extremely preterm with and without post-discharge intervention: Ambivalence, loneliness, and relationship impact. *International Journal of Environmental Research and Public Health*, *17*(24), 9326. https://doi.org/10.3390/ijerph17249326

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *BMJ 322*(7294), 1115–1117. https://doi.org/10.1136/bmj.322.7294.1115

Barfoot, J., Meredith, P., Whittingham, K., & Kerley, L. (2024). Including a relationship-focus in paediatric occupational therapy interventions: Introducing the PAIR Model. *Journal of Occupational Therapy, Schools, & Early Intervention,* , *17*(2), 331–347. https://doi.org/10.1080/19411243.2023.2203416

Battin, M. R., Mulqueeney, A., Mackey, A., Sorhage, A., Alzaher, W., & Stott, N. (2025). Cerebral Palsy associated with neonatal encephalopathy: Review of Te Rēhita a Hōkai Nukurangi Aotearoa—The New Zealand Cerebral Palsy Register (NZCPR) data. *Journal of Paediatrics and Child Health*, *61*(11), 1788-1794. https://doi.org/https://doi.org/10.1111/jpc.70186

Baumeister, R. F., & Leary, M. R. (1997). Writing narrative literature reviews. *Review of General Psychology*, *1*(3), 311–320. https://doi.org/10.1037/1089-2680.1.3.311

Benfer, K., Boyd, R. N., Roe, Y., Fagan, R., Luke, C., Mick-Ramsamy, L., Whittingham, K., Novak, I., Bosanquet, M., McNamara, L., Khandaker, G., Fogarty, L., Cadet-James, Y., Ruben, A., Comans, T., Smith, A., & Ware, R. S. (2023). Study protocol: Peer delivered early intervention (Learning through Everyday Activities with Parents for Infants at risk of Cerebral Palsy: LEAP-CP) for First Nation Australian infants at high risk

of cerebral palsy – an RCT study. *BMJ Open*, *13*(3), e059531. https://doi.org/10.1136/bmjopen-2021-059531

Benfer, K. A., Whittingham, K., Ware, R. S., Ghosh, A. K., Chowdhury, S., Moula, G., Samanta, S., Khan, N. Z., Bell, K. L., Oftedal, S., Bandaranayake, S., Salt, A. T., Bhattacharya, A., Maiti, P., Tripathi, S. K., Morgan, C., & Novak, I., & Boyd, R. N. (2024). Efficacy of early intervention for infants with Cerebral Palsy in an LMIC: An RCT. *Pediatrics*, *153*(4). https://doi.org/10.1542/peds.2023-063854

Bogossian, A., King, G., Lach, L. M., Currie, M., Nicholas, D., McNeill, T., & Saini, M. (2019). (Unpacking) father involvement in the context of childhood neurodisability research: A scoping review. *Disability & Rehabilitation*, *41*(1), 110–124. https://doi.org/10.1080/09638288.2017.1370497

Boychuck, Z., Andersen, J., Bussières, A., Fehlings, D., Kirton, A., Li, P., Oskoui, M., Rodriguez, C., Shevell, M., Snider, L., & Majnemer, A. (2020). International expert recommendations of clinical features to prompt referral for diagnostic assessment of cerebral palsy. *Developmental Medicine & Child Neurology*, *62*(1), 89–96. https://doi.org/10.1111/dmcn.14252

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Succussful qualititive research: A practical guide for beginners.* SAGE.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2022a). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, *9*(1), 3–26. https://doi.org/10.1037/qup0000196

Braun, V., & Clarke, V. (2022b). *Thematic analysis: A practical guide*. SAGE.

Bristow, S., Jackson, D., Shields, L., & Usher, K. (2018). The rural mother's experience of caring for a child with a chronic health condition: An integrative review. *Journal of Clinical Nursing*, *27*(13-14), 2558–2568. https://doi.org/10.1111/jocn.14360

British Association of Perinatal Medicine. (2022). *Service and quality standards for provision of neonatal care in the UK*. https://www.bapm.org/resources/service-and-quality-standards-for-provision-of-neonatal-care-in-the-uk

Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & Quantity*, *56*(3), 1391–1412. https://doi.org/10.1007/s11135-021-01182-y

Byrne, R., Duncan, A., Pickar, T., Burkhardt, S., Boyd, R. N., Neel, M. L., & Maitre, N. L. (2019). Comparing parent and provider priorities in discussions of early detection and intervention for infants with and at risk of cerebral palsy. *Child: Care, Health and Development*, *45*(6), 799–807. https://doi.org/10.1111/cch.12707

Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, *2*(2), 1–13. https://doi.org/https://doi.org/10.1177/160940690300200201

Caesar, R., Colditz, P. B., Cioni, G., & Boyd, R. N. (2021). Clinical tools used in young infants born very preterm to predict motor and cognitive delay (not cerebral palsy): A systematic review. *Developmental Medicine & Child Neurology*, *63*(4), 387–395. https://doi.org/10.1111/dmcn.14730

Caine, V., Clandinin, D. J., & Lessard, S. (2022). *Narrative inquiry: Philosophical roots*. Bloomsbury Academic.

Cameron, K. L. I., Coulston, F., Kwong, A. K., Whittingham, K., Morgan, C., Boyd, R. N., Crowle, C., Sakakini, H., & Spittle, A. (2025). Parents' experiences of early screening for cerebral palsy: A qualitative reflexive thematic analysis. *Developmental Medicine & Child Neurology*, *67*(6), 788–801. https://doi.org/10.1111/dmcn.16190

Cerebral Palsy Alliance. (2025). *Early conversations: A message from parents for health professionals* [video]. YouTube. https://www.youtube.com/watch?v=dPd_S9kLRaE

Cerebral Palsy Clinical Network. (2023). *Early detection of cerebral palsy (CP), intervention and monitoring*. Retrieved May 2, 2026, from https://www.starship.org.nz/guidelines/early-diagnosis-of-cerebral-palsy-cp-intervention-and-surveillance/

Cerebral Palsy Society. (2025). *Cerebral Palsy – Hōkai Nukurangi: The early years kete*. https://cerebralpalsy.org.nz/cerebral-palsy/the-early-years-0-5/

Chakkarapani, E., de Vries, L. S., Ferriero, D. M., & Gunn, A. J. (2025). Neonatal encephalopathy and hypoxic-ischemic encephalopathy: The state of the art. *Pediatric Research*, *98*(7), 2444–2458. https://doi.org/10.1038/s41390-025-03986-2

Chandrasekaran, S. A., John, H. B., Ross, B. J., Arumugam, A., Balan, I., & Samuel, R. (2022). Torn between two worlds: Parental experiences of neonatal follow-up for infants with hypoxic ischaemic encephalopathy in India-a qualitative study using interpretative phenomenological analysis. *BMJ Open*, *12*(11), e063732. https://doi.org/10.1136/bmjopen-2022-063732

Church, P. T., Banihani, R., Thomas, K., Luther, M., Agnew, B., Makino, A., Lam-Damji, S., & Fehlings, D. (2025). Early identification and communication in cerebral palsy: Navigating a collaborative approach for neonatal follow-up programmes. *Acta Paediatrica*, *114*(2), 292-298. https://doi.org/10.1111/apa.17458

Church, P. T., Dahan, M., Rule, A., Janvier, A., Stewart, J. E., Maypole, J. S., Fehlings, D., Litt, J. S., & Banihani, R. (2024). NICU language, everyday ethics, and giving better news: Optimizing discussions about disability with families. *Children 11*(2). https://doi.org/10.3390/children11020242

Clandinin, D. J. (2023). *Engaging in narrative inquiry* (2nd ed.). Routledge.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). SAGE.

Crump, C., Sundquist, J., & Sundquist, K. (2023). Preterm or early term birth and risk of attention-deficit/hyperactivity disorder: A national cohort and co-sibling study. *Annals of Epidemiology 86*, 119-125.e114. https://doi.org/10.1016/j.annepidem.2023.08.007

Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S. J., & Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health*, *18*(1), 174. https://doi.org/10.1186/s12939-019-1082-3

Damiano, D. L. (2026). The E-words for promoting development and neuroplasticity for infants with or at high risk for cerebral palsy. *Developmental Medicine & Child Neurology*, *68*(1), 20–28. https://doi.org/10.1111/dmcn.16477

Dammann, O., Ferriero, D., & Gressens, P. (2011). Neonatal encephalopathy or hypoxic-ischemic encephalopathy? Appropriate terminology matters. *Pediatric Research*, *70*(1), 1–2. https://doi.org/10.1203/pdr.0b013e318223f38d

Dan, B., Rosenbaum, P., Carr, L., Gough, M., Coughlan, J., & Nweke, N. (2025). Proposed updated description of cerebral palsy. *Developmental Medicine & Child Neurology*, *67*(6), 700–709. https://doi.org/https://doi.org/10.1111/dmcn.16274

Darling, J. C., Bamidis, P. D., Burberry, J., & Rudolf, M. C. J. (2020). The first thousand days: Early, integrated and evidence-based approaches to improving child health: Coming to a population near you? *Archives of Disease in Childhood*, *105*(9), 837–841. https://doi.org/https://doi.org/10.1136/archdischild-2019-316929

Dathe, A. K., Huening, B. M., Weber, P. D., Teschler, U., Brasseler, M., Felderhoff-Mueser, U., & Dewan, M. V. (2026). Predictive utility of a

simple cranial magnetic resonance imaging score at term-equivalent age for cerebral palsy. *Developmental Medicine & Child Neurology*, 1-11. https://doi.org/10.1111/dmcn.70219

Davidson, S. A., Thornton, A., Hersh, D., Harris, C., Elliott, C., & Valentine, J. (2025). 'Feeling like you can't do anything because you don't know where to start'—Parents' perspectives of barriers and facilitators to accessing early detection for children at risk of Cerebral Palsy. *Child: Care, Health and Development*, *51*(4). https://doi.org/10.1111/cch.70100

Denzin, N. K., Lincoln, Y. S., Giardina, M. D., & Cannella, G. S. (Eds.). (2024). *The SAGE handbook of qualitative research* (6th ed.). SAGE.

Dewey, J. (1997). *Experience and education*. Free Press. Original work published in 1938

DiBari, J. N., & Rouse, L. (2023). Parent perspectives: Part 2—Considerations for the transition home post-NICU discharge. *Children (Basel)*, *10*(12), 1835. https://doi.org/10.3390/children10121835

Dickinson, C., Sheffield, J., Mak, C., Boyd, R. N., & Whittingham, K. (2023). When a baby is diagnosed at high risk of cerebral palsy: Understanding and meeting parent need. *Disability & Rehabilitation*, *45*(24), 4016–4021. https://doi.org/10.1080/09638288.2022.2144491

Dickinson, C., Whittingham, K., Sheffield, J., Wotherspoon, J., & Boyd, R. N. (2020). Efficacy of interventions to improve psychological adjustment for parents of infants with or at risk of neurodevelopmental disability: A systematic review. *Infant Mental Health Journal*, *41*(5), 697–722. https://doi.org/10.1002/imhj.21871

Dlamini, M. D., Chang, Y.-J., & Nguyen, T. T. B. (2023). Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis. *Journal of Pediatric Nursing*, *73*, 157–168. https://doi.org/10.1016/j.pedn.2023.08.026

Dolan, S., Nowell, L., & McCaffrey, G. (2022). Pragmatism as a philosophical foundation to integrate education, practice, research and policy across the nursing profession. *Journal of Advanced Nursing*, *78*(10), e118-e129. https://doi.org/10.1111/jan.15373

Durie, M. (1994). *Whaiora: Maori health development*. Oxford University Press.

Durie, M. (1998). *Māori health: Te whare tapa whā model*. Te Ara - The Encyclopedia of New Zealand. Retrieved June 1, 2026, from https://teara.govt.nz/en/diagram/31387/maori-health-te-whare-tapa-wha-model

Durkin, M. S., & Yeargin-Allsopp, M. (2018). Socioeconomic status and pediatric neurologic disorders: Current evidence. *Seminars in Pediatric Neurology*, *27*, 16–25. https://doi.org/10.1016/j.spen.2018.03.003

Edmonds, L. K., Sibanda, N., Geller, S., Cram, F., Robson, B., Filoche, S., Storey, F., Gibson-Helm, M., & Lawton, B. (2021). He tamariki kokoti tau: Tackling preterm incidence and outcomes of preterm births by ethnicity in Aotearoa New Zealand 2010-2014. *International Journal of Gynaecology & Obstetrics*, *155*(2), 239–246. https://doi.org/10.1002/ijgo.13855

Eeles, A. L., Burnett, A. C., Cheong, J. L., Aldis, A., Pallot, L., Polonidis, T., Rust, K., Hunt, R. W., Delany, C., & Spittle, A. J. (2021). Identifying research priorities in newborn medicine: A Delphi study of parents' views. *BMJ Open*, *11*(11), e044836. https://doi.org/10.1136/bmjopen-2020-044836

Einspieler, C., Bos, A. F., Krieber-Tomantschger, M., Alvarado, E., Barbosa, V. M., Bertoncelli, N., Burger, M., Chorna, O., Del Secco, S., Deregnier, R.-A., Hüning, B., Ko, J., Lucaccioni, L., Maeda, T., Marchi, V., Martín, E., Morgan, C., Mutlu, A., Nogolová, A.,…Marschik, P. B. (2019). Cerebral Palsy: Early markers of clinical phenotype and functional outcome. *Journal of Clinical Medicine*, *8*(10), 1616. https://doi.org/10.3390/jcm8101616

Einspieler, C., Prechtl, H. F., Ferrari, F., Cioni, G., & Bos, A. F. (1997). The qualitative assessment of general movements in preterm, term and young infants—review of the methodology. *Early Human Development*, *50*(1), 47-60. https://doi.org/10.1016/S0378-3782(97)00092-3

Elvrum, A.-K. G., Eliasson, A.-C., Berg Kårstad, S., Sæther, R., & Söderström, S. (2025). Parents' experiences of participating in the Small Step early intervention program for infants at high risk of cerebral palsy: Essential

components and potential dilemmas. *Disability and Rehabilitation*, *47*(4), 968–976. https://doi.org/10.1080/09638288.2024.2362394

Falke, M. (2024). The basics of trauma-informed care in the NICU. *Neonatal Network*, *43*(5), 323–329. https://doi.org/110.1891/NN-2024-0024

Fauth, R. C., Kotake, C., Manning, S. E., Goldberg, J. L., Easterbrooks, M. A., Buxton, B., & Downs, K. (2023). Timeliness of early identification and referral of infants with social and environmental risks. *Prevention Science*, *24*(1), 126–136. https://doi.org/10.1007/s11121-022-01453-6

Fehlings, D., Makino, A., Church, P., Banihani, R., Thomas, K., Luther, M., Lam-Damji, S., Vollmer, B., Haataja, L., Cowan, F., Romeo, D. M., George, J., & Kumar, S. (2024). The Hammersmith Infant Neurological Exam scoring aid supports early detection for infants with high probability of cerebral palsy. *Developmental Medicine & Child Neurology*, *66*(9), 1255–1257. https://doi.org/https://doi.org/10.1111/dmcn.15977

Fernandes, K. T. M. S., Righetto Greco, A. L., de Oliveira, N. R. G., Medeiros, M., Spittle, A., & Martins Roberto Formiga, C. K. (2025). Family perceptions of barriers and facilitators of a telehealth program to support infants at risk for developmental delays. *Journal of Mother and Child*, *29*(1), 47–54. https://doi.org/10.34763/jmotherandchild.20252901.d-24-00042

Fernández Medina, I. M., Granero-Molina, J., Fernández-Sola, C., Hernández-Padilla, J. M., Camacho Ávila, M., & López Rodríguez, M. D. M. (2018). Bonding in neonatal intensive care units: Experiences of extremely preterm infants' mothers. *Women and Birth*, *31*(4), 325–330. https://doi.org/10.1016/j.wombi.2017.11.008

Filoche, S., Cram, F., Beard, A., Sim, D., Geller, S., Edmonds, L., Robson, B., & Lawton, B. (2018). He tamariki kokoti tau-Tackling preterm: A data-linkage methodology to explore the clinical care pathway in preterm deliveries. *BMC Health Services Research*, *18*(1). https://doi.org/10.1186/s12913-018-3179-6

Findler, L., & Taubman - Ben-Ari, O. (2016). *Grandparents of children with disabilities: Theoretical perspectives of intergenerational relationships*. Springer https://doi.org/https://doi.org/10.1007/978-3-319-45517-4

Fortune, A., Perkins, E., Paize, F., Palanisami, B., & Gladstone, M. (2024). Managing mothers' and fathers' uncertainty during their journey through early neurodevelopmental follow-up for their high-risk infants—A qualitative account. *Child: Care, Health and Development*, *50*(1). https://doi.org/10.1111/cch.13168

Garfinkle, J., Li, P., Boychuck, Z., Bussières, A., & Majnemer, A. (2020). Early clinical features of Cerebral Palsy in children without perinatal risk factors: A scoping review. *Pediatric Neurology*, *102*, 56–61. https://doi.org/https://doi.org/10.1016/j.pediatrneurol.2019.07.006

Gibbs, D., Harniess, P., & Crossley, S.-L. (2019). "The constant by our side"—Mothers' experiences of early intervention therapy services for infants with emerging signs of complex neurodevelopmental difficulties. *Infants & Young Children*, *32*(4). https://doi.org/10.1097/IYC.0000000000000149

Gledhill, N., Scott, G., & Vries, N. K. S. (2018). Routine follow-up of preterm infants in New Zealand. *Journal of Paediatrics and Child Health*, *54*(5), 535–540. https://doi.org/10.1111/jpc.13787

Granero-Molina, J., Fernández Medina, I. M., Fernández-Sola, C., Hernández-Padilla, J. M., Jiménez Lasserrotte, M. D. M., & López Rodríguez, M. D. M. (2019). Experiences of mothers of extremely preterm infants after hospital discharge. *Journal of Pediatric Nursing*, *45*, e2-e8. https://doi.org/10.1016/j.pedn.2018.12.003

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: A qualitative study of carers' interface with services. *BMC Health Services Research*, *16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Green, M., & Solnit, A. J. (1964). Reactions to the threatened loss of a child: A vulnerable child syndrome: Pediatric management of the dying child, part III. *Pediatrics*, *34*(1), 58–66. https://doi.org/10.1542/peds.34.1.58

Griffith, T., Singh, A., Naber, M., Hummel, P., Bartholomew, C., Amin, S., White-Traut, R., & Garfield, L. (2022). Scoping review of interventions to support families with preterm infants post-NICU discharge. *Journal of Pediatric Nursing*, *67*, e135-e149. https://doi.org/10.1016/j.pedn.2022.08.014

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). SAGE.

Hadders-Algra, M. (2021). Early diagnostics and early intervention in neurodevelopmental disorders—Age-dependent challenges and opportunities. *Journal of Clinical Medicine*, *10*(4), 861. https://doi.org/https://doi.org/10.3390/jcm10040861

Håkstad, R. B., Obstfelder, A., & Øberg, G. K. (2016). Parents' perceptions of primary health care physiotherapy with preterm infants: Normalization, clarity, and trust. *Qualitative Health Research*, *26*(10), 1341–1350. https://doi.org/10.1177/1049732315608137

Harding, C., & Levin, A. (2018). NICE guidance for developmental follow-up of children born preterm. *Infant, 14*(2), 62–63. https://www.infantjournal.co.uk/pdf/inf_080_pme.pdf

Harniess, P., Basu, A. P., Gibbs, D., & Bezemer, J. (2025). The interactive work of implementing synchronous video-conference calls—A qualitative study within early intervention for infants with childhood-onset neurodisability. *Health Expectations*, *28*(2). https://doi.org/https://doi.org/10.1111/hex.70215

Harniess, P. A., Basu, A. P., Bezemer, J., & Gibbs, D. (2024). How do parents frame their engagement experience in early intervention? A grounded theory study. *Disability and Rehabilitation*, *46*(14), 3067–3076. https://doi.org/10.1080/09638288.2023.2242788

Harniess, P. A., Gibbs, D., Bezemer, J., & Purna Basu, A. (2022). Parental engagement in early intervention for infants with cerebral palsy-A realist synthesis. *Child: Care, Health and Development 48*(3), 359–377. https://doi.org/10.1111/cch.12916

Harvey, C., Hocking, C., & Jones, M. (2025). Responsive learning in practice: A grounded theory. *Scandinavian Journal of Occupational Therapy*, *32*(1), 2578329. https://doi.org/10.1080/11038128.2025.2578329

Haydon, G., & van der Riet, P. (2017). Narrative inquiry: A relational research methodology suitable to explore narratives of health and illness. *Nordic Journal of Nursing Research*, *37*(2), 85–89. https://doi.org/10.1177/2057158516675217

Health New Zealand Te Whatu Ora. (2026). *Fetal alcohol spectrum disorder*. https://www.healthnz.govt.nz/health-professionals/guidance-standards/topic/conditions/fetal-alcohol-spectrum-disorder

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*, *292*, 114523. https://doi.org/https://doi.org/10.1016/j.socscimed.2021.114523

Hodges, H., Fealko, C., & Soares, N. (2020). Autism spectrum disorder: Definition, epidemiology, causes, and clinical evaluation. *Translational Pediatrics 9*(Suppl 1), S55-s65. https://doi.org/10.21037/tp.2019.09.09

Hosseini, M.-S., Jahanshahlou, F., Akbarzadeh, M. A., Zarei, M., & Vaez-Gharamaleki, Y. (2024). Formulating research questions for evidence-based studies. *Journal of Medicine, Surgery, and Public Health*, *2*, 100046. https://doi.org/https://doi.org/10.1016/j.glmedi.2023.100046

HRC Te Ara Tika the Ministry of Health. (2019). *Te Ara Tika guidelines for Maori research ethics*. https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0

Hunter, B., Dawes, L., Wadsworth, M., Sadler, L., Edmonds, L., McAra-Couper, J., Allen-Mokaraka, T., & Groom, K. M. (2024). An evaluation of the quality, suitability and impact on equity of clinical practice guidelines relevant to preterm birth for use in Aotearoa New Zealand. *BMC Pregnancy and Childbirth*, *24*, 234. https://doi.org/10.1186/s12884-024-06415-0

Hurd, C. L., Pritchard, L., & Yang, J. F. (2024). Perspectives of parents partnering with physical therapists to deliver intensive rehabilitation for their young

children with perinatal stroke: A qualitative study. *Child: Care, Health and Development*, *50*(1). https://doi.org/10.1111/cch.13190

Inder, T. E., Volpe, J. J., & Anderson, P. J. (2023). Defining the neurologic consequences of preterm birth. *The New England Journal of Medicine*, *389*(5), 441-453. https://doi.org/https://doi.org/10.1056/NEJMra2303347

Inguaggiato, E., Sgandurra, G., & Cioni, G. (2017). Brain plasticity and early development: Implications for early intervention in neurodevelopmental disorders. *Neuropsychiatrie de l'Enfance et de l'Adolescence*, *65*(5), 299–306. https://doi.org/10.1016/j.neurenf.2017.03.009.

Jackman, M., Morgan, C., Luke, C., Korostenski, L., Zawada, K., Juarez, M., Webb, A., Blatch-Williams, R., & Crowle, C. (2025). The predictive validity of HINE, Bayley, general movements and MOS-R in infancy. *Early Human Development*, *203*, 106226. https://doi.org/10.1016/j.earlhumdev.2025.106226

Jang, E. E., Burns, S., Hunte, M., Vincett, M., Chiarotto, L., & Church, P. T. (2024). Effects of early intervention on the mental wellbeing and caregiving practices of preterm infant caregivers. *Early Human Development*, *198*, 106112. https://doi.org/10.1016/j.earlhumdev.2024.106112

Johnson, Y. R., Guillory, C., & Imaizumi, S. (2023). Health care disparities in high-risk neonates. *Clinics in Perinatology*, *50*(1), 6780. https://doi.org/10.1016/j.clp.2022.11.008

Jowsey, T., Braun, V., Clarke, V., Lupton, D., & Fine, M. (2025). We reject the use of generative artificial intelligence for reflexive qualitative research. *Qualitative Inquiry*, 10778004251401851. https://doi.org/10.1177/10778004251401851

Kallioinen, M., Eadon, H., Murphy, M. S., & Baird, G. (2017). Developmental follow-up of children and young people born preterm: Summary of NICE guidance. *BMJ*, *358*, j3514. https://doi.org/10.1136/bmj.j3514

Kelly, L. M., & Cordeiro, M. (2020). Three principles of pragmatism for research on organizational processes. *Methodological Innovations*, *13*(2), 205979912093724. https://doi.org/10.1177/2059799120937242

Kim, F., Ryder, S., Marin, A., Zygmunt, A., & Guttmann, K. (2025). Caregiver perceptions of communication about early Cerebral Palsy or high-risk designation in infants. *JAMA Network Open*, *8*(7), e2519421. https://doi.org/10.1001/jamanetworkopen.2025.19421

King, G., Pozniak, K., Teplicky, R., & Earl, S. (2025). The experiences of parents of children with disabilities receiving healthcare services: Negative emotions and associated situations. *Research in Developmental Disabilities*, *156*, 104896. https://doi.org/10.1016/j.ridd.2024.104896

Knis-Matthews, L., Falzarano, M., Baum, D., Manganiello, J., Patel, S., & Winters, L. (2011). Parents' experiences with services and treatment for their children diagnosed with Cerebral Palsy. *Physical & Occupational Therapy in Pediatrics*, *31*, 263–274. https://doi.org/10.3109/01942638.2011.566806

Kolb, B., Harker, A., & Gibb, R. (2017). Principles of plasticity in the developing brain. *Developmental Medicine & Child Neurology*, *59*(12), 1218–1223. https://doi.org/10.1111/dmcn.13546

Kolb, B., Mychasiuk, R., Muhammad, A., & Gibb, R. (2013). Brain plasticity in the developing brain. *Progress Brain Research*, *207*, 35–64. https://doi.org/10.1016/b978-0-444-63327-9.00005-9

Kruijsen-Terpstra, A. J. A., Verschuren, O., Ketelaar, M., Riedijk, L., Gorter, J. W., Jongmans, M. J., & Boeije, H. (2016). Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. *Research in Developmental Disabilities*, *53-54*, 314–322. https://doi.org/10.1016/j.ridd.2016.02.012

Kwong, A. K. L., Eeles, A. L., Anderson, P. J., Badawi, N., Boyd, R. N., Cameron, K. L., Cheong, J. L. Y., Colditz, P., Koorts, P., Crowle, C., Dale, R. C., Doyle, L. W., Fahey, M., George, J., Hunt, R. W., McNamara, L., Morgan, C., Novak, I., Olsen, J. E.,…Spittle, A. J. (2024). The Knowledge Translation of Early Cerebral Palsy (KiTE CP) study: Implementing screening among a high-risk prospective cohort of Australian infants. *Journal of Pediatrics*, *268*, 113949. https://doi.org/10.1016/j.jpeds.2024.113949

Leech, K. A., Roemmich, R. T., Gordon, J., Reisman, D. S., & Cherry-Allen, K. M. (2022). Updates in motor learning: Implications for physical therapist practice and education. *Physical Therapy*, *102*(1). https://doi.org/10.1093/ptj/pzab250

Leggo, C. (2011). Narrative inquiry: Attending to the art of discourse. *Language and Literacy*, *10*, 1–21. https://doi.org/10.20360/G2SG6Q

Lewis, L. (2019). Finding the stories: A novice qualitative researcher learns to analyse narrative inquiry data. *Nurse Researcher*, *26*(2), 14–18. https://doi.org/10.7748/nr.2018.e1578

Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). Oxford University Press.

Linsell, L., Malouf, R., Morris, J., Kurinczuk, J. J., & Marlow, N. (2015). Prognostic factors for poor cognitive development in children born very preterm or with very low birth weight: A systematic review. *JAMA Pediatrics*, *169*(12), 1162–1172. https://doi.org/10.1001/jamapediatrics.2015.2175

Litt, J. S., Halfon, N., Msall, M. E., Russ, S. A., & Hintz, S. R. (2024). Ensuring optimal outcomes for preterm infants after NICU discharge: A life course health development approach to high-risk infant follow-up. *Children*, *11*(2), 146. https://www.mdpi.com/2227-9067/11/2/146

Little, A., Kamholz, K., Corwin, B. K., Barrero-Castillero, A., & Wang, C. J. (2015). Understanding barriers to early intervention services for preterm infants: Lessons from two states. *Academic Pediatrics*, *15*(4), 430-438. https://doi.org/10.1016/j.acap.2014.12.006

Lord, C., Rapley, T., Marcroft, C., Pearse, J., & Basu, A. (2018). Determinants of parent-delivered therapy interventions in children with cerebral palsy: A qualitative synthesis and checklist. *Child: Care, Health and Development*, *44*(5), 659–669. https://doi.org/10.1111/cch.12592

Luke, C., Bos, A. F., Jackman, M., Ware, R. S., Gordon, A., Finn, C., Baptist, D. H., Benfer, K. A., Bosanquet, M., & Boyd, R. N. (2025). Reproducibility of the Motor Optimality Score–Revised in infants with an increased risk of adverse neurodevelopmental outcomes. *Developmental Medicine & Child*

Neurology, *67*(9), 1176 –1185. https://doi.org/https://doi.org/10.1111/dmcn.16256

Luke, C., Mick-Ramsamy, L., Bos, A. F., Benfer, K. A., Bosanquet, M., Gordon, A., Williams, H., Taifalos, C., Smith, M., Leishman, S., Oakes, E., Kentish, M., McNamara, L., Ware, R. S., & Boyd, R. N. (2024). Relationship between early infant motor repertoire and neurodevelopment on the hammersmith infant neurological examination in a developmentally vulnerable First Nations cohort. *Early Human Development*, *192*, 106004. https://doi.org/10.1016/j.earlhumdev.2024.106004

Mackey, A., Sorhage, A., Alzaher, W., & Stott, N. (2022). *The New Zealand Cerebral Palsy register report 2022*. https://cerebralpalsy.org.nz/wp-content/uploads/2022/09/NZCPR-Report-2022-8Sept_FINAL.pdf

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Manning, J. (2017). In Vivo coding. In J. J. Matthes, C. S. Davis, & R. F. Potter (Eds.), *The international encyclopedia of communication research methods* (pp. 1–2). Wiley-Blackwell.

Massey, J., Harniess, P., Chinn, D., & Robert, G. (2025). Barriers and facilitators to parent-delivered interventions for children with or infants at risk of cerebral palsy. An integrative review informed by behaviour change theory. *Disability and Rehabilitation*, *47*(2), 287–301. https://doi.org/10.1080/09638288.2024.2338193

McCarthy, E., & Guerin, S. (2022). Family-centred care in early intervention: A systematic review of the processes and outcomes of family-centred care and impacting factors. *Child: Care, Health and Development*, *48*(1), 1–32. https://doi.org/https://doi.org/10.1111/cch.12901

McCarthy, M., Leigh, G., & Arthur-Kelly, M. (2020). Comparison of caregiver engagement in telepractice and in-person family-centered early intervention. *Journal of Deaf Studies and Deaf Education*, *25*(1), 33–42. https://doi.org/10.1093/deafed/enz037

McCarty, D. B., Letzkus, L., Attridge, E., & Dusing, S. C. (2023). Efficacy of therapist supported interventions from the neonatal intensive care unit to home: A meta-review of systematic reviews. *Clinics in Perinatology*, *50*(1), 157–178. https://doi.org/10.1016/j.clp.2022.10.004

McCashen, W., & Anglicare, A. (2005). *The strengths approach: A strengths-based resource for sharing power and creating change*. St Luke's Innovative Resources.

McManus, B. M., Murphy, N. J., Richardson, Z., Khetani, M. A., Schenkman, M., & Morrato, E. H. (2020). Family-centred care in early intervention: Examining caregiver perceptions of family-centred care and early intervention service use intensity. *Child: Care, Health & Development*, *46*(1), 1–8. https://doi.org/10.1111/cch.12724

Miller, K., Willett, S., McCarty, D., & Dusing, S. C. (2025). Neonatal therapy principles during transition from neonatal intensive care unit to home: A modified Delphi study. *Developmental Medicine & Child Neurology*, *67*(3), 357–364. https://doi.org/10.1111/dmcn.16075

Miller, L., Imms, C., Cross, A., Pozniak, K., O'Connor, B., Martens, R., Cavalieros, V., Babic, R., Novak-Pavlic, M., Rodrigues, M., Balram, A., Hughes, D., Ziviani, J., & Rosenbaum, P. (2023). Impact of "early intervention" parent workshops on outcomes for caregivers of children with neurodisabilities: A mixed-methods study. *Disability & Rehabilitation*, *45*(23), 3900–3911. https://doi.org/10.1080/09638288.2022.2143579

Ministry of Social Development. (2018). *Rapid evidence review: The impact of poverty on life course outcomes for children, and the likely effect of increasing the adequacy of welfare benefits*. https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/information-releases/weag-report-release/rapid-evidence-review-the-impact-of-poverty-on-life-course-outcomes-for-children-and-the-likely-effect-of-increasing-the-adequacy-of-welfare-benef.pdf

Molloy, E. J., El-Dib, M., Soul, J., Juul, S., Gunn, A. J., Bender, M., Gonzalez, F., Bearer, C., Wu, Y., Robertson, N. J., Cotton, M., Branagan, A., Hurley, T., Tan, S., Laptook, A., Austin, T., Mohammad, K., Rogers, E., Luyt, K.,…Peeples, E. (2024). Neuroprotective therapies in the NICU in preterm infants: Present and future (Neonatal Neurocritical Care Series). *Pediatric Research*, *95*(5), 1224–1236. https://doi.org/10.1038/s41390-023-02895-6

Morgan, C., Badawi, N., Boyd, R. N., Spittle, A. J., Dale, R. C., Kirby, A., Hunt, R. W., Whittingham, K., Pannek, K., Morton, R. L., Tarnow-Mordi, W., Fahey, M. C., Walker, K., Prelog, K., Elliott, C., Valentine, J., Guzzetta, A., Olivey, S., & Novak, I. (2023). Harnessing neuroplasticity to improve motor performance in infants with cerebral palsy: A study protocol for the GAME randomised controlled trial. *BMJ Open*, *13*(3), e070649. https://doi.org/10.1136/bmjopen-2022-070649

Morgan, C., Badawi, N., & Novak, I. (2023). "A different ride": A qualitative interview study of parents' experience with early diagnosis and Goals, Activity, Motor Enrichment (GAME) intervention for infants with Cerebral Palsy. *Journal of Clinical Medicine*, *12*(2), 583. https://doi.org/10.3390/jcm12020583

Morgan, C., Fetters, L., Adde, L., Badawi, N., Bancale, A., Boyd, R. N., Chorna, O., Cioni, G., Damiano, D. L., Darrah, J., De Vries, L. S., Dusing, S., Einspieler, C., Eliasson, A.-C., Ferriero, D., Fehlings, D., Forssberg, H., Gordon, A. M., Greaves, S.,…Novak, I. (2021). Early intervention for children aged 0 to 2 years with or at high risk of Cerebral Palsy. *JAMA Pediatrics*, *175*(8), 846. https://doi.org/10.1001/jamapediatrics.2021.0878

Morgan, C., Romeo, D. M., Chorna, O., Novak, I., Galea, C., Del Secco, S., & Guzzetta, A. (2019). The pooled diagnostic accuracy of neuroimaging, general movements, and neurological examination for diagnosing Cerebral Palsy early in high-risk infants: A case control study. *Journal of Clinical Medicine*, *8*(11), 1879. https://doi.org/10.3390/jcm8111879

Mwinbam, M. M., Suglo, J. N., Agyeman, Y. N., & Kukeba, M. W. (2023). Family caregivers' experience of care with a child with cerebral palsy: The lived experiences and challenges of caregivers in a resource-limited setting

in northern Ghana. *BMJ Paediatrics Open*, *7*(1), e001807. https://doi.org/10.1136/bmjpo-2022-001807

National Ethics Advisory Committee. (2019). *National ethical standards for health and disability research and quality improvement*. Ministry of Health. Retrieved May 7, 2026, from https://neac.health.govt.nz/assets/Uploads/NEAC/publications/national-ethical-standards-health-disability-research-quality-improvement-2019.pdf

National Institute for Health and Care Excellence. (2017). *Developmental follow-up of children and young people born preterm*. https://www.nice.org.uk/guidance/ng72/chapter/Recommendations#enhanced-developmental-support-and-surveillance

Nevill, T., Keeley, J., Hunt, S., Skoss, R., Lindly, O., Downs, J., & Blackmore, A. M. (2025). Efficacy of health literacy interventions for caregivers of individuals with neurodevelopmental and chronic conditions: A rapid review. *Children*, *12*(1), 9. https://www.mdpi.com/2227-9067/12/1/9

New Zealand Immigration. (2026). *Parent and grandparent visitor visa*. Ministry of Business, Innovation & Employment Hīkina Whakatutuki. Retrieved April 23, 2026, from https://www.immigration.govt.nz/visas/parent-and-grandparent-visitor-visa/

Novak-Pavlic, M., Abdel Malek, S., Rosenbaum, P., Macedo, L. G., & Di Rezze, B. (2022). A scoping review of the literature on grandparents of children with disabilities. *Disability & Rehabilitation*, *44*(13), 3326–3348. https://doi.org/10.1080/09638288.2020.1857850

Novak, I., Jackman, M., Finch-Edmondson, M., & Fahey, M. (2025). Cerebral palsy. *The Lancet (British ed.),* (406), 174–188. https://doi.org/10.1016/S0140-6736(25)00686-5

Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J., Cioni, G., Damiano, D., Darrah, J., Eliasson, A.C., de Vries, L. S., Einspieler, C., Fahey, M., Fehlings, D., Ferriero, D. M., Fetters, L., Fiori, S., Forssberg, H., Gordon, A. M.,…Badawi, N. (2017). Early, accurate diagnosis and early intervention in Cerebral Palsy:

Advances in diagnosis and treatment. *JAMA Pediatrics*, *171*(9), 897–907. https://doi.org/10.1001/jamapediatrics.2017.1689

Novak, I., Morgan, C., Fahey, M., Finch-Edmondson, M., Galea, C., Hines, A., Langdon, K., Namara, M. M., Paton, M. C., Popat, H., Shore, B., Khamis, A., Stanton, E., Finemore, O. P., Tricks, A., Te Velde, A., Dark, L., Morton, N., & Badawi, N. (2020). State of the evidence traffic lights 2019: Systematic review of interventions for preventing and treating children with Cerebral Palsy. *Current Neurology and Neuroscience Reports*, *20*(2). https://doi.org/10.1007/s11910-020-1022-z

Novak, I., Morgan, C., McNamara, L., & Te Velde, A. (2019). Best practice guidelines for communicating to parents the diagnosis of disability. *Early Human Development*, *139*, 104841. https://doi.org/10.1016/j.earlhumdev.2019.104841

O'Hara, M. W., & McCabe, J. E. (2013). Postpartum depression: Current status and future directions. *Annual Review of Clinical Psychology*, *9*, 379–407. https://doi.org/https://doi.org/10.1146/annurev-clinpsy-050212-185612

O'Shea, R., Jones, M., & Lightfoot, K. (2020). Examining conductive education: Linking science, theory, and intervention. *ARCHIVES of Rehabilitation Research & Clinical Translation*, *2*(4), 100077. https://doi.org/10.1016/j.arrct.2020.100077

Øberg, G. K., Sørvoll, M., Labori, C., Girolami, G. L., & Håkstad, R. B. (2023). A systematic synthesis of qualitative studies on parents' experiences of participating in early intervention programs with their infant born preterm. *Frontiers in Psychology 14*, 1172578. https://doi.org/10.3389/fpsyg.2023.1172578

Ochandorena-Acha, M., Noell-Boix, R., Yildirim, M., Cazorla-Sánchez, M., Iriondo-Sanz, M., Troyano-Martos, M. J., & Casas-Baroy, J. C. (2022). Experiences and coping strategies of preterm infants' parents and parental competences after early physiotherapy intervention: qualitative study. *Physiotherapy Theory & Practice*, *38*(9), 1174–1187. https://doi.org/10.1080/09593985.2020.1818339

Ophelders, D. R. M. G., Gussenhoven, R., Klein, L., Jellema, R. K., Westerlaken, R. J. J., Hütten, M. C., Vermeulen, J., Wassink, G., Gunn, A. J., & Wolfs, T. G. A. M. (2020). Preterm brain injury, antenatal triggers, and therapeutics: Timing is key. *Cells (Basel, Switzerland)*, *9*(8), 1871. https://doi.org/10.3390/cells9081871

Ormerod, R. (2020). The pragmatic logic of OR consulting practice: Towards a foundational view. *Journal of the Operational Research Society*, *71*(11), 1691-1709. https://doi.org/10.1080/01605682.2019.1630331

Orton, J., Doyle, L. W., Tripathi, T., Boyd, R., Anderson, P. J., & Spittle, A. (2024). Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database of Systematic Reviews*, *2*(2), CD005495. https://doi.org/10.1002/14651858.CD005495.pub5

Paine, S. J., Li, C., Wright, K., Harris, R., Loring, B., & Reid, P. (2022). The economic cost of Indigenous child health inequities in Aotearoa New Zealand-an updated analysis for 2003-2014. *The New Zealand Medical Journal*, *136*, 23–45. https://doi.org/10.26635/6965.5874

Paleg, G., Pool, D., Hidalgo-Robles, Á., Frumberg, D., Livingstone, R., & Damiano, D. (2025). Where's the evidence? Challenging therapists to stop legitimizing dynamic movement intervention and Cuevas Medek exercises. *Pediatric Physical Therapy, 38*(1), 138–143. https://doi.org/10.1097/PEP.0000000000001261

Perinatal and Maternal Mortality Review Committee. (2021). *Fourteenth annual report of the Perinatal and Maternal Mortality Review Committee | Te pūrongo ā-tau tekau mā whā o te Komiti Arotake Mate Pēpi, Mate Whaea hoki: Reporting mortality and morbidity 2018 | Te tuku pūrongo mō te mate me te whakamate 2018*. Health Quality & Safety Commission. https://www.hqsc.govt.nz/assets/Our-work/Mortality-review-committee/PMMRC/Publications-resources/report-pmmrc-14th-v2.pdf

Perinatal and Maternal Mortality Review Committee. (2024). *Sixteenth Annual Report of the Perinatal and Maternal Mortality Review Committee | Te Pūrongo ā-Tau Tekau mā Ono o te Komiti Arotake Mate Pēpi, Mate*

Whaea Hoki: Reporting Mortality and Morbidity 2021. https://www.hqsc.govt.nz/assets/Our-work/Mortality-review-committee/PMMRC/Publications-resources/16thPMMRCReport_FINAL.pdf

Peterson, M. D., & Hurvitz, E. A. (2021). Cerebral palsy grows up. *Mayo Clinic Proceedings*, *96*(6), 1404–1406. https://doi.org/10.1016/j.mayocp.2020.10.006

Pineda, R., Misikoff, M., Ghahramani, S., Smith, J., & Mathur, A. (2025). Description and evidence on the supporting and enhancing neonatal intensive care unit sensory experiences (SENSE) program. *Acta Paediatrica*, *114*(4), 731–742. https://doi.org/10.1111/apa.17293

Poulsen, H. S., Minet, L. R., Laulund, L. W., Ytterberg, C., & Hansen, A. (2026). Parent and therapist perceptions of early therapy for infants with or at risk of Cerebral Palsy: A scoping review. *Child: Care Health and Development*, *52*(1), e70232. https://doi.org/10.1111/cch.70232

Prechtl, H. F., Einspieler, C., Cioni, G., Bos, A. F., Ferrari, F., & Sontheimer, D. (1997). An early marker for neurological deficits after perinatal brain lesions. *The Lancet*, *349* (9062), 1361–1363. https://doi.org/10.1016/S0140-6736(96)10182-3

Purdy, I. B., Craig, J. W., & Zeanah, P. (2015). NICU discharge planning and beyond: recommendations for parent psychosocial support. *Journal of Perinatology*, *35*(S1), S24-S28. https://doi.org/10.1038/jp.2015.146

Raghupathy, M. K., Jahangir, S., Khurana, S., Lewis, L. E. S., & Rao, B. K. (2025). 'I did not know we could exercise this small premature baby': Challenges experienced by parents while implementing early intervention for their preterm infants-A qualitative perspective. *Child: Care, Health and Development*, *51*(2), e70045. https://doi.org/10.1111/cch.70045

Rescher, N. (2005). Pragmatism. In T. Honderich (Ed.), *Oxford companions of philosophy* (2nd ed, pp. 741–743). Oxford University Press.

Restall, G. J., & Egan, M. Y. (2021). Collaborative relationship-focused occupational therapy: Evolving lexicon and practice. *Canadian Journal of*

Occupational Therapy, *88*(3), 220–230. https://doi.org/10.1177/00084174211022889

Røhder, K., Hansen, J. E., & Væver, M. S. (2025). Postnatal depressive symptoms in mothers of infants at high risk of cerebral palsy: The role of delayed infant communicative development. *Disability and Rehabilitation*, *47*(14), 3671–3678. https://doi.org/10.1080/09638288.2024.2425745

Romeo, D. M., Cowan, F. M., Haataja, L., Ricci, D., Pede, E., Gallini, F., Cota, F., Brogna, C., Vento, G., Romeo, M. G., & Mercuri, E. (2021). Hammersmith Infant Neurological Examination for infants born preterm: Predicting outcomes other than cerebral palsy. *Developmental Medicine & Child Neurology*, *63*(8), 939–946. https://doi.org/10.1111/dmcn.14768

Ropero-Padilla, C., Rodriguez-Arrastia, M., Bernabé-Zuñiga, J. E., Alias Castillo, A. J., Rueda-Ruzafa, L., & Del Mar Sánchez-Joya, M. (2025). Experiences of parents with very premature-born children at risk of neurodevelopmental disorders: A qualitative study. *Nursing in Critical Care*, *30*(3). https://doi.org/10.1111/nicc.13182

Rosenbaum, P. (2021). Developmental disability: Families and functioning in child and adolescence. *Frontiers in Rehabilitation Sciences*, *2*, 709984. https://doi.org/10.3389/fresc.2021.709984

Rosenbaum, P., Susanne, K., Mary, L., Gillian, K., & and Evans, J. (1998). Family-centred service. *Physical & Occupational Therapy In Pediatrics*, *18*(1), 1–20. https://doi.org/10.1080/J006v18n01_01

Rosenbaum, P. L., Imms, C., Miller, L., Hughes, D., & Cross, A. (2025). Perspectives in childhood-onset disabilities: Integrating 21st-Century concepts to expand our horizons. *Disability and Rehabilitation*, *47*(10), 2682–2692. https://doi.org/10.1080/09638288.2024.2394647

Rosiek, J., & Clandinin, D. J. (2019). Curriculum and teacher development. In *Journeys in narrative inquiry* (pp. 191–208). Routledge.

Ryll, U. C., Krumlinde-Sundholm, L., Verhage, C. H., Sicola, E., Sgandurra, G., Bastiaenen, C. H. G., & Eliasson, A.-C. (2021). Predictive validity of the Hand Assessment for Infants in infants at risk of unilateral cerebral palsy.

Developmental Medicine & Child Neurology, *63*(4), 436–443. https://doi.org/https://doi.org/10.1111/dmcn.14739

Saldaña, J. (2021). *The coding manual for qualitative researchers* (4th ed.). SAGE.

Sanders, M. R., & Hall, S. L. (2018). Trauma-informed care in the newborn intensive care unit: Promoting safety, security and connectedness. *Journal of Perinatology*, *38*(1), 3–10. https://doi.org/10.1038/jp.2017.124

Sandle, M., Sheppard, A., Fletcher, A. A., Berry, M., & DeVries, N. (2020). Early identification of infants at risk of cerebral palsy: Developing the use of general movement assessment in routine clinical practice in a tertiary neonatal unit in New Zealand. *The New Zealand Medical Journal (Online)*, *133*(1514), 63–66.

Sapiets, S. J., Totsika, V., & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. *Journal of Applied Research in Intellectual Disabilities*, *34*(3), 695–711. https://doi.org/10.1111/jar.12852

Savin-Baden, M., & Major, C. H. (2025). *Qualitative research: The essential guide to theory and practice* (2nd ed.). Routledge.

Seideman, R. Y., & Kleine, P. F. (1995). A theory of transformed parenting: Parenting a child with developmental delay/mental retardation. *Nursing Research*, *44*(1), 38–44.

Seruya, F. M., Feit, E., Tirado, A., Ottomanelli, D., & Celio, M. (2022). Caregiver coaching in early intervention: A scoping review. *American Journal of Occupational Therapy*, *76*(4). https://doi.org/10.5014/ajot.2022.049143

Sharma, E., & Chaturvedi, S. K. (2023). Habilitation models for neurodevelopmental disorders. *Journal of Psychosocial Rehabilitation and Mental Health*, *10*(4), 405–407. https://doi.org/10.1007/s40737-023-00377-w

Shaw, R. J., St John, N., Lilo, E. A., Jo, B., Benitz, W., Stevenson, D. K., & Horwitz, S. M. (2013). Prevention of traumatic stress in mothers with preterm infants: A randomized controlled trial. *Pediatrics*, *132*(4), e886-e894. https://doi.org/10.1542/peds.2013-1331

Shonkoff, J. P. & Meisels, S. J. (2000). Preface. In J. P. Shonkoff & S. J. Meisels (Eds.), Handbook of early childhood intervention (2nd ed.). Cambridge Publications.

Simpson, M. L., McAllum, K., Fox, S., Unson, C., Hancock, T. O., & Carlson, A. (2025). Love, support and structural holes: Māori whānau carer experiences in collective family care systems. *Ageing and Society*, *45*(9), 1826-1847. https://doi.org/10.1017/S0144686X24000448

Smith, M., & Kurian, M. A. (2012). The medical management of cerebral palsy. *Paediatrics and Child Health*, *22*(9), 372–376. https://doi.org/10.1016/j.paed.2012.04.002

Sorhage, A., Keenan, S., Chong, J., Byrnes, C., Blackmore, A. M., Mackey, A., Hill, T., Han, D. Y., & Stott, N. S. (2022). Respiratory health inequities among children and young adults with Cerebral Palsy in Aotearoa New Zealand: A data linkage study. *Journal of Clinical Medicine*, *11*(23), 6968. https://www.mdpi.com/2077-0383/11/23/6968

Spence, C. M., Stuyvenberg, C. L., Kane, A. E., Burnsed, J., & Dusing, S. C. (2023). Parent experiences in the NICU and transition to home. *International Journal of Environmental Research and Public Health*, *20*(11), 6050. https://doi.org/10.3390/ijerph20116050

Spittle, A., & Treyvaud, K. (2016). The role of early developmental intervention to influence neurobehavioral outcomes of children born preterm. *Seminars in Perinatology*, *40*(8), 542–548. https://doi.org/https://doi.org/10.1053/j.semperi.2016.09.006

Spittle, A. J., Cameron, K., Doyle, L. W., & Cheong, J. L. (2018). Motor impairment trends in extremely preterm children: 1991-2005. *Pediatrics*, *141*(4). https://doi.org/10.1542/peds.2017-3410

Spoto, G., Nicotera, A. G., Butera, A., & Di Rosa, G. (2024). Editorial: Neurodevelopment and preterm birth. *Frontiers in Neurology*, *15*. https://doi.org/10.3389/fneur.2024.1412711

Stats NZ–Tatauranga Aotearoa. (n.d.). *Population*. Retrieved May 28, 2026, from https://www.stats.govt.nz/topics/population/

Stats NZ. (2024). *Detailed ethnicity infographics from 2023 Census*. Retrieved April 30, 2026, from https://www.stats.govt.nz/infographics/detailed-ethnicity-infographics-from-2023-census/

Sukal-Moulton, T., Barbosa, V. M., Sargent, B., Boswell, L., de Regnier, R.-A., Bos, A. F., & Peyton, C. (2024). Baby Observational Selective Control AppRaisal (BabyOSCAR): Convergent and discriminant validity and reliability in infants with and without spastic cerebral palsy. *Developmental Medicine & Child Neurology*, *66*(11), 1511–1520. https://doi.org/10.1111/dmcn.15924

Thelen, E., & Smith, L. B. (1994). *A dynamic systems approach to the development of cognition and action*. MIT Press.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Treyvaud, K., Spittle, A., Anderson, P. J., & O'Brien, K. (2019). A multilayered approach is needed in the NICU to support parents after the preterm birth of their infant. *Early Human Development*, *139*, 104838. https://doi.org/10.1016/j.earlhumdev.2019.104838

Väliaho, A., Lehtonen, L., Axelin, A., & Korja, R. (2021). Mothers' experiences of parenting and everyday life of children born at 23 weeks of gestation – a qualitative descriptive study. *BMC Pediatrics*, *21*(1). https://doi.org/10.1186/s12887-020-02478-y

Van Der Kemp, J., Ketelaar, M., I, M, M, & J. (2024). Exploring parents' experiences and needs during disclosure of a Cerebral Palsy diagnosis of their young child: A scoping review. *Child: Care, Health and Development*, *50*(6). https://doi.org/10.1111/cch.13327

van Maren-Suir, I., Ketelaar, M., Brouns, B., van der Sanden, K., & Verhoef, M. (2018). There is no place like @home!: The value of home consultations in paediatric rehabilitation. *Child: Care, Health and Development 44*(4), 623–629. https://doi.org/10.1111/cch.12573

Vasudevan, P., & Suri, M. (2017). A clinical approach to developmental delay and intellectual disability. *Clinical Medicine*, *17*(6), 558–561. https://doi.org/10.7861/clinmedicine.17-6-558

Verhaegh, A. P., Nuijen, N. B., Aarts, P. B., Nijhuis-Van Der Sanden, M. W. G., Willemsen, M. A., Groen, B. E., & Vriezekolk, J. E. (2022). Parents' experiences with a home-based upper limb training program using a video coaching approach for infants and toddlers with unilateral cerebral palsy: A qualitative interview study. *BMC Pediatrics*, *22*(1). https://doi.org/10.1186/s12887-022-03432-w

Vigod, S., Villegas, L., Dennis, C.-L., & Ross, L. (2010). Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. *BJOG: An International Journal of Obstetrics & Gynaecology*, *117*(5), 540–550. https://doi.org/https://doi.org/10.1111/j.1471-0528.2009.02493.x

Vitale, S. A., & Falco, C. (2014). Children born prematurely: risk of parental chronic sorrow. *Journal of Pediatric Nursing*, *29*(3), 248–251. https://doi.org/10.1016/j.pedn.2013.10.012

Vitrikas, K., Dalton, H., & Breish, D. (2020). Cerebral Palsy: An overview. *American Family Physician*, *101*(4), 213–220. https://www.aafp.org/pubs/afp/issues/2020/0215/p213.htm

VNT Association. (2024). *What does a VNT do*. Retrieved May 5, 2025, from https://vnt.org.nz/

Volpe, J. J. (2009). Brain injury in premature infants: A complex amalgam of destructive and developmental disturbances. *Lancet Neurology*, *8*(1), 110–124. https://doi.org/10.1016/S1474-4422(08)70294-1

Vurrabindi, D., Hilderley, A. J., Kirton, A., Andersen, J., Cassidy, C., Kingsnorth, S., Munce, S., Agnew, B., Cambridge, L., Herrero, M., Leverington, E., McCoy, S., Micek, V., Connor, K. O., Grady, K. O., Reist-Asencio, S., Tao, C., Tao, S., & Fehlings, D. (2025). Facilitators and barriers to implementation of early intensive manual therapies for young children with cerebral palsy across Canada. *BMC Health Services Research*, *25*(1), 503. https://doi.org/10.1186/s12913-025-12621-z

Vyas, S. S., Ford, M. K., Tam, E. W. Y., Westmacott, R., Sananes, R., Beck, R., & Williams, T. S. (2021). Intervention experiences among children with congenital and neonatal conditions impacting brain development: Patterns of service utilization, barriers and future directions. *The Clinical Neuropsychologist*, *35*(5), 1009–1029. https://doi.org/10.1080/13854046.2020.1871516

Wallois, F., Routier, L., & Bourel-Ponchel, E. (2020). Chapter 25 - Impact of prematurity on neurodevelopment. In A. Gallagher, C. Bulteau, D. Cohen, & J. L. Michaud (Eds.), *Handbook of clinical neurology* (Vol. 173, pp. 341–375). Elsevier. https://www.sciencedirect.com/science/article/pii/B9780444641502000265

Wang, F., & Feng, K. (2025). Worldwide prevalence and disability from preterm-associated developmental intellectual disability during childhood and adolescence. *Early Human Development*, *202*, 106218. https://doi.org/10.1016/j.earlhumdev.2025.106218

Whittam, S., Torning, N., & Patching, J. (2021). A narrative inquiry approach to understanding senior intensive care nurses' experiences of working with new graduate nurses. *Journal of Clinical Nursing*, *30*(21-22), 3314–3329. https://doi.org/10.1111/jocn.15844

Whittingham, K., Crandon, T., Mak, C., Sheffield, J., Wright, A., Kirby, G., & Boyd, R. N. (2025). Experiences of parents of children with Cerebral Palsy participating in an online parenting course grounded in Acceptance and Commitment Therapy. *Child: Care, Health & Development*, *51*(3), e70075. https://doi.org/10.1111/cch.70075

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Sorrow, coping and resiliency: Parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*, *35*(17), 1447–1452. https://doi.org/10.3109/09638288.2012.737081

Williams, S. A., Nakarada-Kordic, I., Mackey, A. H., Reay, S., & Stott, N. S. (2024). Prioritized strategies to improve diagnosis and early management of cerebral palsy for both Māori and non-Māori families. *Developmental*

Medicine & Child Neurology 66(8), 1074–1083. https://doi.org/10.1111/dmcn.15847

Williams, T. S., McDonald, K. P., Roberts, S. D., Westmacott, R., Dlamini, N., & Tam, E. W. Y. (2019). Understanding early childhood resilience following neonatal brain injury from parents' perspectives using a mixed-method design. *Journal of the International Neuropsychological Society*, *25*(04), 390–402. https://doi.org/10.1017/s1355617719000079

Wilson, D., Moloney, E., Parr, J. M., Aspinall, C., & Slark, J. (2021). Creating an Indigenous Māori-centred model of relational health: A literature review of Māori models of health. *Journal of Clinical Nursing 30*(23/24), 3539–3555. https://doi.org/10.1111/jocn.15859

Wise, N. J., & Gellasch, P. A. (2022). Identification to intervention: A perspective from parents of children with Cerebral Palsy. *Nursing Research*, *71*(6), 441–449. https://doi.org/10.1097/nnr.0000000000000619

Wyeth, E. H., Derrett, S., Hokowhitu, B., Hall, C., & Langley, J. (2010). Rangatiratanga and oritetanga: Responses to the Treaty of Waitangi in a New Zealand study. *Ethnicity and Health*, *15*(3), 303–316. https://doi.org/10.1080/13557851003721194

Wynd, D. (2015). *'It shouldn't be this hard': Children, poverty and disability*. Retrieved May 2, 2026, from https://www.cpag.org.nz/publications/150317childdisabilitypdf

Yeomans, E., Butler, A. E., Hunt, R. W., & Copnell, B. (2026). Interventions to enhance family-centred care in the neonatal intensive care unit: A scoping review. *Intensive and Critical Care Nursing*, *93*, 104313. https://doi.org/10.1016/j.iccn.2025.104313

Yin, R. K. (2016). *Qualitative research from start to finish* (2nd ed.). The Guilford Press.

Yinger, O. S., Jones, A., Fallin-Bennett, K., Gibbs, C., & Farr, R. H. (2024). Family-centred care for LGBTQ+ parents of infants in the neonatal intensive care unit: An integrative review. *Children*, *11*(6), 615. https://doi.org/10.3390/children11060615

Zaidman, E. A., Scott, K. M., Hahn, D., Bennett, P., & Caldwell, P. H. (2023). Impact of parental health literacy on the health outcomes of children with chronic disease globally: A systematic review. *Journal of Paediatrics and Child Health*, *59*(1), 12–31. https://doi.org/10.1111/jpc.16297

Zamkowska, A., & Koczańska, M. (2025). Scaffolding strategies in the play of preschool children with special educational needs: A systematic review of inclusive practice research. *International Journal of Special Education*, *40*(2), 145–160. https://doi.org/10.52291/ijse.2025.40.28

Zwicker, J. G., Missiuna, C., Harris, S. R., & Boyd, L. A. (2012). Developmental coordination disorder: A review and update. *European Journal of Paediatric Neurology*, *16*(6), 573–581. https://doi.org/10.1016/j.ejpn.2012.05.005

Appendices

A: Practice Interview Reflection

Thursday, 4th of September 2025

Reflection Practice Interview

I conducted a practise interview with a colleague who had a child with a congenital orthopaedic concern, as she has parental experience but was not a developmental concern. I set up this opportunity to practise my interviewing skills, see how the questions flowed, practice technical aspects such as recording and notice how I was as an interviewer.

I was surprised how hard the interview was, as it was much harder than I expected. Some questions needed reviewing as they were quite clunky and didn't flow well. Furthermore, I noticed that I was far more emotional and invested than I expected to be. I found myself wondering if the participant was okay and what she might be feeling as we talked about her experiences with her child. I observed her facial expressions and emotions as she recalled the stories, including joy, smiles, frowns, and wonder. I notice that, although this experience was nearly five years ago for the participant, there was no difficulty recalling the stories.

What I learned from this process was that, even though I am an experienced interviewer, the clinical setting is slightly different. At times, I noticed that I was stumbling over questions. I found myself overthinking some of the questions. I wondered whether I would attempt to protect the participant during the interview process.

At the end of the interview, I invited my colleague to share feedback. Her feedback was that the interview process flowed quite well but offered ideas for rewriting several questions. I asked my colleague about how I positioned my body and how comfortable she was with her physical position. She liked that I was to the side and wasn't looking directly at her. She liked that she could see me, but not directly at me, so she could look away to think.

After the interview, I found myself ruminating on the interview and wondering how I could have made the experience better. I read the transcript and listened to the interview recording, paying attention to how I asked the questions. I listened to how I used minimal encouragement, the use of silence, and my voice to actively listen. I used silence well without filling the space with words.

This was a valuable experience. I need to make sure that I am kind to myself, not aim for perfection and remember to relax. The participants' stories aren't mine; if supervision is required, then access this to keep myself safe. The semi-structured interview has been reviewed and edited.

B: Email to Colleagues Recruitment

Tena koutou katoa,

As part of a master's thesis at the University of Waikato, I am completing a qualitative inquiry to explore the experiences of whānau, parents and caregivers in accessing early intervention services for pēpi/infants born preterm or with health complications, during the first two years of life in the Waikato region. I hope to explore parents/caregivers' retrospective perceptions of early intervention services and how these experiences may shape future service delivery and development. The study will evaluate any identified barriers/enablers to accessing services and how these can be mitigated.

How can you help?

I am requesting your help, if possible, to recruit participants. I need to recruit up to 12 parents, whānau/extended family or caregivers of pēpi/infants, who have been through Waikato Hospital's Early Detection service, between the years of 2017 – 2024. They must have met the criteria to receive the General Movements Assessment (GMA) in the NICU or within the first 3 months of life. The result of the GMA could have been Absent/Abnormal fidgety and/or a suboptimal Motor Optimality Score-Revised (MORS-R) at or below 24 and/or suboptimal Hammersmith Infant Neurological Examination (HINE) or a motor concern identified that requires follow-up intervention. The participant's children will be at least 2 years of age at the time of the interview. Recruitment will take place from approximately October 2025 to February 2026, or until enough families are recruited.

Who?

I am a seeking a cohort that represents the population in Waikato, which may include Māori or non-Māori. It will be encouraged, where possible, to have whānau members interviewed as small groups, as the shared experience of the extended family will provide additional depth to the data.

What is the process, and what can potential participants expect?

If you have any whānau/families that you identify that may want to participate and share their experiences, could you please contact them? Please provide them the attached information and gain verbal consent for me, as the lead investigator to make contact them to discuss the research further. Their time commitment will be a 30–60-minute interview, either face-to-face or over videoconference. Interviews will be conducted by myself or if whānau are Māori, they have a choice to have an interviewer who is Māori. There will be a short follow-up meeting to present a summary and possible quotes from their conversation that maybe used within the study write-up, as a process of providing an opportunity for participants to check and authenticate the findings.

Further information

Please find attached information and consent forms, which provide more detail. Thank you for your support in assisting me with this research. Please don't hesitate to contact me on 0212297834 or email Tania.bright-johnstone@waikatodhb.health.nz if you have any further questions.

Ngā mihi nui

Tania Bright-Johnstone
Master's Candidate, University of Waikato/NZRP
Supervisor – Dr Samantha Heath email - samantha.heath@waikato.ac.nz

C: Recruitment Flyer

Experiences of whānau, parents and caregivers in accessing early intervention/ therapy services during the first two years of life in the Waikato region

ARE YOU

interested in talking about your experiences in accessing early intervention/therapy services?

DO YOU

have a child who had a General Movements Assessment at 3 months of age?

We invite you and your extended whānau/ family to take part in an interview to share your experiences and opinions.

When babies have been born prematurely or had a difficult start to life, they can have greater chance of having developmental difficulties, therefore receive early screening.

Your experiences will help understand how to improve access to early therapy and services for children who have come through an early screening program.

The outcome of this research is a University of Waikato Masters thesis.

Approved by the University of Waikato Ethics Committee, Reference Number: HREC(Health)2025#47

THE UNIVERSITY OF WAIKATO *Te Whare Wānanga o Waikato*

Te Whatu Ora Health New Zealand Waikato

What would be involved?

You will have an interview either face-to-face or via videoconferencing (teams or face time), that will take between 30-60 minutes, at a time and place that suits you.

You will be provided with kai (refreshments) and a $20 voucher to thank you for your contribution to this study.

Interested in more information?

Contact Tania Bright-Johnstone

Email - tania.bright-johnstone@waikatodhb.health.nz

Mobile - 0212297834

D: Participant Information Sheet

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

Health New Zealand
Te Whatu Ora

Participant Information Sheet

What has been your experience in receiving early intervention/therapy for your baby?

Locality: Waikato Region – Health New Zealand **Ethics committee ref:** HREC(Health)2025#47

Lead investigator: Tania Bright-Johnstone – Physiotherapist (NZRP), Master of Health Sciences Candidate, University of Waikato. Contact 0212297834 or tania.bright-johnstone@waikatodhb.health.nz

Supervisor: Dr Samantha Heath – Health Sciences Division, University of Waikato samantha.heath@waikato.ac.nz

Your pēpi/baby was born either preterm and/or had a stay in the Neonatal Intensive Care Unit (NICU) and had a General Movements Assessment (GMA) video at 3 months of age. When pēpi/babies are born early or have a difficult start to life, they may have a higher chance of having delayed development and may need to access specialist early intervention/therapy, such as physiotherapy, occupational therapy or speech language therapy to support pēpi/babies moving, learning, playing and communication. This research aims to listen to experiences of whānau/families who have been through this early detection service and if the intervention/therapy offered meets you and your babies' specific needs. Extended family, Koroua/kuia/grandparents, aunties/uncles, often support parents in their journeys, so if there are members of your whānau/family who would like to be interviewed with you, it would be welcomed. The purpose of this study is to see ways in which accessing and participating in these early therapies can be improved, using these experiences.

This information sheet will help you decide if you and/or your extended family would like to take part in an interview. It provides information on why we are doing this project, what it involves taking part, and what happens after the end of the project. You are welcome to ask any questions and if you need any information regarding the project, please contact the lead investigator.

If you agree to participate, you will be asked to sign a consent form. There is a copy on the last page of this document. You will be given a copy of the Participant Information Sheet and the Consent Form to keep. If the interview is on videoconference, then your consent will be verbal and this will be recorded, you will also receive a copy of this consent. The outcome of this research will be a Master's thesis.

Who am I?

I am a physiotherapist with over 30 years' experience, who provides early intervention to tamariki here in the Waikato. I work at the Child Development Centre at Waikato Hospital. I am passionate about supporting whānau/families throughout the early years, so that their pēpi/infants can have the best start to life. This research is part of a master's thesis I am doing at the University of Waikato. I was born in the Waikato; and although I have worked and lived all over Aotearoa, I call Hamilton my home.

What is the purpose of the study?

The purpose of this research is to see ways in which accessing and participating in early therapies can be improved, to ensure babies get the right therapy at the right time, in a way that suits. This will help inform how we can improve services, specifically for whānau/families who live in the Waikato, but maybe be helpful for other regions beyond.

What will my participation in the study involve?

You have been invited to take part in this project as you are a family member of a baby who has had a GMA at 3 months of age, and you live in the Waikato region. You may have been offered on-going therapy, or you may have been given developmental advice and had follow -up with Plunket or Tamariki Ora.

If you choose to take part, you will be interviewed by yourself or along with your extended whānau/family, to share your experiences and views on the early services/therapy you received in the first 2 years of baby's life. You are welcome to share any photos of your pēpi/baby during our time together. You are also welcome to have a support person with you, even if they are not involved in the interview.

The interview will take place by yourself or with as many of your whānau/family as you want, face-to-face or over videoconference, such as 'Teams'. If you identify as Māori, you can choose to be interviewed by an interviewer who is Māori. To accurately remember your and your family's views, the conversation will be recorded. It will take between 30-60 minutes for the initial interview, with a short follow up meeting, if you would like, either face-to face or over the phone, to discuss a summary our conversation. The summary can be emailed if preferred. This is important to ensure that your stories have been accurately understood. There will be a short survey before the interview, to gather background information, such as your age, ethnicity, what your first language that you speak with is, what relation you are to your child, the age of your child, if your child has a specific diagnosis or delays in their development, and any therapy your child has received.

If during our conversations we identify that your child needs extra support, we will provide information and support on how to access the most appropriate service.

What are the possible benefits and risks of the study?

The study is hoping to use the information gathered to improve access and the service delivery of the early intervention/therapy services to under 2-year-old infants, in the Waikato. You will be provided the opportunity to discuss a summary of the conversation. You will also be sent a summary of the key outcomes identified and intended service change identified, at the end of the study.

Some kai/home baking will be provided during the interview, if face-to-face, and you will be offered a $20 grocery voucher to say thank you for your time.

It can be hard to talk about some of the experiences you and your whānau/family had, therefore if you have questions or concerns, or if you become distressed at or after the interview, let the interviewer or lead investigator know. You will be provided with help to find on-going support if required.

What are my rights?

Whether or not you take part is your choice. If you don't want to take part, you don't need to give a reason, and it won't affect the care you receive, and your relationship with your therapy or medical team.

Your views will be combined with other participants to work out how to create new ways of working with pēpi/babies and their whānau/families who had a premature birth or a challenging start to life. All contributions will remain anonymous and none of the material in the results will personally identify you or your baby. You are invited to provide a pseudonym or a fictitious name of your choice.

What happens after the study or if I change my mind?

If you want to take part in the project now, but change your mind later, you can pull out of the project at any time- before, during or after the interview. Withdrawing can take place until 2 weeks after a summary of your interview has been given (short follow-up). You don't need to give a reason for withdrawing. If you withdraw, your recording, along with any transcripts will be destroyed and will not be used as part of the final report.

Identifying participants for this study will begin in July 2025 and the study will be completed by July 2026.

Electronic data collected is password- protected in a secure drive. Hard copy data is securely stored in locked storage. The University of Waikato securely stores any information collected for up to 5 years, then it is destroyed.

Māori Data Sovereignty

Māori data sovereignty is about protecting information and knowledge that is about and comes from Māori people. We recognise the taonga (treasure) of the data collected by this study and it will remain in Aotearoa New Zealand. Māori will be consulted to ensure the meanings upholds and are respectful of Māori knowledge, worldviews and self-determination. By taking part in this study, the outcomes will be communicated and will promote equitable outcomes for all those who use the service. Your views will be communicated using strength-based lens.

Results of this research may be published in professional journals or presented at conferences. You and your pēpi/infant's identities will not be revealed. Data generated from this research maybe available for future research, however confidentiality and anonymity always remain.

Who do I contact if for more information or if I have concerns?

If you have any questions or concerns or complaints about the study at any stage, you can contact.

Tania Bright-Johnstone Phone – 0212297834 Email-tania.bright-johnstone@waikatodhb.health.nz

Dr Samanatha Heath (Supervisor) Email - samantha.heath@waikato.ac.nz

If you want to talk to someone who isn't involved in the study can contact

Health and disability advocate on:

Website https://www.advocacy.org.nz

Freephone 0800 555 050 or Email advocacy@advocacy.org.nz

For Māori Health support

If you require cultural support talk to your whānau in the first instance.

Te Puna Oranga are available for cultural support throughout the duration of the research. A member of Te Puna Oranga can be contacted at Waikato Hospital Phone 07 834 3644 Extension 97844

This research project has been approved by the Human Research Ethics Committee (Health) at the University of Waikato as HREC(Health) 2025#47.Any questions or concerns about the ethical conduct of this research may be sent to the Secretary of the Committee, email humanethics@waikato.ac.nz, postal address: Human Research Ethics Committee (Health), University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240)

Ngā mihi nui and thank you for reading this and considering being part of this study

E: Consent Form

Consent Form

Interpreters are available on request

Experiences of whānau, parents and caregivers in accessing early intervention services for pēpi/infants born preterm or with health complications, during the first two years of life in the Waikato region.

- I have read or have had read to me in my first language and understand the Participant Information Sheet.
- I have been given sufficient time to consider whether to or not to participate in the study.
- I have been given the opportunity to use a legal representative, whānau/family support or a friend to help me ask questions and understand the study.
- I am satisfied with the answers I have been given regarding the study, and I have a copy of the consent form and information sheet.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time (before, during and after the interview) without the need to explain, and without this affecting my child's medical/therapy care.
- If I withdraw from the research, I understand that any audio recording, notes and transcript will be destroyed.
- I consent to the research staff collecting my views through being asked questions during an interview, including information collected about me and my child's health condition and service provision.
- I agree to have my interview recorded.
- I understand that confidentiality and anonymity (privacy) will be ensured. That no material, which could I identify me personally or my child, will be used in any reports arising from this study.
- I understand that this research is part of research master's thesis
- I know who to contact if I have questions about the project.
- I wish to receive a summary of the results from this project Yes ☐ No ☐
- I wish to receive feedback face-to face, to validate summary Yes ☐ No ☐

Address or email address I would like results summary to be sent to or face to face follow-up.

Declaration by participant: I consent to take part in this project

Participants name:

Signature: Date:

Declaration by member of research team: I have given verbal explanation of the research project to the participant and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researchers name:

Signature: Date:

F: Interview Questions

Interview protocol

Project: Caregivers' Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry

Time of interview: _____

Date: _____ **Place:** _____

Interviewer: _____ **Interviewee:** _____**P**_____

Interview Procedure

This study is looking at the early intervention/therapy services your child received up until they turned 2 years. We are interested in your experiences about this so that we understand how we can improve services for other whānau. We have some questions to ask you but welcome any thoughts you might have regarding this.

Do you have a karakia (Te Reo Māori or English) or an opening prayer that you might find helpful?

Do you have any further questions about the research? You have right to withdraw at any time. The interview will take no longer than 60 minutes (set at timer to ensure that time is adhered to/exit strategy).

Questions will be asked and they can be repeated if needed. There are no wrong answers. You are welcome to talk about what is important to you, positive and negative experiences.

You may choose not to answer certain questions.

I want to acknowledge this is difficult topic, having a baby born prematurely or a difficult start to life and interview will be stopped if needed.

The interview will be taped and transcribed. You will have a chance to look at this story to check it. Your results will be confidential, and you will not be identified individually.

Informed consent

Please sign the informed consent form signalling your willingness to participate.

Questions

Tell me about _____ child/grandchild/mokopuna?

Prompt -what does he/she like doing, what lights them up. Welcome the sharing of photos.

No.	Te Whare Tapa Wha	Description	Question	Notes
1.	**Taha Hinengaro (Mental & Emotional Wellbeing)**	**Starting out**	Take me back to when your pēpi came home from NICU. What were those early days like, and when did you first connect with a therapist or service? In the NICU?	
2.		**Coping and strengths**	What helped you and your whānau get through that time? Where did you find strength and support?	
3.	**Taha Tinana (Physical Wellbeing)**	**Assessments and first impressions**	How did the early assessments (like the General Movements Assessment or first screening) and any diagnoses affect your hopes, feelings, and outlook for your child and your whānau?	
4.		**Experiences with therapy**	Tell me about your experiences with early intervention: -the timing -the type of support you received -how realistic it felt in your daily life. What made it helpful or challenging?	
5.	**Taha Whānau (Family & Social Wellbeing)**	**Whānau, community, and relationships**	Who has been part of your support network (family, friends, community, therapists), and how have those relationships made a difference for you and your pēpi?	
6.	**Taha Wairua (Spiritual Wellbeing)**	**Looking back and moving forward**	When you reflect on the first two years, what do you wish had been different, and what are you most grateful for? What advice would you give to your therapist?	
7.	**Whenua (Connection to Land, Roots, Identity)**	**Living your best life**	Today, what supports, values, or practices help you, your whānau and your child to live your best life?	

Closing

I have no further questions, is there anything you would like to bring up, or ask about, before we finish?" (Liamputtong, 2013 p. 62).

Final Karakia

Thank you for taking time to participate. I appreciate you taking time to do this. I would like to have the opportunity to talk to you either face to face or over the phone or by email, with a summary of our conversation and possible quotes that maybe used in the final write-up. Again, let me reassure you that your confidentially with be maintained, please feel free to contact me on the number I have provided on the information sheet.

G: Participant Questionnaire

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

Health New Zealand
Te Whatu Ora

Project Title Caregivers' Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry

Project supervisor Dr Samanatha Heath
Lead investigator Tania Bright-Johnstone

Participant Questionnaire

Pseudonym: _____

1. What is your age? (tick one)

☐ 16–25

☐ 26–35

☐ 36–45

☐ 46–55

☐ 55+

2. What is your ethnicity? (tick as many as apply and add details where relevant)

☐ NZ Māori

☐ New Zealand European / Pākehā

☐ Samoan

☐ Cook Island Māori

☐ Tongan

☐ Niuean

☐ Chinese

☐ Indian

☐ Other: _____

1

3. Where do you live? (tick one)

☐ Hamilton city

☐ Small town

☐ Rural area

4. Relationship with the child? (tick one)

☐ Mum

☐ Dad

☐ Koroua / Kuia/Grandparent

☐ Aunty / Uncle

☐ Family Friend

☐ Other: _____

5. What is your child's age?

Years: _____ Months: _____

6. What is your child's sex? (tick one)

☐ Male

☐ Female

☐ Another identity: _____

6. Does your child have a diagnosis or developmental concerns? (tick as many as apply)

☐ Cerebral Palsy / Hōkai Nukurangi ☐ GMFCS level I II III IV V

☐ Global Developmental Delay

☐ Autism / Takiwātanga

☐ Language Concerns

☐ Vision Problems

☐ Hearing Concerns

☐ Other: _____

☐ No Concerns ☐ Unsure

2

7. What therapy services have you accessed in your child's first 2 years? (tick as many as apply)

☐ Visiting Neurodevelopmental Therapy (CDC)

☐ Physiotherapy (CDC)

☐ Occupational Therapy (CDC)

☐ Speech Language Therapy (CDC)

☐ Wana Tamariki (Conductive Education)

☐ McKenzie Centre

☐ Premmie Playgroup

☐ Other: _____

☐ Unsure

☐ None

8. How old was your child when you first saw a therapist?

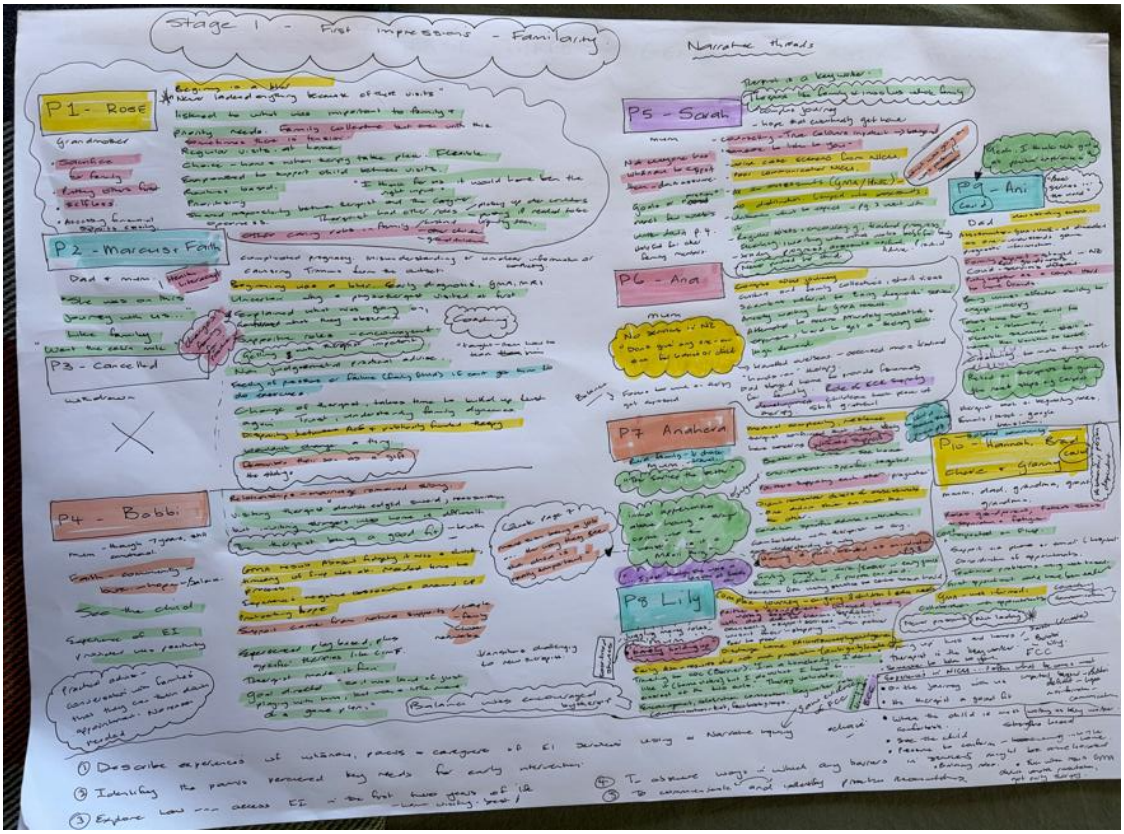
Age: _____

9. How often did you see them?

_____

Ngā mihi nui – thank you

H: Data Analysis – Phase 1: Familiarity



I: Data Analysis – Phase 2: Coding

CODE	DEFINITION	EXAMPLES
Administrative, Practical and Logistical Supports		
financial	Economic impact and strain experienced by the family due to caregiving responsibilities, medical needs, and other demands associated with managing the household and supporting family members. There are direct and indirect costs, as well as emotional and relational impacts.	While there is provision for reimbursement of travel costs from the National Travel Assistance, the system is paper-based, and it is easy to lose pieces of paper that are worth money. *"…that process could be a little bit more streamlined for the patients and parents and whatnot. Because we did lose a piece of paper."* (Brad) *"That is big. I know it's hard, but financially, but it's important. And they, I mean, we think about it, these kids, need the support, but the parents need the support as well, or the carers need the support."* (Rose)
Timing of support	Parents' perception of the timing of the delivery of services, information and resources, whether it was prompt and efficient or delayed, and of whether the processes, referrals and appointments were made without unnecessary delays.	Anahera felt that starting therapy very early was beneficial, as it meant her baby was beginning to form new pathways. *"I felt like the, because it was quite early for us, being that he is a premmie, it was good to get it in early. I think if you left it too late, it would just be harder. It would be harder on the baby or the child to relearn those pathways if you didn't start them as they were picking it up. That's sort of what I think. The earlier the better."* (Anahera) *"I think it was about right. I think possibly thought, well, maybe they could follow this up a little bit earlier. You know, after having such an intensive and long NICU stay, I think a lot of our appointments kind of got pushed out because of the COVID. And I mean, I know that's a valid reason, but to go from such hands-on experience and then to come home with nothing for quite a long time, like a few months is quite a long time."* (Hannah)
Early Intervention Practice and Approaches		
accessibility of services	The ease at which families can obtain and use services, supports and resources when needed, without undue barriers. Includes physical access, information access, financial access (private vs public), timeliness and equity (reachable regardless of background or circumstance)	*"For us that worked and super convenient, you know, like, because you're already, you've got to get your baby down to Plunket and …it's a mission anytime you want to go out the house. And so having them come to you is so helpful."* (Bobbi) It's most convenient to do a combination of Kindy and home. (Marcus and Faith) Being rural also meant they could not access services such as the McKenzie Centre (a private preschool and early intervention service). Firstly, because they lived too far from the centre, they were excluded from attending, and the time and cost of travel were prohibitive. (Anahera)
child centred	Refers to the experience in which the approach to early intervention places the child's needs, preferences, abilities and wellbeing at the forefront of decision-making and practice, and considers family context and social environment.	Bobbi felt strongly around how professionals "see" children, and Bobbi felt they were lucky with their vising therapist, as she saw the child and their family. *"I just think like seeing the child and the person, the human being, is so important."* (Bobbi)
choice	Ability and opportunity of an individual or family to select available options and make	Rose always felt she was given choice by therapist about how and when the therapy would take place; (Rose)

	decisions according to preferences, values and needs. This includes informed decision-making, such as risks and benefits, access to options (multiple paths), autonomy and empowerment.	Initially therapy, on a weekly basis, was at home; both with the physiotherapist and the conductor as this was best for their daughter. This was because she takes a long to time to adapt to new situations. Even when they eventually went to the centre, Wana Tamariki (Conductive Education) for hour long planned sessions, they transitioned her very slowly, initially going for 10 then 15 minutes. (Ani)
coaching, motivating and encouraging	Activities, actions and communication that inspire, support and positively reinforce the caregiver's effort and persistence. This includes confidence-building, practical instruction, skill development and strategy selection.	*"I think her empathy was good. Positivity to put things in place was really good. Like keeping things not necessarily on track, but saying, "hey, I know it's been really rough, but there is a light at the end of the tunnel. We're going to work on this." Early intervention is where we want to be. And you know, just making sure that you understand if you don't put these things in place now, it's not going to be as beneficial later. And I don't know, I just thought she was a breath of fresh air. She was just beneficial to my child's growth."* (Anahera)
creativity	Experiences where caregivers or therapists develop new ways to solve everyday problems, including problem-solving, adapting routines, and creating strategies to meet the child's or family's needs. Involves play, imagination, and using everyday and home items to achieve goals, without specialised equipment.	*"Also got a walker at the garage, yeah. And one of my customers, they got a big office. Sometimes I just take a walker and (my child) and I'm walking over there and my wife just hold her to walk like one or two hours. She pretty like to that. And after that, she very tired, she back home and fall asleep."* (Ani) *"Yeah, so we'll try in different ways like going to the park and having the ladder and trying to get him up on his left foot first rather than the right, if he's not going to do the things at home, and 'cause he loves the slides, so he's going to climb that ladder."* (Faith)
early assessments	Families' and caregivers' recall, attitudes and experiences of early diagnostic assessment, including tools like the General Movements Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE): This includes perceptions, feelings, memories and responses to these assessments early in life.	Hannah remembers the General Movements assessment (GMA) and that it was assessing their daughters' risk of Cerebral Palsy and other developmental concerns related to early birth. Hannah felt that while the term Cerebral Palsy is confronting, the therapist explained things well. *"I do remember that… talking to me a lot, … but about cerebral palsy and what that kind of practically looked like. So, it's pretty full-on term, but once you actually understand it… But yeah, I do remember the test, but it's about them being informed about why they're doing it."* (Hannah)
family centred	Experiences where practices and approaches recognise families as central to a child's wellbeing and actively involve them in planning, decision-making, provision of equipment and service delivery. This includes collaboration with professionals, respect for family knowledge and values, empowerment of family members and provision of services that support both the child and the family.	*"It wasn't standard formula and I think and that's it was personal to every family which is probably what was beneficial the most."* (Anahera)
frequency	How often is therapy provided, and how acceptable is this?	The therapist saw him as much as she could, which was quite a lot at the beginning, about fortnightly. *"I think for us it would have been the right input."* (Rose)

		"I think our visiting therapist said, I can come weekly, I can come more than that during this constraint period. And it was kind of up to us how much support we wanted." (Bobbi)
Goal directed	Reported experiences from parents and caregivers describe activities, strategies and interventions that are intentionally planned and focused on achieving specific and meaningful outcomes. They need to be relevant and meaningful to the child and family.	The ideas were play based but just with a bit more intention. *"So, it was kind of just playing with him, but with a little bit of a game plan in the back of my mind"* (Bobbi) *"We know what the next mission is for the next three weeks so do and it's just if you forget little things like how you could make kind of make it easier if something's not working you can always go back to it and it's printed in front of you so you can't really if you're your phone breaks or whatever, you know, you've still got the hard copy. Or you can give it to Nan and then Nan's at her house doing the same thing. So, it's pretty good."* (Sarah)
Setting where therapy takes place	This refers to parents/caregivers' preferences and experiences regarding where therapy or intervention takes place, including home, early intervention centres (ECE - daycare, preschool, kindy, kohanga), hospitals, child development centres (inpatient or outpatient), and specialist early intervention centres	*"I preferred it being at home... having our therapist in the home and adapting to our surroundings was beneficial because, you know, we should say, okay, well, you've got stairs. At the time we had bigger stairs, okay, that's an obstacle we need to pay attention to.'"* (Anahera) *"I know that's why, I know that's why our therapist was always very happy to come up and play it at home, which is, you know, it's their own space. It's how they really are, and they're relaxed and even taking our child down and meeting her at the local Hospital, which isn't a big deal for us. She would have said it's still not quite the same as seeing her as her in her own space."* (Hannah) *"I don't like it (people coming into her home), but I do what I have to do. You know what I mean? I don't like going out to meet people either, though. So, it was like the easiest of the two evils"* (Lily)
supportive therapeutic practices	Professional practices and strategies that provide guidance, encouragement and practical assistance to children and caregivers. They are characterised by empathy, responsiveness, collaboration and empowerment. This includes routine-based practical advice, such as strategies, instructions and therapy exercises, that support caregivers in supporting the child.	*"I think her empathy was good. Positivity to put things in place was really good. Like keeping things not necessarily on track, but saying, "hey, I know it's been really rough, but there is a light at the end of the tunnel. We're going to work on this." Early intervention is where we want to be. And you know, just making sure that you understand if you don't put these things in place now, it's not going to be as beneficial later. And I don't know, I just thought she was a breath of fresh air. She was just beneficial to my child's growth."* (Anahera) The visiting therapist provided equipment to support their daughters' feeding and muscle strength. They received "hands-on" therapy. She taught stretches and how to "scaffold" movements to help their daughter reach her next milestone. This was delivered in a play-based way. (Hannah)
Therapist compensating for system failure	Experiences recalled where the therapist took on roles that other professionals fail to take up, such as explaining the child's disability or outcome. This could relate to being given information that the caregiver doesn't understand or to coordinating services that otherwise are not the therapist's role.	It took the physiotherapist to explain what was really going on for their son, which they thought was not her role but were grateful she did. *"It took the therapist to tell us, not a paediatrician. so that was where we were, like a bit upset, like the paediatrician should be telling us this stuff, not a physiotherapist, but we were thankful that they were able to tell us, because otherwise we wouldn't none the wiser."* (Faith)
Therapy ideas realistic to put in place	Therapy ideas that are doable, have realistic time commitments, are functional, and can be part of routine. Caregivers' perception of therapy outside of face-to-face sessions.	This was doable because she only had one child and she had full Her therapist was so good at engaging with them and was great at suggesting what they could do between visits. Between visits, Rose felt the suggested play ideas were doable and they did everything they could to support her grandson's development. (Rose)

		Sarah found the play ideas and activities were easy and realistic to put in place, as she didn't need any specialised equipment, it was just floor time. (Sarah)
Uncertainty about role of therapist	Caregivers' lack of clarity or understanding regarding the definition, purpose, and responsibilities of the therapist's role in their child's care. This misunderstanding of the therapist's role, expertise, and expectations, such as calling the physiotherapist a doctor.	For Bobbi, therapy such as physiotherapy or occupational therapy was different than she imagined it would be. (Bobbi) The physiotherapist visited their home when he was very young. Initially they were very confused why a physiotherapist would visit. *"We were a little bit puzzled, but our physiotherapist she was awesome."* (Marcus)
Family Life, Roles and Relational Dynamics		
Attachment and bonding	Attachment and bonding refer to the emotional connection and relational processes between a child and their caregiver, encompassing the caregiver's emotional tie to the child and the developing reciprocal relationship that provides the child with a sense of safety, comfort, and security. This connection is shaped by early interactions, responsiveness, and ongoing caregiving experiences, and supports the child's emotional regulation, development, and wellbeing.	Sarah needed to be with her daughter to complete her cares. *"So, you had to be up there extra that a normal parent would be up there. You know, you looked like you lived up there."* (Sarah) Things were very difficult for a while and now the important things that support them to live their best life are just being together as a whānau. *"Hanging out together and playing and just being kids, you know, siblings and loving each other and things like that."* (Sarah)
caregiver selflessness and sacrifice	The accounts describe placing their child's or grandchild's and family's needs ahead of their own, giving up time, employment opportunities, personal wellbeing or aspirations to provide care, advocacy and support. "Doing whatever it takes", shaped by love, responsibility and necessity.	*"I couldn't just manage the work and the baby, so I quit. So, by quitting my job helped me to take care of my baby. Because we had to choose something at that time, because I didn't have my mother, she (mother) was allowed only for six months to stay, but he (son) wasn't already two months."* (Ana) For a time, Anahera needed to reduce her working days to support her family and be at home for her son. She has now returned to work three days a week. During the holidays, she reduces her hours, and the children are looked after by whānau, for which Anahera is grateful. Her husband travels frequently for his job, and this balance works well for their whānau. (Anahera)
Caregivers' future	Caregiver looking beyond their caregiving role towards their child.	As Rose looks towards the future, she would like to look towards going back to work, however this takes a lot of planning and there are many things that need to be put in place. (Rose) *"But now it's time for me to get out there. And so, this is why I feel that like education … (is) really important because it helps the rest of us plan our own lives and getting out there to do something with our lives instead of being stuck." (Rose)*
Carer with many roles	The multiple roles a caregiver has, including providing financially for the family, caring for other family members, managing practical tasks, and meeting their own needs.	Rose also cares for her husband…Rose also has other family members, children and grandchildren, in and out of the city where she lives, who she likes to visit and spend time with. She helps look after her other grandchildren to support her family. Rose is the main caregiver while her grandsons mother works, however when her daughter isn't working, she jumps on board. *"Because at the end of the day, it's really to help him and help her to be able to pay the bills and work."* (Rose)

couple resilience and partnership	The experience of how partners support each other, work together and maintain their relationship while adapting to the stressors and challenges of a difficult start to life and disability.	*"I'm just grateful for Brad and Hannah. They've done a wonderful job with all the help right from the beginning, right from day one. They've been really marvellous"* (Cherie) *"That was a pretty hard time for us because she does not sleep. One day she falling asleep at 8 o'clock in the morning the whole night. And those days, normally she falling asleep like 3 or 4 o'clock. So, my wife and me just take the shift to sleep."* (Ani)
Family life	Everyday family routines, roles, relationships and interactions as experienced within the family unit or the extended family	They describe that the last few years have been busy. (Marcus and Faith) He is son Marcus' first child and Faith's fourth child (11, 9 and 7 years old). They now have a family of five children, with the three older children (1 boy and 2 girls) spending time between their father house and Marcus and Faith's home. (Marcus and Faith) Marcus describes that their son ties them all together and that is just works!
Family values and culture	Parents' or carers' experiences of how shared beliefs, faith, traditions, cultural practices and values guide family priorities, decision-making and responses to raising their infant and family.	During this time, her husband continued to work, and Ana's mother was able to obtain a 6-month visa to stay in New Zealand to help, as is customary in Ana's culture. (Ana) They have a strong Christian faith and incredibly supportive friends and family, which helped them through this time. Prayer was crucial, and people stepped up. (Bobbi)
Fathers' roles	The unique experience of what it is to be a father with a child at risk of or diagnosed with disability, and the roles that they fill.	This is Marcus's job, playing with their son at the playground or at the zoo. Marcus is very hands on. (Marcus and Faith) *"Oh yeah that's my job."* Marcus *"He'll jump from the playground with them."* Faith *"It was a hard time for Brad because he had to leave at the worst times sometimes. And it was probably more difficult for him to deal with because he wasn't seeing the everyday thing. And the imagination can play havoc in that place."* (Cherie)
Grandparent roles	Experience of parents or caregivers, either as a grandparent who is the main caregiver or in supportive roles, in how grandparents support the infant and wider family.	Rose (Grandmother) cares for her grandson day-to-day. Rose didn't want to put her grandson in the care of others. (Rose) Her mother (grandmother) looked after the other two children. *"…or you can give it to Nan and then Nan's at her house doing the same thing. So, it's pretty good."* (Sarah) *"Yes, Cherie (Grandparent) probably spent the most time with me. She took care of all the practical parking and feeding me and everything, because Brad had to go back to work. So, Cherie did a lot of the hard yards."* (Hannah)
Parents' existing experience, resourcefulness and capability	Experiences where parents and carers are recognised as experts, drawing on their prior experience, inherent capabilities and skills to adapt, problem-solve and manage the demands of caregiving. "Knowing what to do" or "having done this before"	Bobbi felt it was reassuring that by just playing with her child it is helping, as she wanted to do all she could do to help her child. (Bobbi) Bobbi didn't just rely on the therapist to find all the answers, and they were very practical about finding their own solutions. She gave an example of her son learning how to put his shoes on, they found a way that worked for him by doing research and spending hours in the shoe shop finding the right shoes. (Bobbi) *"Because they originally wanted to send her through to McKenzie Centre, but we'd had bad experience with McKenzie Centre with our eldest son. So, I said no. No, and I regret that… Well, my older child went for feeding issues and speech. And yeah, we had a bad experience with their feeding therapy, but I think it may have helped my Lily with her cognition*" (Lily)
separation	Experiences of separation due to physical distance, or	There were some difficult times such as having to go home at night, being separated from her son; her mum not being able to visit him

	emotionally or relationally within the family, because of circumstances surrounding their infant, often related to the early days and weeks in the NICU.	in the NICU, which meant by the time he came home, 2 months had already lapsed on her visitor visa…Ana wanted to be in NICU when the doctor comes to do rounds, either in the morning or in the evening, as she wanted to talk with them. This meant she was away from home a lot. (Ana) Initially, Ana's mother remained in New Zealand to support and care for her family. Ana remembers it was a difficult time when her mother had to go home. (Ana)
Support networks - friends	Experiences of parents or caregivers in non-family members' supportive roles.	Bobbi set up a Facebook page for close family and friends, to update them daily. This also helped people to know how they could support them. *"Yeah, we were really lucky and really open and yeah, I think being open was quite helpful for us because we had good people around us."* They didn't access counselling or psychology over the first few years, instead leaning on each other as a couple and using their close networks. (Bobbi)
working together as a family (the collective)	Family members are part of a dynamic process in which family/whānau coordinate efforts, adapt roles and support each other to navigate stressors and manage challenges as a collective. "Pulling together, the whānau as a team". This includes aunties, uncles, grandparents, as well as parents.	*"And dad was obviously at home with the kids, with my other two"* (Sarah) What helped Sarah and her partner to get through this time, was keeping connected as a family unit. Sarah felt this was only going to be for this time and eventually, they would all be together. *"But yeah, this really... Just the kids, really, and just sticking together and doing it. It's not a forever thing, you know, it's going to be some hard patches, but we'll eventually get home."* (Sarah) What was going on for them was personal. These close relationships made a difference to them. Sarah's brother has Autism and epilepsy, so Sarah's mum has quite a lot on, along with work. If her brother is at home, he is the fun uncle and plays on the tramp or watches TV with the kids. He doesn't get sick of playing with the kids, which is a support. (Sarah)
Information, Communication and Understanding		
clear record keeping	This refers to caregivers' record-keeping so that they can refer to it later.	*"Probably the hard copies that we got... I think every stuff like that in an e-mail can get lost pretty quickly. We had a little portfolio thing. Just kind of how to scaffold the next movement more."* (Hannah) *"It was really easy with those papers and things."* (Sarah)
Communication that is inadequate or causes harm	This captures instances where communication from professionals is perceived by parents or carers as overwhelming, poorly timed, unclear, or emotionally insensitive. It includes the delivery of distressing information without adequate explanation, support, or consideration of the recipient's emotional state or level of understanding. Coding focuses on communication that contributes to confusion, fear, or distress rather than clarity, reassurance, or shared understanding. Does not follow trauma-informed or family-centred care practices.	At one stage Marcus was under the impression that they would need to go the specialist paediatric hospital in New Zealand (Starship) for a year. So, when they told them they could take their son home, they were surprised. There were mixed messages. Initially the medical staff said their son had toxoplasmosis. Marcus understood that his son's brain was being eaten by bugs. (Marcus and Faith) Overall, both Faith and Marcius feel that they were given conflicting information. "*So, we were like, so it was just a lot of on-off things."* (Faith) *"With the hospital, they just kept telling us their terms and we were both, oh, we don't understand."* (Marcus and Faith) Sarah didn't really understand some of the medical terms and the doctors used "big words" (Sarah). Sarah felt like she had to remember what the words were and do some research at home. Sarah was able to stop the doctors, asked questions when she didn't understand and write down the words. (Sarah) *"I didn't understand all the medical terms like and he was using big words, and I'm like I'm going to remember what that is and how to spell it you know and*

		then when I go home I'm going to research…I did stop and I'm like wait what is that you know to understand and I would go to like oh you know all these other big words and I'm not understanding anything you're saying …well if you don't understand anything here's a piece of paper on the back and front…" (Sarah)
condition-specific advice	Information and guidance provided to parents or carers that is directly tailored to a child's diagnosed or suspected condition.	*"Even just for her in the future, you know, having cerebral palsy, what does that mean for our child? How can, when she goes to Nana's, how can it support her at Nana's house too, not just at home? Things like that."* (Sarah)
Clear communication	Communication in which information is conveyed clearly, respectfully and in ways that are understandable to parents or caregivers, while remaining responsive to their questions, emotional cues and level of health literacy. This includes adapting language, timing and the depth of information, checking for understanding and supporting parents in making sense of their child's situation and care.	Their therapist will always communicate on how their son is developing and will give feedback if it's a Kindy session and they aren't there. This helps them to "keep on the same page" (Faith). This communication helps Faith remember so of the appointments that her son has. *"I love it to be honest because it actually keeps me on my toes when she's asking me because I'll be like oh, I think it oh hang on let me double check you know so it makes me rethink."* Faith (Marcus and Faith) *"And they're kind of timely as well. I don't think they kind of flooded us with anything that we kind of didn't unnecessarily need to know. But they kind of drip read it to us, gave us the time to process it, and they welcomed questions as well."* (Hannah)
Openness	Instances when parents and caregivers experience openness from professionals, demonstrated through honest, transparent and receptive communication. It includes willingness to share information, acknowledge uncertainty, ask and respond to questions, and openly engage with family members, therapists and others involved in the child's care to support shared understanding and collaboration.	*And we'd review it at the end of every session. She'd say, "Am I happy? Is there anything I want to talk about?" And I was like, "no, this is great". You know, we're just, it was really in-depth, which was the most beneficial part. It wasn't just a skim over."* (Anahera)
Reminders	This code captures actions taken by professionals, parents or carers to prompt or reinforce important tasks, appointments or follow-ups related to the child's care. It includes verbal, written or electronic cues that help ensure timely participation in interventions, reviews or other necessary activities.	*"It is, especially when, you know, life's gotten full on and then you're like, oh, what was that that I needed to do? So, I go back on, oh, that's you know, this is how it's meant to go."* (Marcus and Faith) This communication helps Faith remember so of the appointments that her son has. (Marcus and Faith) Communication with the therapist was easier through email, rather than phone calls or texts. (Ani)
Technology	Experiences of technology-telecommunication, social media	*"I think... I think now it would be different. I think the technology is a lot more cohesive. it's a lot more normalised to have a meeting, a Zoom meeting like this. But, when we were doing the first two years, it was actually just a mission for to do a Zoom meeting because of terrible internet and lots of different reasons and then being how uncomfortable they are. So, I don't, I think that was an issue at the time that I don't think it would be anymore."* (Hannah) *"I prefer to text over phone calls because when I text, I can get out what I want. Whereas when I'm on a phone call, I have to think about what I'm saying and it gets all jumbled."* (Lily)

Truth	Referring to honesty, accuracy and openness in communication. This overarching definition relates to caregivers' perceptions of whether this has been done well or not.	*"Yeah, everyone was transparent and kind and they were all very supportive just to help us in whatever way they could do."* Ana Bobbi describes her paediatrician as amazing, who they still see at the Hospital to this day. They don't see her as often now, but she is always honest and blunt. They can take what she says seriously. *"We love her (Paediatrician). Like she's such a, she's just honest."* (Bobbi)
Withholding information	This code captures instances in which information about the child's condition, care or interventions is intentionally or unintentionally withheld from parents, carers or other relevant parties. It also includes situations where a lack of disclosure limits understanding, decision-making or participation in care..	Marcus and Faith felt they weren't communicated what was going on for the son, finding out later. *"And then towards the end they did a scan and then when I ended up sick, so I never got told anything from that scan. And then when I got sick, I ended up in hospital and that's when they said, your son's had a stroke". "It took the therapist to tell us, not a paediatrician. so that was where we were, like a bit upset, like the paediatrician should be telling us this stuff, not a physiotherapist, but we were thankful that they were able to tell us, because otherwise we wouldn't none the wiser."* (Marcus and Faith)
Living with Uncertainty, Emotion and Adjustment		
Adjustment and acceptance	The dynamic, non-linear process by which parents, caregivers and families recalibrate expectations, roles, meaning and coping strategies over time in response to their child's diagnosis or ongoing needs, and eventually come to acceptance. The acknowledgement and coming to terms with a child's disability	*"I… just totally come to peace with is life can be really different and look really different and still be just phenomenal, you know. And, but that takes time. Like, I didn't, arrive at that straight away." (Bobbi)* *"I was not sure I was prepared for because I didn't know if I would be able to handle a child with a disability because when they tell you your child might have, say, Down syndrome or whatever you go, I don't think I can do that. Like, that's hard work. But I'm so glad that I ignored it and went ahead because really, it's very mild and he lives a very full life. There is not much that holds him back apart from probably his own caution." (Anahera)* *" we'd kind of processed it and we weren't afraid of the words anymore". (Bobbi)*
Agency and self-advocacy	Captures parents' or carers' ability to make decisions and act (agency), as well as their active assertion of needs or advocacy for their child (self-advocacy) to support wellbeing and access to care.	Also, in the beginning Bobbi felt like she had to run things by therapist and ask if it's ok. Over the years she has gained more agency as a parent and will make decisions without feeling like she needs this permission. (Bobbi) Faith said would tell herself to stand her ground, especially in the hospital, tell them what she thinks is happening. She was afraid at times to stand up to the experts, but she would be more assertive as a mother. (Marcus and Faith) *"So, it probably was the right call for them to just go, you know what, there's heaps of other people around here. This, that field wasn't a priority. There weren't any issues there. I don't remember any."* (Brad)
Ambiguity	Experiences of uncertainty or lack of clarity about the child's condition, care, or next steps, leading to confusion or difficulty in making decisions	Initially, when they got home, everything seemed all right. They did some of their own research and noticed that their baby was starting to change. They felt that what they were reading about and what they were told about babies with Cerebral Palsy did not match what their daughter was doing. This was very confusing. *"Like, you know, maybe a couple of them do, but like they said our child's like up here, high as peek, you know, why is she doing these things?"* (Sarah)
Balanced life	Parents' or carers' efforts to manage multiple roles and responsibilities—such as work, family, personal wellbeing and caring for their child—while striving for a	While they were in the country of origin it was easier to do the home therapy activities. After returning to NZ, it was more difficult as Ana felt by focusing too much on therapy, she would get depressed. "*My mind can't keep revolving around that because if I keep*

	sense of stability, equilibrium and overall wellbeing. It includes the strategies, priorities and trade-offs made to maintain balance amid the demands of daily life.	*thinking like what he is doing, if he's doing this? then I'll get into depression"* (Ana)
Change in situations or context	This captures experiences of new or evolving circumstances in the child's or family's life. It includes changes such as new routines, transitions between care settings, new therapists or therapies, and adjustments to services. The focus is on how external conditions or contexts change and how parents and carers adapt to them.	Marcus just wanted the old one (therapist) back, *"Probably the challenge, my most challenging thing that annoyed me of the therapy, …(it) couldn't be change(d) and it did upset me. … got so attached and everything to our first physiotherapist and then they swapped. That took me a long time to actually get used to the next person … bring first physiotherapist back."* Marcus *"Cause we, and our child had gotten so used to first physiotherapist, so it was a big change."* Faith
Changing in child over time	Observed or experienced changes in the child's abilities, behaviours or health over time. This includes physical, cognitive, emotional or social development, as well as responses to interventions.	The decisions they now are making are about bigger things with greater consequences, such as surgery, and Bobbi is grateful she now has this confidence. *"…the parents are the parents, you know, and like, in the end, whatever decision they make is the decision that is going to be made."* (Bobbi)
Complexity	This highlights the complex care for a child with a difficult start, like prematurity, or with disabilities involving medical, developmental, behavioural, and social needs. It covers multiple conditions, interventions, appointments, therapies, and supports, plus the challenges parents face in coordinating care, making decisions, and managing uncertainty. This may include missing therapy due to complexity.	*"Yeah, although the like we have an appointment with conductive but conductive education appointment at afternoon, but like one or two o'clock in the morning, she got seizure, we have to go to the hospital. We miss a lot of therapy time."* (Ani)
Early life overwhelm - a blur	This describes parents' first months with their child as a time of intense, rapid, and confusing events, including disorientation, fragmented memory, and the feeling that time and experiences blur due to medical care, interventions, or caring for a newborn with health or developmental concerns.	It was all a bit of a blur (Marcus and Faith) *"But yeah, we don't, I personally don't remember too much of the first round."* Faith *"I don't think we really thought much about the future."* (Brad) The first part of Rose's grandson coming home was a bit of a blur and she couldn't remember exactly when she first saw a visiting therapist. (Rose)
Emotional	Relating to feelings the expressed in response to situation. These can be varied and complex. Such as happiness, sadness, fear, anger	Marcus describes this time was hard and it was difficult to control his feelings.
anxiety		Ana describes feeling anxious, waiting for the results, however, was reassured by this assessment being a normal result. (Ana) When asked what she would tell herself in hindsight, Ana said not to compare her baby with any other babies, as because each child is different. *"Since he was my first child, sometimes me and my husband, we*

		thought, now if we think, we think like we should have not overthink so much." (Ana)
	fear	*"…bugs were eating his brain, and we're like, Oh, he's only two days old."* (Marcus) *"That was really hard for Marcus coping with that, thinking that he was going to lose his son."* Faith
	guilt and disappointment	When they can't find time to do the exercises Faith describes her feeling as being "gutted", especially when he resists them. (Marcus and Faith)
	joy	Bringing her son home from the NICU was a joyful time for everyone. (Ana) Coming home from hospital sounded like it was joyful. Bobbi described this as *"…the best thing ever after being in the hospital"* (Bobbi).
	Overwhelming	Getting to know your baby, being a new mum, learning to breastfeed, and having people turn up to your house was a lot. (Bobbi) *"Just having the family around us, helping when I got overwhelmed* (Lily)
	Shock	Sarah found the timing of this communication of what the doctors knew challenging. It was two after the MRI, before she found out the results. Sarah said they (the doctors) had the results for a whole week before telling her anything. A meeting was called. While whānau attending was encouraged by the NICU, none of her immediate family could attend, as her Mum had to work and her partner had had to look after the other children. Sarah did not want to delay the meeting, as she was being discharged very soon, she felt rushed and went ahead with the support of a support worker. The doctors put up "horrific photos" (Sarah) on the big screen. The support worker ended up crying and Sarah was in shock. (Sarah)
gratitude for health professionals	Thankfulness conveyed towards the health professionals that care for the parents, caregivers and their child. This can encompass feeling conveyed as an inpatient, to nurses, doctors and therapists at any point along the journey.	While Ana had high praise for the physiotherapist (described as a doctor at times) and was grateful for her support, *"…physiotherapist, she's amazing. She's wonderful."* (Ana), Ana found that the New Zealand system did not provide enough therapy. Ani spoke positively about the therapies his child received, describing speech language therapy, physiotherapy, occupational therapy, and conductive education as meeting her needs and providing a solid foundation for her future. *"We don't have the negative thought. We think that's good for our child, good for our child in the future."* (Ani)
Hope	Parents' or carers' feelings of optimism, expectations or desire for positive outcomes regarding their child's health, development or future, including sustaining motivation and resilience in the face of uncertainty or challenges.	Even though one lovely doctor had some early honest and difficult conversations around managing expectations regarding hopes and dreams for their child, Bobbi had faith that their child could achieve all that they had hoped for him. (Bobbi)…For Bobbi the diagnosis of Cerebral Palsy never 'killed' her dreams she had for her son, she never saw it that way, remaining hopeful. (Bobbi) Sarah and her partner's daughter have defied the odds. She's healthy and thriving now. (Sarah)
Imagined child	Parents' feelings, expectations, hopes, fears or concerns about a child they anticipate or imagine, including experiences during pregnancy, prenatal diagnosis or early uncertainty before the	A few weeks after coming home, when their son was very little, a visit from their neurodevelopmental therapist (Occupational therapist) made them realise it was taking longer to reach his milestones. This was when there was less uncertainty, and it became clear that some adjustment would be needed. (Anahera)

	child's actual arrival or confirmed condition. It encompasses the emotional processing of possibilities, imagined scenarios and anticipated caregiving.	
Noticing difference	Parents or carers notice a difference in their child's development, movement or health.	*"And we were just sent home and at the start she started showing like quite bad, you know, couldn't turn on one side, limp, one arm wouldn't be moving and we, you know, we thought, okay, maybe this is, you know, what they were talking about."* (Sarah) *"And whereas if we hadn't had that intervention, we wouldn't even think about doing that. We just, oh, he's left-handed. We'll just go with the left hand."* (Anahera)
On-going worry and stress	Persistent or recurring thoughts of concern, anxiety or emotional strain for the parent or caregiver regarding the child's health, wellbeing or development, including navigating setbacks and illness.	Unfortunately, their daughter had a seizure at 2 years of age, around Chinese New Year and she regressed in her skills. Their daughter was with her grandparents at the time of the first seizure and it was very scary for them. Since then, she has trialled different medications to control the seizures and needed to manage the side effects (Ani)
In the spotlight	Parental or caregiver feelings of being in the spotlight, needing to 'put on' a performance, or being a certain way to portray an image or meet perceived expectations. Feelings that their child needs to do well in assessments. This can include feeling under scrutiny by health professionals.	*"…there is pressure that goes with it, but I think it's like, it's like when people come to your house, I do remember a few times feeling like, is this an assessment of him or me, you know, like, as a mum, like, do I need to clean the house before these people come… you're a new mum, like, I, you know, I'm just getting to grips with breastfeeding and like, then I've got people rocking up and it's a mess."* (Bobbi) *"I preferred it being at home. I was a bit apprehensive at first because I was like, oh, a stranger coming into my home and assessing my environment, which is probably quite a thing. I don't know if it's a Māori thing? We just get a little bit like, oh, we don't want people coming in and thinking we're not doing a good job or, you know, they'll judge us about the way we do things because we do things a bit differently."* (Anahera)
Positivity	Expressions of optimism, hope, or a constructive outlook, including a focus on strengths, progress, or positive meaning or outcomes despite challenges.	On reflection, they can see that he has come far and are grateful, having seen other children in wheelchairs, so they tend to look on the positive side of things. *"So, it makes us just look on the brighter side of life and thankful that he can move around."* (Faith) *"It's changed it for the better. Hasn't changed it in any negative way. And I know it's just made us a more open family, more open with the kids. …he's like a big blessing to our house."* (Faith)
Proactive caregiving – doing all they can	Parents' or carers' persistent and active efforts to support their child's health, development and wellbeing through advocacy, problem-solving and seeking necessary care or services. This includes providing every opportunity for a full life.	*"I think for me, it was very doable because I've only got one child and like, I was full commitment, you know, like, which I would have been, you know, regardless of what was happening…"* (Bobbi) *"So, you had to be up there extra that a normal parent would be up there. You know, you looked like you lived up there."* (Sarah)
Protective withdrawal	When demands are perceived as too hard or unmanageable, parents or caregivers may decide not to pursue available services or engage further.	She hasn't tried to access it so didn't really know. (Rose) *"I imagine if ministry is like this, it may be a little bit the same. I don't know. Until I've gone through the whole experience, I would never really know."* (Rose)
Sitting with uncertainty	Capacity to tolerate uncertainty or unresolved outcomes, including remaining emotionally present	*"Waiting and thinking like what it will be, how it will be? Obviously, the waiting. I'm someone who always get tensed or anxious in the waiting time for a doctor result. But my husband is very calm. He is very practical. He told like it*

	and coping without immediate answers or certainty.	*should be fine, nothing to worry. But still, I hear from an expert like you, I will be a little restless."* (Ana)
Trauma	The experiences or events that are perceived as overwhelming or distressing and that have lasting emotional, psychological or embodied impacts on an individual's sense of safety, wellbeing or capacity to cope.	Sarah and her partner's daughter was born very prematurely, born at 28 weeks and weighing 1250 grams. She had many complications associated with being born so early, including sepsis, intestinal issues requiring a stoma and brain bleeds. This was an incredibly rough journey for her daughter, and she required many major surgeries. (Sarah)
Navigating Service, Systems and Access		
accessed early therapy	Was able to access early therapy following early detection or screening, without undue barriers.	Ana learnt early on that she needed to adjust her son's age for prematurity, by two months, for his developmental milestones. Ana's son was referred to the Child Development Centre seamlessly for developmental follow-up by the NICU. (Ana) *"I felt like the, because it was quite early for us, being that he is a premmie, it was good to get it in early. I think if you left it too late, it would just be harder. It would be harder on the baby or the child to relearn those pathways if you didn't start them as they were picking it up. That's sort of what I think. The earlier the better."* (Anahera)
accessible services	Services that are easy to access, use or benefit from, including considerations of availability, affordability, physical access, clarity of information and responsiveness to individual needs.	Ana and her husband found a therapy provider close to their home, as she couldn't drive and her husband was working. They were fortunate to find a provider close to their home, which was very good. (Ana)
coordination of services and therapist taking on role of keyworker	Instances reported by the parent or caregiver in which the health professional or therapist assisted with engagement in health or education services, helping the parent or caregiver navigate or engage in services. Acting as the 'middleman', intermediary, or keyworker.	Without this support they wouldn't have known what to do or explain what was going on to other professionals involved in his care. *"...like she's (physiotherapist) the middle person. And you know, we're grateful because otherwise we wouldn't know what we're doing. We wouldn't know how to explain things to the paediatrician. They know in their medical term how to explain it better than us. So, it has been great support, they've been awesome."* (Faith) *"She helped us get referrals to other services… I think she helped us with getting the SLT. And trying to get those appointments sorted. I don't remember seeing the SLT. I think we only saw them once or twice, and then we were discharged as well. But that was through the ministry."* (Lily)
Difficulty accessing	Instances where parents or caregivers face barriers to obtaining therapy or support, including challenges related to availability, eligibility, wait times, cost, location or complexity of the referral process.	*"…the services here (NZ) is a little different. They don't give any one-on-one for babies or child."* (Ana) "*So then, because even physiotherapist knows, there are no therapy services are not that often given here in New Zealand*" Ana Ana tried to access therapy privately; however, she found there was a 2-month wait and it was expensive. (Ana)
Early diagnosis	The child received an early diagnosis. Includes ease of access and memory of assessments, and any impact of the early diagnostic process.	*"I think they diagnosed him before that video. I'm pretty sure they diagnosed him before that video. When he was born."* (Faith) There was a lot of assessments and scoring. (Bobbi)
Covid related	Experiences described by parents & Caregivers where Covid influenced usual care	Follow-up was complicated by COVID restrictions. They recall that the first meeting with the visiting therapist was online. There were technical problems with the Wi-Fi, as they sat in the car park of the local rural hospital. In the end, they gave up and met their therapist

		face-to-face. (Brad & Hannah). *"Which was great, because everybody was sanitizing and things."* (Brad) *"It definitely had a big impact on the follow-up and stuff that we had and obviously us being in our rural town as well."* (Hannah)
Inequity	Experiences and situations in which parents or caregivers experience unfairness, unequal access or disparities in resources, opportunities or treatment based on social, economic, cultural or systemic factors	But they have seen after children who are under ACC (accident Compensation Corporation) funded get different things. *"Oh, there's no, there's, I know for a fact there definitely is, I just, because I've known someone else with the cerebral palsy, and they get, you know, they do these other things, and it's like, well... How come we haven't been told about that yet?"* (Marcus and Faith) *"And that was compounded too with Plunket, essentially when, oh, you're under hospital care, we won't even visit yet. Well, I think we had one or two Plunket visits. So, we had Plunket. Not necessarily support, but reassurance from them. But there was no tracking from that side of it."* (Brad) Being rural also meant they could not access services such as the McKenzie Centre (a private preschool and early intervention service). Firstly, because they lived too far from the centre, they were excluded from attending (Anahera)
Many appointments	The number of appointments, either at home, in health, or in education. This includes the perception or impact of these appointments.	*"And a lot of it, we, a lot of the appointments, we travelled down to the next closest town Hospital to the outpatients and kind of met them halfway. Just depending on the schedules of everybody involved."* (Brad)
Transitions	the parents and carers' perceptions regarding transition, either to a new therapist or a service change	One thing Bobbi would change was retaining her original visiting therapist for longer, as there was a stage where her son was seen by physiotherapists at the Child Development Centre, just before he was two years old. (Bobbi) *"Probably the challenge, my most challenging thing that annoyed me of the therapy, …(it) couldn't be change(d) and it did upset me. … got so attached and everything to our first physiotherapist and then they swapped."* (Marcus) *"Cause we, and our child had gotten so used to first physiotherapist, so it was a big change."* (Faith)
Perceived indifference from medical staff	Instances where medical professionals are perceived as unresponsive, inattentive or indifferent to parents' concerns, questions or needs, resulting in a sense of being unsupported or overlooked	She felt like she wasn't listened to by the medical staff. (faith) She felt the medical staff were not interested in her baby as his vital signs were fine. (Faith)
Preparation for discharge home from NICU or hospital	Instances where parents or caregivers discuss the information, training, resources and support provided to safely and confidently care for their child after leaving the hospital or NICU	Ana felt she had been well prepared for her son to come home *"And I think the information is from the staff, the doctors, and them reassuring that all will be okay. And if it wasn't going to be okay, that they would work through the process. So, the staff there were really good, eh?"* (Cherie)
Role of counselling and support services	The role of counselling and support services in supporting parents and carers' emotional and mental well-being. These may be specific services, such as True Colours, or general.	Sarah found the counselling and support provided by True Colours (NGO), both in and out of the NICU, amazing. They would text to ask if everything was ok, about the other children, and whether they needed any support at home. Even just offering "do you need to talk?" and "how was NICU today?" (Sarah) *"They (True colours) were just, they were amazing. As soon as you came out of surgery, went into NICU, they were there waiting, you know, so you knew that as soon as you did get there and things were a bit hard, that there was someone kind of, you know, waiting and things like that"* (Sarah)

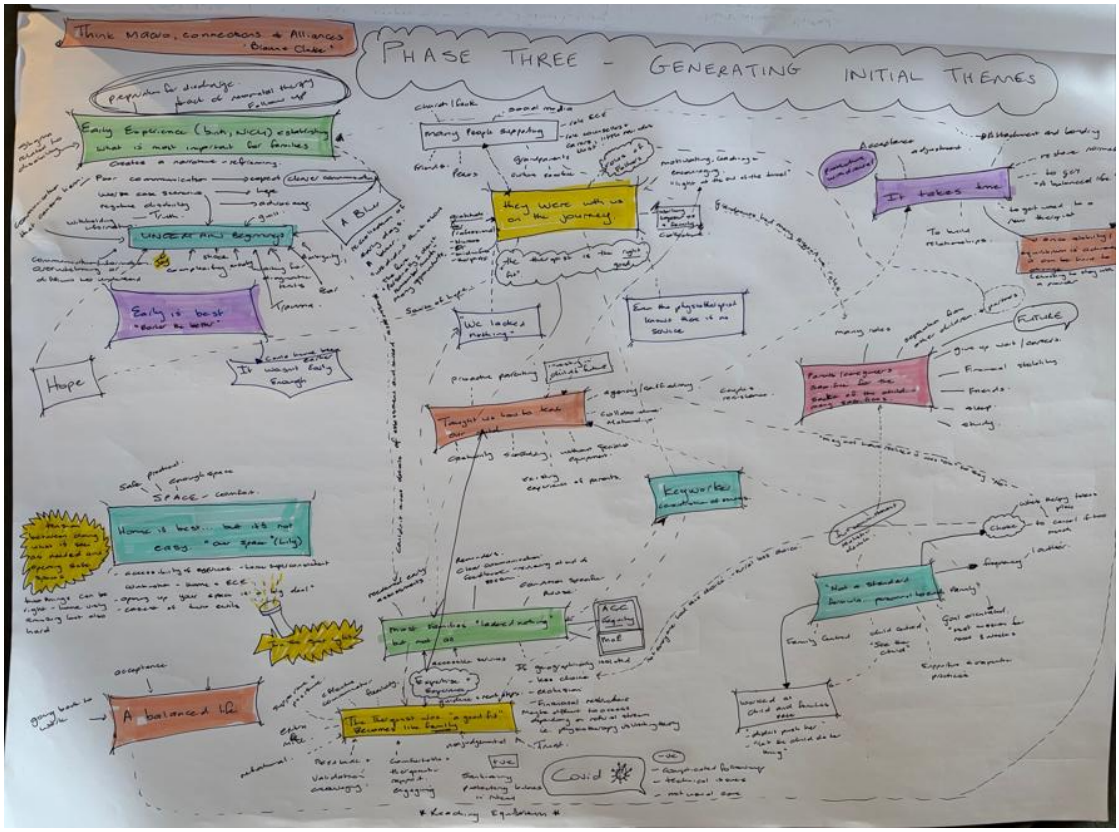
Role of ECE	This relates to the role of Early Childhood Education in supporting children and their parents with therapy goals.	By the time she got a job, he had started trial sessions. The specialists at the Child Development Centre recommended going to childcare. *"The best thing that we did was sending him to daycare."* (Ana) *"This is a win-win situation. It's not just a one-man job to make a child speak."* (Ana) Kindy has helped bring out his personality, and he has learned a lot from being around other children his age. (Marcus and Faith)
Role of MOE	This relates to the role of the Ministry of Education in supporting parents, carers and their children.	*"…but I think it's more than two years now since we've been waiting. And they really, for me, I think out of the whole process, Ministry of Education, for somebody like my grandson, who can go to school, even though he's got the delay, he can still do it. But it's how we move forward with it that they then become important to us. And we need the guidance in that area."* (Rose)
Stigma related to disability	Instances where disability is perceived negatively, devalued, or associated with shame, blame, or social disadvantage. This can come from any source, including health professionals, family, or community.	*"Well, just because like, so again, like going back to the hospital, whenever they would sort of mention the possibility of cerebral palsy, it was always with a, we're really sorry…it's not looking good, it's probably cerebral palsy… it always came with this, like, just negativity around it, you know? And like, I didn't know anything about cerebral palsy, you know, and then that's kind of your first, like, learning of it is that this is something that comes with negative association, which I don't think it needs to be."* (Bobbi)
Progress, Achievement and Meaning-Making		
Achievement and celebration	Child and parents or caregivers successfully reaching a goal or completing something they have wanted to do. This could mean adapting the environment or putting strategies in place to support success.	*"Every time our visiting therapist comes, she's just like, Oh my goodness! She sounds like she's."* (Sarah) *"He amazes us daily on different things that we didn't realise he could actually do"* (Marcus and Faith) *"We can pat ourselves on the back."* Rose
Feedback and validation	Instances in which parents or carers describe receiving responses from professionals (e.g., therapists) that acknowledge, affirm, or normalise their experiences, concerns, emotions, or efforts. This includes feeling listened to, reassured, taken seriously, or having their knowledge of their child recognised, which contributes to emotional support, confidence, or trust in the relationship.	Their therapist will always communicate on how their son is developing and will give feedback if it's a Kindy session and they aren't there. (Marcus and Faith) Each time the therapist would come, see would notice there has been improvement. Rose felt this was good feedback. (Rose) The visiting therapist used an assessment to track her daughter's progress. (Sarah)
Investing in the child's future	Experiences where parents or caregivers explain how their early support will benefit the future.	*"We don't have the negative thought. We think that's good for our child, good for our child in the future."* (Spicy Ani)
Restoring normalcy	Returning to life and routines that seem typical or expected after a period of disruption.	They settled into home life, and their wee boy was doing all the things a newborn baby should. *"I think by the time we got the call from (our visiting therapist), it was like a couple of weeks out of hospital and we were expecting it, but kind of we'd like adjusted back into normal life, … and (our child) was very, regular baby kind of thing."* (Bobbi)
Therapeutic Relationship, Trust and Collaboration		

Collaborative relationship	Interactions between parents or carers and therapists or early intervention providers (ECE and specialist teachers) are characterised by partnership, mutual respect, shared decision-making and open communication. These interactions include working together to set goals, problem-solve and coordinate care to support the child's development and wellbeing.	*"…it was two-way. It wasn't just one."* Rose *"… not when she needs to come and things like that, working around each other and things like that."* (Sarah) *"The conductor took maybe four months, maybe much better. Then after maybe one month, the conductor come to our place weekly and we go into the conductive. But the plan was one hour session. But the first couple of times we only can be there like 10, 15 minutes. (Our child) was crying, we have to come back home. And then the time longer and longer, half hour, one hour."* (Ani)
Comfortable and therapeutic rapport	Parents' or caregivers' sense of ease, trust and emotional safety in interactions with therapists, enabling open communication, honest questions, and confidence in the care provided. Parents' and caregivers' trust that the therapist has the child and family's interests at the centre of their practice.	*"She (physiotherapist) made us feel comfortable and like she'd come in and we were all felt, we just all felt comfortable."* (Marcus and Faith) *"… the time that we're comfortable, and … a time that I felt comfortable with, and she'll be on with it, so we never did lack…"* (Rose)
consistency and continuity	Parents or carers' perspective that services are reliable, seamless and uniform over time. It may reflect experience of disruption and adjustment to this.	*"I would have loved to keep our visiting therapist for longer. She was good."* (Bobbi) *"I think consistency is the key."* Hannah)
Effective communicator	A therapist has a communication style in which parents experience the therapist as conveying information clearly and accurately, being an active listener, and adapting their communication style to the situation. This helps keep everyone on the same page.	The physiotherapists used several ways to communicate the home programs, including drawing diagrams or printing information to explain what was meant. Another therapist used texts with step-by-step instructions. Their therapist is always communicating via text. This helps them to *"keep on the same page".* (Marcus and Faith)
Encouraging	The therapist can motivate, support and cheerlead the parents or caregivers, helping them continue their role in parenting their child.	Rose didn't know what it would be like not to get that encouragement, as it was her experience that the therapist always encouraged her, but thought that without this encouragement, it might have set them back. (Rose) She (Physiotherapist) was very encouraging. (Sarah)
engaging	Parents or caregivers observe that the therapist can attract and hold the child's and/or parents' attention and interest. This can be achieved through toys, singing and play, etc.	Her therapist was so good at engaging with them (Rose)
Expertise and experience of the therapist	Parents or carers' experience of the therapist's knowledge and skills in this specialist area. This can include coaching, hands-on skills, teaching and education, as well as perceived life experience.	*"The thing that really helped us with our therapist was that we got the pram in the chair and they're quite small, you can you can pack them down and mum can use those because she's got low muscle tone, so you've got to have the prongs in the seat and make sure she's not slipping and things like that but like yeah even little things like that."* (Sarah) There has been a bit of trial and error with some equipment, like her walker. She was "really dangerous" (Sarah) on this. She flipped

		it and smashed her head on it. The therapist ended up taking the walker back. (Sarah)
Flexibility	The parents or caregivers experience or perception of the service/ therapists to be able to adapt to changing needs, challenges and circumstances of the family	There was flexibility and she felt it was up to them how much support they wanted. Bobbi also had to option to turn down appointments. (Bobbi) There was a great deal of flexibility with therapy and this fitted in around other appointments at the hospital such as hearing or eye specialist appointments. This meant everything could be fitted in. *"All those different types of things up the hospital, eye tests and things. So just making sure everything fits so we can all kind of get it done and not miss anything."* (Sarah)
Goes the extra mile - above and beyond	Parents or carers' experience of the therapist making additional effort beyond what is expected to support, assist or achieve a positive outcome.	Marcus described that their physiotherapist would do more than they expected and went the extra mile. '*Yeah, she did that extra mile to.'* (Marcus)
Good fit	The parents' or caregivers' experience of the alignment between the therapists' approach, style and personality and the individual needs of the child and family. Closely aligned with collaboration	*"But I think we got very, very lucky with (our visiting therapist) because she was a good fit for us and the way that we kind of roll through the world, and optimists."* (Bobbi) *"But I think if we had have had somebody that we didn't gel with or it could have been an entirely different experience. "*(Bobbi) *'But our physiotherapist she was awesome.' 'It might have been totally different if we got someone else, you know what I mean? "(Marcus)*
Guidance- next steps	Experience of parents or caregivers who relied on the therapist's guidance	*"It should do it at home for visits...mostly like a lot of equipment, just going, right, here's a chair that you can use to help her reflux and kind of use her muscles. But she came in and did home visits for a long time and just taught, showed me how to do stretching, just the little movements. She was actually really good kind of basically just playing with our child when she was really little and going, okay, this is where she is now, and this is what will start happening next…It was more like, this is how you can scaffold the next steps. Yeah, she was pretty hands-on with us really."* (Hannah)
Non-judgemental	Parents or caregivers experience the therapist's approach as non-critical, unbiased and free of preconceived notions, accepting parents' or caregivers' choices and experiences as they are.	They worried that the new therapist would not 'get them' especially Marcus' jokes, as he has a "major sense of humour" (Marcus and Faith) The physiotherapist gave lots of non-judgemental practical advice, (Marcus and Faith)
Relational	Therapist's interpersonal attributes and interactions as experienced by parents, carers, and the child. These include warmth, empathy, respect, responsiveness, and the ability to build trust and supportive connections that foster engagement, collaboration, and positive experiences in care.	The therapist always made her daughter feel comfortable. She would use distraction to make sure it wasn't too overwhelming. As soon as the therapist comes, her daughter will stop everything and crawl to the door to great her. (Sarah) *"Yeah, she loves our therapist."* (Sarah)
Supportive-positive	Parents or carers' experience of the relationship with the therapist is collaborative, trusting and encouraging.	*"She (the therapist) was amazing. Yeah. She listened to me blubber and carry on quite a few times about things that were totally unrelated."* (Anahera) *"Very valuable (therapy). Yeah. None of the other kids had any of that. But yeah, we had a great team when she was younger."* (Lily)

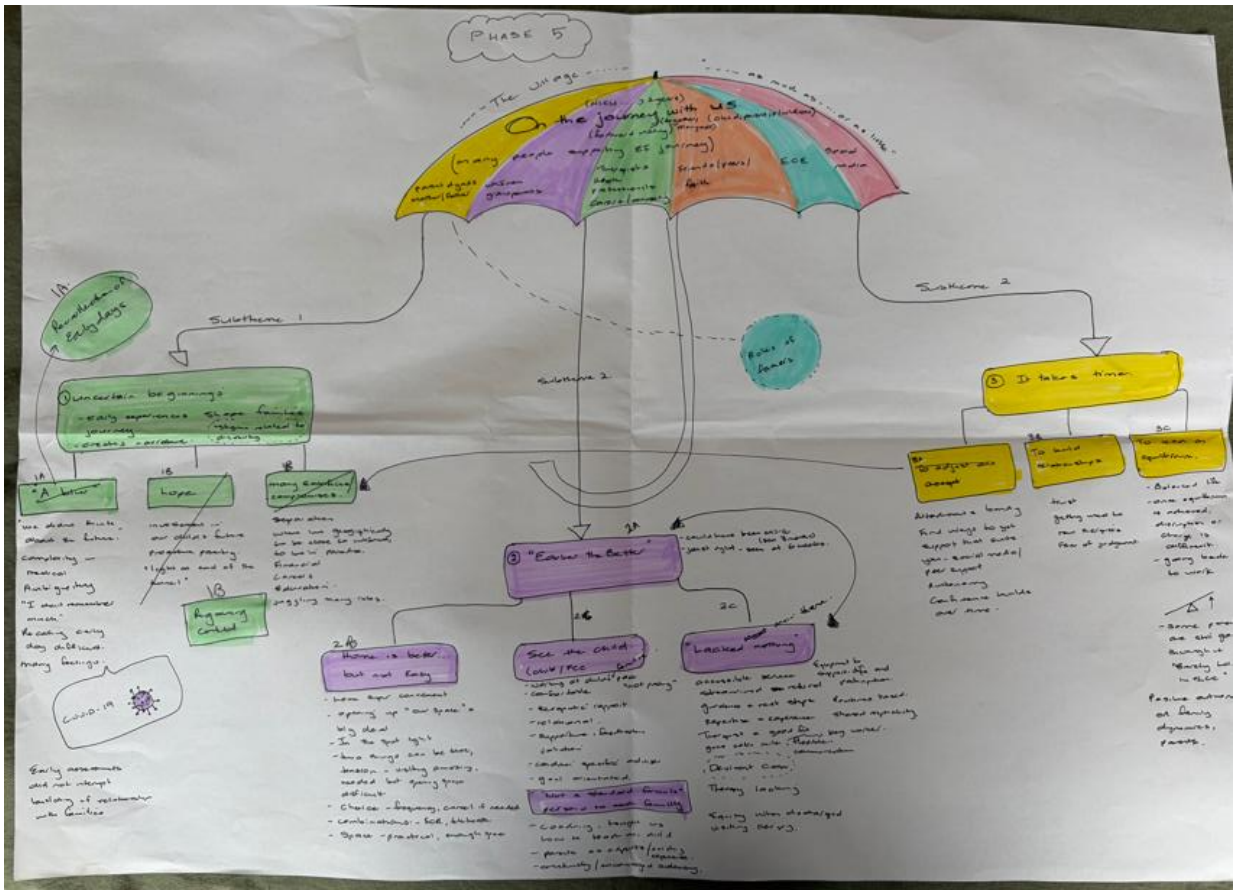
Takes time to build relationships	Parents and caregivers experience that it is a gradual process to build a trusting and collaborative relationship with the therapists	But she does know that they have spent so much time with her visiting therapist (occupational therapist) (Rose) The therapist did take a while to get to know their kind of humour but now she laughs with them. (Marcus and Faith)
Therapist becomes like family	Parents or caregivers experience of the therapist forming a close relationship, which is hallmarked by ease, openness and trust that feels like family.	*"She (physiotherapist) made us feel comfortable and like she'd come in and we were all felt, we just all felt comfortable. Sort of like she was family kind of thing. You know, so it was just, oh Physiotherapists here, come on in, you know. Do you want a coffee? ... and it just felt like she was on this journey with us and she made things a lot clearer for us along the way so it actually felt good having her next to us and that support."* Faith The visiting therapist has become like family. When she arrives, she will pick the baby and give her a cuddle. All the kids love her. They are excited to see her and she often brings toys and bubbles for everyone to play with. (Sarah)
Trust	Experiences in which the parents or caregivers convey confidence in the therapist's reliability, honesty and competence	The relationship Bobbi had with the visiting therapist was significant. One of the important features was trust. *"(Our visiting therapist) was just amazing and like, to this day, I still feel like I could trust her, you know?* (Bobbi)

J: Data Analysis – Phase 3: Initial Threads



K: Data Analysis – Phase 4: Refinement of Threads

L: Data Analysis – Phase 5: Refining and Naming of Threads and Sub Threads



M: "Big Tent" Criteria for Excellent Qualitative Research (Tracy, 2010)

Criteria for quality	Various means, practices and methods that achieved
Worthy topic	• The researcher identified a research gap • Add contextual elements (e.g., NZ-specific, whānau perspectives) to what is already known
Rich rigor	• Recruited no of participants hoped for, significant and interesting • Field notes, semi-structured interview, transcription details
Sincerity	• Reflexivity- positionality and stance provided, including biases • Transparent/clear documentation • Transparent in decision made (Journal, note-taking and audit trail)
Credibility	• Thick description • Crystallisation - multiple data sources (transcripts and artifacts), multiple theories • Member checking- from participants, encourage edits • Triangulation -peer review (Te Ao Pakeha and Māori)
Resonance	• Way re-presented • Audience • "Evocative" (Tracy, 2010) storytelling
Significant contribution	• Provided practice recommendations (pragmatic) • Practical contribution- practice recommendations and policy changes provided in summary
Ethical	• Completed procedural ethics (locality, cultural and institutional) • Use of a co-researcher was needed • Considered the vulnerability of population trauma-informed care as • Sharing of data and outcomes with participants and beyond
Meaningful coherence	• Did it achieve its stated purpose? Research objective achieved with pragmatic outcomes, implications for policy and practice and areas for future research • Qualitative methods – researching experience • Relating back to literature

N: Ethics Approval

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Roger Moltzen
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Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

04 July 2025

Tania Bright-Johnstone
Health Sciences
Division of Health
By email: tmb57@students.waikato.ac.nz; tania.johnstone2@gmail.com

Dear Tania,

HREC(Health)2025#47: Caregivers' experiences of intervention following early screening for adverse neurodevelopmental outcomes: a narrative inquiry

Thank you for your responses to the Committee feedback.

We are now pleased to provide formal approval for your project.

Please contact the Committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

_____

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee

O: Locality Approval

Te Whatu Ora
Health New Zealand
Waikato

with IK?

Research Registration

It is a requirement that all research and audit conducted within Te Whatu Ora Health New Zealand (Waikato) be registered with the Research Office. By registering your project early on, even when it is still at the concept stage, we can assist you with advice and guidance relating to design, contracts, funding, ethics approval and much more. Once you have completed and submitted the registration form (below) you will receive copies of the relevant Waikato Approval of Research Forms. These need to be circulated for the appropriate signatures and returned to us. You will receive a fully signed copy for your project file.

Complete this form and email it to WKresearch@tewhatuora.govt.nz to commence your registration with us. We endeavour to respond within 2-3 working days. If you have not had a response and you have time constraints on your project please contact us by phone on **(07) 8398899 ext 23589.**

RD025040	**Caregivers' Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry**

Project Personnel

(PI)External PI name:	Mrs Tania Bright-Johnstone
External PI organisation:	University of Waikato
Mobile phone number:	0212297834
Email address:	Tania.bright-johnstone@waikatodhb.health.nz

Waikato PI name:	Mrs Tania Bright-Johnstone
Mobile phone number:	0212297834
Email address:	Tania.bright-johnstone@waikatodhb.health.nz

All Waikato Co-Investigators:	NA
Research Nurse/Co-ordinator:	
Other Waikato contacts:	

If no Waikato employed investigator, a Waikato contact or supervisor is required:	Dr Samanatha Heath (Supervisor)- University of Waikato Rangi Harrison (PhD candidate University Waikato) who will assist lead investigator with interviews and with interpretation of data for Māori participants
Mobile phone number:	0272692869
Email address:	samantha.heath@waikato.ac.nz / r.harrison@waikato.ac.nz

Nominate the primary contact person for this research:	Mrs Tania Bright-Johnstone
Mobile phone number:	0212297834
Email address:	Tania.bright-johnstone@waikatodhb.health.nz

Host Waikato department	Child development Centre

Department/Service Sign-off

Dept/Service /Org	Role	Name	Signature	Date signed

As Operations Manager, by signing this I confirm

- I have discussed the research project and resource implication for this department with the principal investigator and that the Principal Investigator has discussed these resource implications with any affected services / staff members.
- All researchers/students from the department involved in the research project have the skills, training and experience necessary to undertake their role.
- I support the research project being conducted; and confirm there are suitable and adequate facilities and resources for the research project to be conducted at this site.

Te Whatu Ora
Health New Zealand
Waikato

Research Registration

			Signature	Date Signed
Allied Health	Operations Manager	Lindsay Pooley		12/7/25
	Chief AHS+T Officer	Clare Tahu		9/7/25

As Director / Executive Director, by signing this I confirm:

- All costs incurred by Waikato Unit/Service in regard to the research project are included in an approved research budget (including those costs which will be incurred by contributing units, eg laboratory). For studies involving researcher time only, the researcher has the time to undertake the study.
- Research is not commenced until all required approvals have been obtained.

Rural & Community	Director	Rachel Swain		
Hospital & Specialty	Group Director Operations	Stephanie Doe		
Te Puna Oranga	Māori Research Review Ctte	Hina Pokaia	*See attached letter*	N/A

Please return to the Research Office (via Sarah Brodnax, Level 2 Hockin) along with required documents as identified in the checklist for final approval.

Office use only:
Quality & Patient Safety, Waikato

It is the responsibility of the Director of Quality & Patient Safety or Chief Medical Officer to ensure that the research approval process has been followed, that required internal and external approvals are evident and that the research project fits within the strategic direction of Waikato.

Signature: Margaret Fisher **Date:** 29/09/2025

Name: MARGARET FISHER **Position:** CMO

P: Health New Zealand – Te Whatu Ora Waikato's Te Puna Oranga Māori Consultation Research Review Committee

Waikato

Te Whatu Ora
Health New Zealand

Te Puna Oranga Māori Research Review Committee

7 May 2025

Re: Māori Consultation for 'Caregivers' experiences of intervention following early screening for adverse neurodevelopmental outcomes: A Narrative Qualitative study'

Name of Applicant: Tania Bright-Johnstone

Tēnā Koe Tania,

Thank you for submitting the above research proposal to the Te Puna Oranga Māori Research Review Committee for Māori consultation. The research application has been reviewed in order to support and prompt the researcher to think about how this research will improve health outcomes and eliminate inequity for Māori living within the Waikato region.

1. The Committee acknowledges the researchers for collecting ethnicity data as part of a demographic background of the participant to improve data collection for Māori in order to improve Māori health outcomes and reduce inequity for Māori.

2. The Committee encourages the research team to actively recruit equal numbers of Māori and non-Māori. Any Research that involves Māori participation would require sufficient face to face time for fully informed consent to occur. Inclusion of the whānau of the Māori participant should be encouraged to support the continued engagement of the Māori participant in the research process.

3. The Committee encourages all research that involves participation of individuals, especially Māori participants to fully inform them regarding the detail of tissue collection. One consent form for the current use of Tissue. One consent form for the future use of tissue (this should be clear to the participant).

4. Studies using retrospective data must respect Māori data as outlined in Te Mana Raraunga: ***5.1 Respect***. *The collection, use and interpretation of data shall uphold the dignity of Māori communities, groups and individuals. Data analysis that stigmatises or blames Māori can result in collective and individual harm and should be actively avoided.*

   Reference: Te Mana Raraunga: Principles of Māori Data Sovereignty. Brief #1 | October 2018.
   https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5bda208b4ae237cd89ee16e9/1541021836126/TMR+Ma%CC%84ori+Data+Sovereignty+Principles+Oct+2018.pdf (Accessed August 2019)

5. If cultural issues arise for the Māori participant during any research, they will inform the research team during the study that an issue has occurred. Cultural issues may not be obvious to the participant or the researcher prior to commencement of the research.

6. The Committee encourages the research team to continue to consult with Te Puna Oranga, Māori Health service at any time, should they have any further queries.

7. Feedback regarding this research is appreciated and can be shared back to the Kaunihera Kaumatua via Te Puna Oranga Māori Health Service

The Committee endorses this research proposal with the consideration of the above cultural recommendations where appropriate and requests the researcher to collect ethnicity data for all study participants seen at Waikato hospitals for our own internal records.

Hina Pokaia
Te Puna Oranga - Māori Health Service

Page 1 of 1

Q: Researcher Safety Protocol

Researcher safety protocol

Project Title Caregivers' Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry
Project supervisor Dr Samanatha Heath
Lead investigator Tania Bright-Johnstone

Prior to leaving for the interview, I will provide my supervisor the address of participant in a sealed envelope.

On arrival at the place where the interview takes place, I will position the car safety for a safe exit.

I will assess the venue for signs of danger and reschedule the interview if required or safety concerns.

Before entering text my supervisor "I have arrived at interview", with time expectation.

Once in interview completed, text supervisor "leaving interview, time..."

If interview for some reason runs over time, my supervisor will ring or text me to check on my safety.

If contact cannot be made, my supervisor will open the envelope and drive to the address to establish my safety.

Project supervisors' details
Dr Samantha Heath
samantha.heath@waikato.ac.nz

R: Participant Feedback Card

Thank you so much for being part of the research exploring your experiences of early intervention services in the Waikato. Your time and contributions were greatly appreciated.

There are numerous findings and practical implications, which have been summarised for you.

Findings

- Many people supported participants and their children, helping them take part in early therapy.
- Participants valued non-judgemental therapists who took time to get to know them and their child, and worked at the child's pace.
- Home was seen as the best place for therapy in the first two years, but it was not always easy. Flexible services and those that consider individual preferences are best.
- Clear and honest communication from the NICU to home was important.
- Follow-up support and assessments were not always understood.
- Families in rural areas and small towns could access early therapy services but often travelled further and had fewer choices.

What will we do?

- The important findings from this study will be communicated to service providers.
- Referral pathways will be reviewed.
- Early assessment processes and the information provided to families will be reviewed.
- It is proposed that the visiting service for families in rural or small towns be extended to reduce travel and other barriers.

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

S: Student Confidentiality

Student Researcher's Confidentiality Agreement

Project Title - Caregivers' Experiences of Intervention Following Early Screening for Adverse Neurodevelopmental Outcomes: A Narrative Inquiry
Project supervisor Dr Samantha Heath
Lead investigator Tania Bright-Johnstone

- o I understand that all material collected during the interviews and post-discussion is confidential
- o I understand that the content of the interviews can only be discussed with the researcher and their supervisor
- o I will not keep any recordings or notes from the interviews

Student Researchers signature: _____
Student Researchers name: _____
Student Researchers contact details: _____
_____

Date _____
Project supervisors' details
Dr Samantha Heath
samantha.heath@waikato.ac.nz

T: Editor's Permission to Use Models

From: Tania Johnstone <tania.johnstone2@gmail.com>
Sent: Saturday, May 16, 2026 12:52 AM
To: CCHadmin <cchadmin@wiley.com>
Subject: Permission request to reproduce a model for Master's thesis University of Waikato New Zealand

To whom it may concern

I am a postgraduate student currently completing a master's thesis. I am writing to request permission to reproduce two models published in one of your journals as part of my thesis.

Firstly, the ***model of influences on parent-delivered therapy*** is presented on page 666 of the following article published in *Child: Care, Health and Development*:

> Lord, C., Rapley, T., Marcroft, C., Pearse, J., & Basu, A. (2018). Determinants of parent-delivered therapy interventions in children with cerebral palsy: A qualitative synthesis and checklist. *Child: care, health and development*, *44*(5), 659–669. https://doi.org/10.1111/cch.12592

The second one, the figure is ***"Facilitators to a 'good journey' through neurodevelopmental follow-up"*** presented on page 8 of the following article published in *Child: Care, Health and Development:*

> Fortune, A., Perkins, E., Paize, F., Palanisami, B., & Gladstone, M. (2024). Managing mothers' and fathers' uncertainty during their journey through early neurodevelopmental follow-up for their high-risk infants—A qualitative account. *Child: Care, Health and Development, 50*(1), e13168. https://doi.org/10.1111/cch.13168.

The models would be reproduced solely for academic purposes within my Master's thesis, which is non-commercial. The figure would be fully referenced and acknowledged in accordance with journal and publisher requirements.

Please let me know if any additional information or a formal permissions process is required. Thank you for your time and consideration.

Kind regards,
Tania Bright- Johnstone
Master's student
University of Waikato, New Zealand
Student email tmb57@students.waikato.ac.nz

From: CCHadmin <CCHadmin@wiley.com>
Sent: Wednesday, May 20, 2026 20:08
To: Tania Johnstone <tania.johnstone2@gmail.com>
Subject: Re: Permission request to reproduce a model for Master's thesis University of Waikato New Zealand

Dear Dr. Bright-Johnstone,
Thank you for reaching out to me.
Upon confirmation from the Editors, you may include the requested figures/models in your Master's thesis with appropriate acknowledgement and citation to the original published articles.
Please reach me in case of any further assistance.
Kind Regards,
Amirthavarshini Chidambaram
Editorial Assistant
Child: Care, Health & Development
cchadmin@wiley.com

From: Web Queries <webqueries@mch.govt.nz>
Sent: Friday, 22 May 2026 14:09
To: Tania Bright-Johnstone <Tania.Johnstone@TeWhatuOra.govt.nz>; Web Queries <webqueries@mch.govt.nz>
Subject: RE: Re Permission and attribution query for Te Whare Tapa Whā image use in master's thesis

You don't often get email from webqueries@mch.govt.nz. Learn why this is important
Kia ora Tania

You may use this image for the purpose you describe. The attribution should be:

Te Ara - The Encyclopedia of New Zealand
Source: Mason Durie, *Whaiora: Maori health development*. Auckland: Oxford University Press, 1998, pp. 68–74

Ngā mihi
Jamie