



# Prematurity in Aotearoa New Zealand

## A Position Paper

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baby Māui into the sea

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Crack! The egg  
started to open up!  
Oh no! It's too early!!

The book "Earlybird - Te Manu Moata" by Burgess-Manning & Cooper (available in Te Reo and English from <https://www.championfoundation.co.nz/shop.html>) uses a story to help families process their experience of a premature birth. Every preterm baby in New Zealand is given a free copy during their stay in NICU supported by the Champion Foundation. Dr Lance O'Sullivan says the book is an "invaluable resource" for families of premature infants.

## Foreword

This position paper has been funded by the Champion Foundation, based in Ōtautahi Christchurch, New Zealand. The Foundation is the fund-raising arm of the Champion Centre. The Centre, established over forty years ago, is a non-governmental organisation and provides early intervention services for pēpe and tamariki (babies and children) (0-6 years) who have special needs or whose development is at risk. The Centre is part-funded by the New Zealand Manatū Hauora/Ministry of Health, Te Tāhuhu o te Mātauranga/Ministry of Education and Te Manatū Whakahiato Ora/Ministry of Social Development, but is heavily reliant on charitable donations to provide its

core services to children and their whānau (families). One of the Centre's programmes provides monitoring and intervention for infants and children born premature and their caregivers. This position paper will draw on this experienced clinical and professional perspective to explore the science.

### **The Champion Centre service for children born premature and their families**

The Centre's monitoring, assessment and intervention programme for children born premature and their families is provided for baby/parent dyads as soon as possible after they leave NICU and continues until school

entry for children born either less than 32 weeks gestational age or for those with other risks. The multi-disciplinary programme supports, as a core element of the programme, primary whānau relationships, as well as monitoring developmental progress. The programme is flexible and can meet the needs of families who may need extra support to establish responsive infant/parent interactions from the earliest weeks. The programme understands the bi-directional nature of influence, including an awareness of the child's characteristics, as well as his or her medical vulnerability and assesses the extent to which this affects interaction within the dyad. Support is provided regularly (up to weekly) from referral and often includes help to establish feeding and sleeping. Parents meet other parents with premature babies at the Centre. The service is provided by a professional team who work together to offer a fully integrated intervention. Psychologists and social workers are core members of the team, so that if needed, trauma and dysregulation in the dyad can be addressed from the start. Parental mental health can be monitored, and the team has developed links to the local Mother and Baby Mental Health Service and Under Fives Team of the Child, Adolescent and Family Mental Health Service. Further detail about the service has been published (1). Based on the experience

of delivering services to premature children, the Champion Centre has developed a reading book for children to read with their parents.

As a result of their academic and clinical experience over the last 20 years, the authors believe it would be of benefit to provide, for professionals who work with premature tamariki and their whānau throughout the lifespan, a summary of the up-to-date research evidence that guides best practice for this vulnerable group. The authors will connect the strands of research data which help to understand the medical, psychological, educational and social impacts and consequences of prematurity. Research suggests whilst many children born preterm will do well, others will continue to struggle throughout the lifespan.

To intervene successfully with this group of children and adults, we need to understand

- what the data tells us,
- how it links together,
- what it means for intervention and surveillance.

## Endorsements from our reviewers:

**Professor Terrie Inder**, Recently appointed to the Chair of the Center of Neonatal Research, Children's Health of Orange County, California. Until September 2022, Terrie Inder, who is originally from Ōtautahi Christchurch, was the Mary Ellen Avery Professor of Pediatrics in the Field of Newborn Medicine at Harvard Medical School, U.S.A.

much data put in the beautiful lens for a New Zealand whānau-integrated perspective....

We need a neuroscience-driven approach to improving brain recovery from injury - which is more effective in the newborn brain than it is at any other time of life, in addition to the family-integrated programs, parent mental health and the transition to home support.

"WOW - what a wonderful summary of so

Huge congratulations and well done! Thank



you on behalf of all the New Zealand babies and families who will benefit from your efforts"

**Dr. Peter McIlroy FRACP; Paediatrician NMDHB**

**Chair - Te Pā Harakeke / Nurturing Care in the First 1000 Days working Group (South Island Child Health Alliance)** The authors....

"have done an amazing job at presenting a narrative that is well researched, and wide ranging".

**Professor Neil Marlow, Emeritus Professor of Neonatology, University College London, EGA Institute for Women's Health, Faculty of Population Health Sciences.**

"This is a well-researched and presented opinion piece examining services for the premature newborn in New Zealand in the context of the world literature. It is mandatory reading for all professionals and health care planners as it sets out the huge long term benefits for families/whānau from well-targeted intervention and service provision for this neglected group."

**Dr. Carolyn Blackburn, Reader in Interdisciplinary Practice and Research with Families Birmingham City University, UK**

"The number of children born prematurely globally is 15 million (1 in every 10 live babies) every year according to the World Health Organisation which take an active interest in this important area of child development and family welfare. This important position paper outlines the implications of this for New Zealand in terms of prevalence (7.5% of live births), policy and family support practice. The emotional, practical and psychological impact of premature birth for parents and wider family members should not be underestimated and this paper brings that impact into sharp focus through a careful synthesis of contemporary research, lived and embodied experiences and recommendations for everyone involved in children's lives. The Champion Centre in New Zealand is internationally recognised as delivering a gold standard early intervention service for children born prematurely in the context of family life and realistic aspirations. During my month-long research Fellowship with

them, I observed the most reflective empathetic, respectful, strengths based and interdisciplinary approach to supporting children and families. This paper should be read by everyone who supports children born prematurely and the recommendations for policy and practice acted upon with urgency. With a rising number of children born prematurely, with complications from pre-term birth cited as the leading cause of death among children under five years of age... this is not an issue any government can afford to ignore. I wholly endorse this paper and recommend it to all child and family services, policy makers and practitioners".

**The Infant Mental Health Association of Aotearoa New Zealand -** "A very

comprehensive report about prematurity. It also highlights the need to invest in early parent-infant relationships with our premature pēpi."

**Professor Barry Carpenter CBE, OBE, D.Litt, PhD. Oxford Brookes University, UK.**

"This is a beautifully-crafted report, drawing together the current international discourse on children born prematurely. With the international insights of many years of research and practice Alison Gray and Patricia Champion map out the many challenges in life faced by these children and their families. They coherently and convincingly argue that there is now a strong evidence-base clearly illustrating that with timely and purposeful interventions what might initially have been bleak outcomes for these children, can be transformed into hope and positive opportunities....In the context of a supportive family, and with sustained input from a range of skilled practitioners, across the disciplines, the lives of these children are open to a wide range of possibilities.

However, to achieve these goals, a service infrastructure needs to exist to fully implement the research-informed, evidence-based practice that has evolved over the last two decades in particular. We now have a rich and full understanding of the needs of this new generation of children; now is the time to grasp that hard-earned knowledge and translate it meaningfully into practice that truly meets need".

“A person’s  
a person no  
matter how  
small!”

From Dr. Seuss's 'Horton Hears a Who'  
1954 by Random House.

A close-up photograph of a newborn baby lying on its back, held gently by a person's hands. The baby's head is resting on the hands, and its arms are raised. The baby is lying on a white surface, likely a scale, with a colorful striped blanket visible below. A digital display on the scale shows '0.0'. The background is softly blurred, showing a hospital room with a yellow wall and a white door frame.

Around 4,503  
(7.5% of live births)  
babies are born  
preterm (earlier than  
37 weeks gestational  
age) every year  
in New Zealand

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This research reinforces that pēpi are our precious taonga. We note the significance of whānau as the korowai of our tamariki and this study further reinforces the wrap around supports that professionals can add to their kete of knowledge and experience so that our pēpi have the best possible start in life.

**Mō tātou, ā, mō kā uri ā muri ake nei**  
**For us and our children after us**

Arihia Bennett MNZM, CEO Te Rūnanga o Ngāi Tahu



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# Executive Summary

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## What is the issue?

Around 4,503 (7.5% of live births) pēpē/ babies<sup>2</sup> are born preterm (earlier than 37 weeks gestational age) every year in Aotearoa New Zealand (2). A premature end to a pregnancy creates an acute emergency for infants, parents, whānau and healthcare staff. Over recent years, survival rates for babies born early have improved significantly, however the lifelong impacts of an early birth have not improved (3). For many pēpē/infants born preterm, subtle difficulties with brain processes may impede their progress through childhood and into adulthood. Research evidence clearly suggests that many babies, children and adults who were born early, have challenges which may require varied support services as they proceed through life. The tamariki/children most at risk are those infants born earliest, especially under 32 weeks gestational age, and infants from whānau/families who, in addition to a preterm infant, have other social, health and economic difficulties.

## What is the current response?

Currently in Aotearoa New Zealand, there is

a disparity in services available to babies and children born premature. Neonatal Intensive Care Units services are often over-worked and under-funded to provide the early emotional and relationship-based care to babies and parents which will give families the best possible start. After babies leave hospital, follow-up services across Aotearoa New Zealand are inconsistent. Longer term, early childhood educators, teachers, social workers, psychologists and other practitioners are often not familiar with the challenges for children born preterm. Kaupapa Māori services are not widely available. Agency responses are often siloed and unconnected.

## What needs to happen?

Research shows that with sensitive parenting and where needed, informed professional supports, many tamariki/children born preterm can develop well, and in the long run have no more difficulties than their full-term peers. Clear evidence suggests that supporting positive infant-parent relationships is crucial and intervening as early as possible will do most to promote long-term positive outcomes. Kaupapa Māori services can be holistic and involve and support the wider whānau. Greater access to holistic services

<sup>2</sup> Te Reo Māori (Māori language) is an official language of Aotearoa New Zealand. We have used the following translations interchangeably through the text. Pēpē/ babies; tamariki/children; whānau/families. Kaupapa Māori services refer to those services where Māori language and culture underpins the nature of the service. The NZ government has obligations under Te Tiriti o Waitangi (Treaty of Waitangi) to ensure reciprocity, active protection, partnership, equity, and equal treatment for all peoples in Aotearoa New Zealand.

needs to more widely available to Māori and all whānau/families of children born preterm. The cost of acting early and preventatively can lower the overall cost of services for children born preterm and their families throughout the life span. To improve services for children, professionals from education, social services and health and their funders, need to all become familiar with the issues of prematurity and collaborate to develop interventions, which support children's ongoing positive relationships and developmental progress. Health care obligations under Te Tiriti o Waitangi must also be applied, including Tino rangatiratanga; equitable outcomes for all; active protection; kaupapa Māori services should be available where possible and all services should be provided in a culturally-appropriate way, Māori must be co-designers of services in Aotearoa New Zealand.

## The aims of this paper

- This paper advocates for increased funding to provide better and more consistent intervention services for children and adults born premature, especially those which address the challenges early and preventatively.
- This paper will provide information about prematurity for professionals and practitioners by bringing together the diverse evidence from medicine, psychology, education and social science research, in order to guide best practice and intervention. This paper will be made available at no cost on the Champion Centre website. Whilst not specifically written for parents, we acknowledge that some parents may access it in order to read more widely. Leaflets about prematurity, specifically written for parents, are also available on the Champion Centre website.

## Connecting the brain to the rest of the body – Centre on the Developing Child Report

“Implications: Policies and programs that reduce stress, prevent toxic exposures, and provide support for pregnant mothers and families with infants and toddlers will result in better health outcomes across the lifespan and save billions in health care costs. Taken another way, if we delay early investments until later in the preschool period, we will miss a critical opportunity to build a stronger foundation for a healthier and more productive adult population.”

From: National Scientific Council on the Developing Child (2020). Connecting the Brain to the Rest of the Body: Early Childhood Development and Lifelong Health Are Deeply Intertwined Working Paper No. 15



# Introduction

## Māui, our first baby born premature

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To tangata whenua, the first people of Aotearoa New Zealand, Māui was a daring demigod. His early days, weeks and years were a tale of amazing survival. One of the many stories about Māui tells that when his mother, Taranga was pregnant, her labour began too early.

When her tiny pēpē was born premature, she was very frightened and cast him into the sea, wrapped in her hair (see cover illustration).

He drifted, tangled in seaweed and carried by sea creatures, until he reached the shore. He was found, barely alive, on the beach by a tohunga, a special man. The tohunga wrapped the pēpē in a feather cloak and hung him in the rafters above the warmth of the fire. He loved and cared for Māui, teaching him about the ways of the fish, the birds and of people. When he was older, Māui returned home to Taranga, and his older brothers. His mother was overwhelmed to find him alive, and she welcomed him home and called him Māui-tikitiki-a-Taranga, Māui-formed-in-the-topknot-of-Taranga. The old stories tell us that Māui grew up to have great powers, but also that he was a trickster and a maker of

mischief. Out fishing with his brothers, it was Māui, who with his fishing hook pulled up the North Island, Te Ika a Māui, from the ocean and his waka became the South Island, Te Waka a Māui.<sup>3</sup>

For present day parents<sup>4</sup> of babies born premature, they will understand Taranga's fear. They may still be amazed by their infants' feats of survival. They may also notice their children's tendency towards mischief. This paper aims first to explore and interpret accessibly, the issues of risk and resilience for children and tamariki born premature today in Aotearoa New Zealand; next the evidence for intervention will be reviewed; and finally, recommendations for best practice in this country will be summarised.

As far as we know, there has been no recent review of the wide range of interdisciplinary evidence concerning prematurity and the implications for practice.

3 We acknowledge our former Champion Centre Kaiwhakapuawai, Huia Matariki Bracken for pointing out the relevance of this story. The text above is summarised from an adaptation by Wiremu Grace on [www.careers.govt.nz](http://www.careers.govt.nz). 4 We use the term 'parent' in this paper to include any primary caregiver of an infant or child, including mother, father, and foster/adoptive parents.

A typical pregnancy lasts 40 weeks. Premature birth is defined as a birth which occurs before 37 weeks' gestation. Latest New Zealand Manatū Hauora/Ministry of Health reports from 2018, show that a total of 7.5% of all infants were born preterm in New Zealand (4,414 babies) (2). Around 0.5% percent of babies were born at a gestational age of less than 28 weeks and 0.8% of babies were born at 28-32 weeks' gestation and 6.2% of babies were born at 32-36 weeks' gestation. Most infants born preterm were also born at a low birthweight (defined as less than 2500g by the World Health Organisation (4)). Low birthweight is also a risk factor for ongoing challenges.

The 2018 Manatū Hauora/Ministry of Health report states that there has been little change in the percentage of babies born preterm since 2008, although overall births in New Zealand have decreased over the last decade. The cost of health care services for infants born preterm is higher than their full-term peers and as gestational age at birth decreases, so health care costs increase (5).

## At-risk pregnancies

Babies born preterm are more likely to be born to women over 40 or under 20 years of age, to Māori, Indian and Pasifika women and to women experiencing social and economic deprivation. Twin and multiple birth pregnancies are less likely to reach full term. Maternal stress also increases the risk of prematurity (as a result of the effects of stress on the body's neuroendocrine and immune systems (6-9)). Rates of preterm delivery vary across New Zealand; in 2017 the highest rates of prematurity in New Zealand were in the South Island's West Coast DHB (9.3%), Mid Central (9.4%) and Tairāwhiti DHB (9.2%) on the North Island.

### Definition of preterm birth:

Babies born alive before 37 weeks of pregnancy are completed. Sub-categories of preterm birth, based on weeks of gestational age:

Extremely preterm (less than 28 weeks)

Very preterm (28 to less than 32 weeks)

Moderate to late preterm (32 to less than 37 weeks)

From Preterm Birth - World Health Organisation 2018

# Evidence from developmental science

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There is extensive research in the field of prematurity which examines the development of children and adults born premature. These studies come essentially to a similar conclusion, which is that

- children born premature (i.e. birth less than 37 weeks' gestation) are at risk of poorer outcomes
- the earlier in gestation an infant is born, the greater the risk of long-term challenges. Having said this, other factors occurring during the pregnancy for mother and/or baby can increase the risks for a baby born later in gestation (such as intra-uterine growth restriction, maternal sepsis, low liquor volumes).

Evidence suggests the long-term risks for children born premature include poorer physical health, atypical neurological and psychological development and adverse family/whānau dynamics and functioning.

New Zealand research teams, especially in Ōtautahi Christchurch and Tāmaki Makaurau Auckland, have contributed internationally to the understanding of the effects of prematurity.

The goal of this paper is to determine the most appropriate and practical strategies for intervention for children born premature across a broad range of contexts. It is beyond the scope of this paper to review fully the wide range of international research results published. Therefore, in discussing the science underpinning our understanding of prematurity, we have chosen to cite studies which have particular relevance to intervention strategies; where possible, we have highlighted Australasian research.

## What do we know about survivors of prematurity when they are adults?

Prematurity tends naturally to be associated with infancy and is thought by many, to need considering only when children are very young. However, there is now overwhelming evidence that this is not the case (10). The consequences of an early birth inarguably



continue into adulthood for around two thirds of individuals born earlier than 32 weeks gestational age (11). Darlow and colleagues (12) in an Ōtautahi Christchurch follow-up study of children born both very early and at very low birthweight in 1986 reported that as young adults (age 22-23 years), study participants were more often welfare dependant, had lower rates of tertiary education, had fewer friends and had more breathing difficulties than a comparison group of young adults born the same year. Further research has also suggested that adults born very preterm have other psychological challenges which include - tending to be risk-averse, less likely to be in a relationship and less likely to have children (11), have poorer attention skills (13-15), poorer cognition at 19 years (16), more mental health difficulties in adulthood (14, 17) and lower IQ (18). Higher rates of physical health problems have also been identified including - poorer brain myelination (19), premature ageing (20), brain differences (21), increased risk of chronic renal disease, hypertension and heart disease (22), respiratory problems and reduced insulin sensitivity (23), and endocrine/metabolic disease (24).

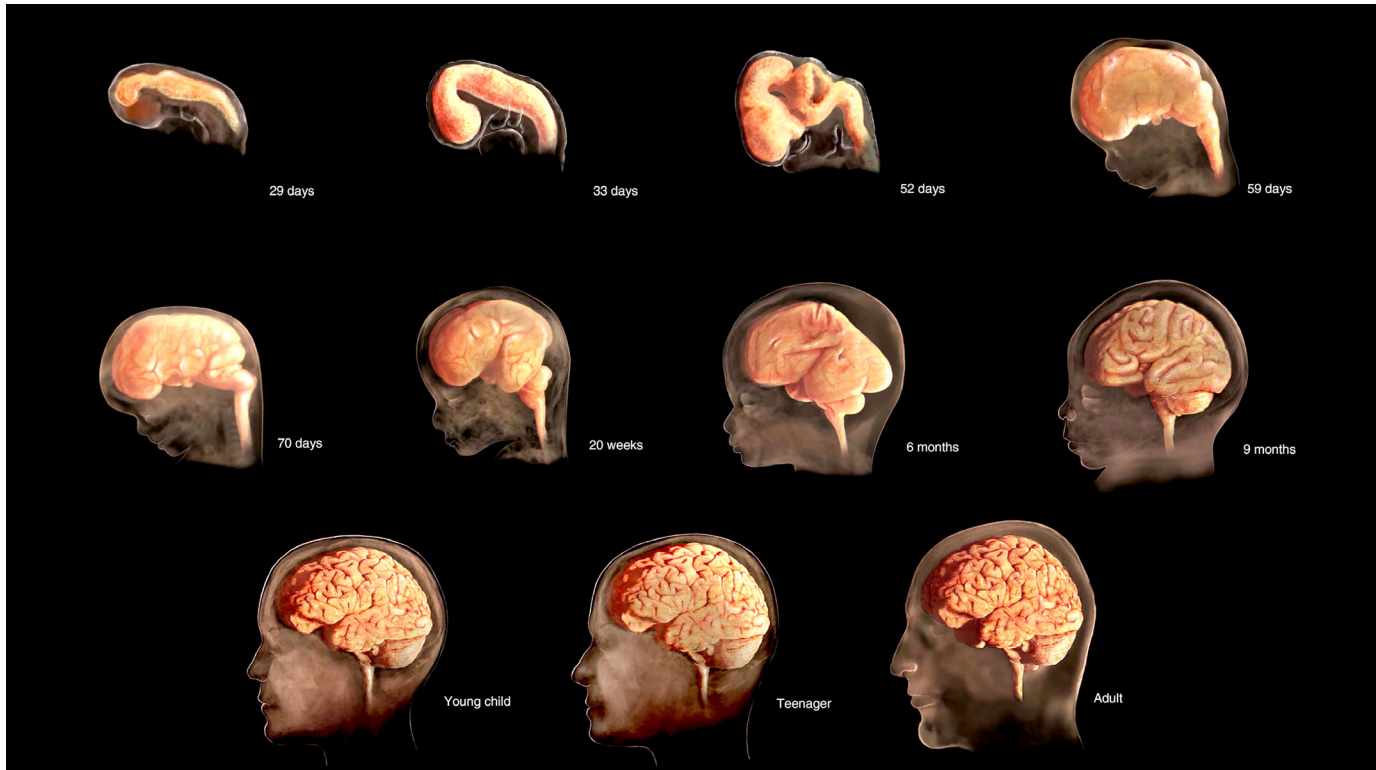
Perez and colleagues (25) interviewed adults who were born early and reported that eighty five percent of the individuals interviewed felt that their prematurity was still significant to them as adults and was not well understood by the professionals with whom they had contact as adults. Spiegler and colleagues (11) propose that prematurity may best be seen as a 'chronic condition', with a need for long-term follow up and awareness by professionals. Nevertheless, it is important to note that Spiegler and colleagues found that many adults who were born very early, are nevertheless performing well. Indeed, a Canadian survey also found that when asked, parents reported their preterm children were mostly well and healthy. Parents felt that paediatric tests and assessments failed to acknowledge the joy and wonder their preterm children brought to their family. This is valuable information, but it is also important to understand that there will nevertheless be challenges for some families and professionals need to listen carefully to parents' holistic view of the child.<sup>5</sup>

## Continuing Effects In Adulthood of Being Born Premature

- higher rates of welfare dependency
- lower rates of tertiary education
- fewer relationships
- fewer become parents
- poorer attention skills
- poorer cognitive skills/lower IQ
- poorer mental health
- poorer brain myelination & premature ageing
- poorer physical health, including cardiac and breathing difficulties

Examination of the early indicators that point children towards better or poorer long-term outcomes is required to plan for effective interventions. Addressing these risks early, may avert the high cost to the individual and to the state, for those born premature who do less well.

<sup>5</sup> <https://www.cpb-fbpc.org/post/parent-defined-outcomes-of-prematurity-exploring-the-results-of-the-second-phase-of-the-parent-voice>.



Images © StoryMD.com

At birth, infants born preterm are medically and physically very fragile. They will usually be admitted immediately to a hospital's Neonatal Intensive Care Unit (NICU) and may stay for several months. Survival rates for infants born premature have improved dramatically over recent years (3). Nevertheless in 2018, approximately 82% of foetal deaths and 63% of infant deaths registered, were preterm (less than 37 weeks' gestation), the majority of which were extremely preterm (less than 28 weeks' gestation); in total there were nearly 500 deaths in preterm babies under 12 months old in New Zealand in 2018 (26). The risks are greatest for those infants born at the lowest gestational ages. During their stay in NICU, babies born preterm are at risk of developing very serious and sometimes multiple medical problems including anaemia, breathing difficulties, infections or sepsis and intraventricular haemorrhage<sup>6</sup>.

## A common story

Nicholas\* was born in New Zealand by emergency caesarean section at 25 weeks weighing 475 grams. His parents report that in his first month of life he had chest compressions, collapsed lungs, 6 different ventilators, oscillators, hundreds of suctions from the lungs, heel sticks, excreting faeces from the stomach, 8 cm cut from the bowel, 30 blood transfusions, 4 kidney failures, a spinal tap. (\*Name changed. Data supplied by his family.)

These early weeks in a Neonatal Intensive Care Unit can be highly stressful for the infant. (Parent and staff stressors are discussed later). The NICU environment is busy and noisy; multiple and changing caregivers are involved with infants. Babies in NICU have been found to experience frequent 'complex, multi-sensory and painful stimuli' up to 70 times a day (27) whilst for some- or even much of the time, babies are deprived of the supportive presence of a parent (28). Indeed, some researchers now refer to the NICU period as being one of 'toxic stress' (29). As Als (30) points out, the womb is the biologically-intended environment for the foetus for nine months of development, rather than an incubator. Importantly the NICU period often coincides with a stage of considerable brain and organ growth, as well as developmental changes for the baby. Medical science is as yet unable to recreate the ideal conditions for foetal growth outside the womb and this, together with stressors experienced in NICU, can have a negative impact on brain development for babies.

Science is developing an increasingly complex understanding of early infant behaviour. There is evidence that early stress may permanently alter brain structure and function (31-33).

The implications of very early environments and relationships are now considered key building blocks for later development (34); being born premature, adds further complexity to an already complicated picture. From an evolutionary point of view, an infant born full-term is ready to receive caregiving behaviours which support and manage his or her brain and body arousal. This helps with regulation and soothability. For full-term infants, positive caregiving supports the infant's hormonal balance of cortisol and oxytocin. For a baby born preterm, this hormonal balance is disrupted and the endocrine system is immature (35). This has the effect that during the early

weeks and months, the brain of a baby born preterm is not mature enough to receive or use the soothing behaviours in which a parent naturally begins to engage with their newborn. As a result, the brain of the infant born preterm has an increased risk of difficulty with self-regulation (36). At this very early stage, the close association between the child's body and the brain are seen most clearly.

## Self-regulation and executive function skills

Self-regulation refers to the individual's ability to maintain a steady and balanced emotional, physiological or attentional state. In babies, challenges with self-regulation may lead to sleeping, feeding and interactional difficulties. As the infant brain develops, self-regulatory abilities are at the core of developing executive function skills. These underlie the individual's ability to control and regulate impulses, work towards a goal, maintain focus and attention and operate working memory. The building blocks of these skills are laid both before birth and during the first few years of life, within the co-regulatory behaviours of first relationships. The parenting context of this development will be explored later. Good self-regulation and then executive function skills are crucial to positive long-term outcomes.



Challenges with regulation can negatively affect feeding, sleeping, emotional states and interactions (36, 37). High rates of difficulties in the infant's ability to process sensory stimuli have been identified and these difficulties are associated with later behavioural challenges (38). (As will be explored later in the parenting section, each baby's responses occur in the context of parent/child interaction, and this very much influences the degree of difficulty that an infant will experience).

*If we attend only to the early medical fragility of premature infants, then we may fail to address their psychological fragility.*

## Follow-up after leaving NICU

On leaving the neonatal intensive care unit, plans are made by professionals and families about the need for further monitoring of the baby's health and development. Most babies will be seen again by their neonatologist and medical health problems will continue to be monitored and attended to by health care staff once babies are home. On discharge from NICU, it can be difficult to determine what the developmental challenges might be for babies born preterm. According to Msall and colleagues (39) around 50% of children born before 28 weeks have special health care needs and around 20% have major developmental disorders. Particular care and attention at follow-up may be afforded to those babies born earliest. However, even those children born only moderately or late preterm i.e. those children born 32-36 weeks are at some continued risk, compared to full-term children (40, 41). The Australian & New Zealand Neonatal Network (ANZNN) has published follow-up data from 2019 for nearly 5,000 babies born earlier than 28 weeks gestational age or less than 1,000g birthweight in Australia and New Zealand

(42). The data indicated that around 15% of these infants had moderate to severe developmental difficulties by age 2-3 years. This was defined by the ANZNN as children having been found on assessment to have moderate to severe cerebral palsy, hearing impairment requiring amplification, visual impairment, moderate to severe language, cognitive or motor delay. Infants who are at risk of developing serious disabilities can often be identified before they have been discharged home from NICU. These children will usually be referred for developmental follow-up and early intervention. A clearer picture of the child's difficulties will become more evident over the first few years. At school in New Zealand, most children with significant disabilities will qualify for individualised extra support through the Ministry of Education.

However, many infants born preterm appear well on discharge home from NICU. The medical and developmental consequences of a premature birth may only become apparent over time. Strong evidence suggests that even though appearing well in early infancy, the brains of infants born preterm are different from those of their full-term peers. Furthermore, these neurological differences can have long-term effects on the individual and whilst not severely disabling, may still have a significant negative impact throughout childhood and into adulthood. These children will need careful follow-up and as we shall explore later, may benefit from preventative early intervention. These risks increase the earlier children are born.

*Evidence suggests that whilst survival rates for extremely preterm babies improved in the last two decades, rates of neurological impairments at age 11 years have remained stable (43, 44). Preterm children are nearly three times more likely to need special education (45).*

## Early childhood

As babies grow into toddlers and pre-schoolers, evidence suggests that there is still a linear relationship between gestational age at birth and later outcomes. Research has found that in their preschool years children born preterm score less well than their full-term peers on a number of different measures, including cognition (46, 47), social competence (47, 48), language and communication skills (49) and motor coordination (50). The risk of poor general health, hospital admissions and illness also rises with increasing prematurity (51). However, children born at later gestational ages (i.e. between 32 and around 37 to 38 weeks gestational age) may be regarded as low risk but cannot necessarily be assumed to be no risk (52, 53).

In considering developmental progress at this stage, it is important to note that the skills children learn are all developmentally interrelated. During this sensorimotor period (0-2 years), the infant's motor system, for example, underlies all important developmental opportunities for engagement with social partners and objects, from which cognition and language, and social understanding develops. Poorer fine motor skills in babies born preterm at corrected age 6 months were found to be associated with poorer assessed communication skills at 12 months, showing the cascading effects of delays in one area on other areas of development (54). So, what may look like a child at 12 months of age with delayed communication skills, may on deeper investigation reveal other underlying challenges which also need to be addressed.

The dysregulation of feeding, sleeping and emotional states observed in infancy, changes in nature as children grow. Sensory, emotional and behavioural dysregulation continues in new ways to impact many toddlers and pre-schoolers who were born premature.

Sleep difficulties have been found to be more common in children born premature even up to 11 years of age (55). A Christchurch longitudinal study found that emotional or behavioural adjustment problems were shown by 37% of extremely preterm children and 13% of very preterm children compared to 11% of full-term comparison children (46).

**Early self-regulatory difficulties, when assessed at 20 months were shown to predict increased risk for later attentional and academic problems assessed at 8 years (56).**

In recent years, researchers have proposed a link between early dysregulation and learning delays in children born premature with challenges in executive function skills (57, 58). Executive functioning refers to the mental processes that enable the regulation of emotions, as well as planning, the ability to focus attention, remember instructions, and juggle multiple tasks successfully<sup>7</sup>. The maturation of the brain's prefrontal cortex is crucial to the development of executive function skills. These areas are the last to develop and therefore may be most readily affected by a preterm delivery. Executive function and self-regulation skills depend on three types of brain function: working memory, mental flexibility, and self-control which are highly interrelated, and successful demonstration of executive function skills requires them to operate in coordination with each other (59). Researchers propose that an early birth and the early weeks spent outside of the uterus impacts the development of these skills. The development of skills in paying attention and applying focus seem to be highly associated with executive functioning. Attentional deficits and hyperactivity are widely reported to be another area of significant difficulty for children born early and may well underlie problems reported in other areas of functioning (60). If children cannot pay attention, remember instructions or regulate their emotional states adequately, it is likely that children's performance on standardised

<sup>7</sup> An excellent introduction to the concept of Executive Functioning can be found on this Harvard University website

<https://developingchild.harvard.edu/resource/tag/executive-function/>

tests of skills including cognition, language

and motor skills may well be impacted. Indeed, executive functioning is regarded as a crucial driver for a range of later challenges, including language, cognition and pro-social behaviour. Schnider and colleagues (58) suggest that difficulties with executive function skills partly explain the higher rates of behavioural challenges reported in children born early. Difficulties with executive functioning will impair children's learning in school or at home and negatively affect their behaviour. The fundamental importance of good self-regulation skills and their association with long-term positive outcomes for children is supported by data from the Dunedin Multidisciplinary Health and Development Study (61). In children born preterm, if self-regulation skills are impaired, then many aspects of their future development; their learning; their functioning in society, relationships, mental health and so on, may be at risk. The crucial importance of good executive function skill development in minimizing intergenerational disadvantage is further supported by a Koi Tū: The Centre for Informed Futures evidence briefing (2021) (62).

Throughout early childhood, self-regulation skills are developing, determined in part by the infant brain, but are influenced for better or worse by caregiving relationships (63, 64).

## The school years

As children born premature grow towards later childhood and adolescence, evidence suggests a continuity in the challenges facing them at school age. These, in turn, lead eventually to the difficulties that adults face, described above. Ongoing difficulties in the school years are reported for: -

- academic achievement (65, 66)
- fine motor skills (67)
- school readiness (68)
- mathematics (69)
- inattention (70, 71)
- executive function problems (58, 70)
- multiple domains (46, 72, 73).

Twilhaar and colleagues highlight the importance of cognitive difficulties, which for children born very or extremely preterm may affect as many as 70%. These cognitive challenges may have far-reaching consequences for an individual's life chances, academic and socioeconomic success (45). Authors have also reported that difficulties tend to persist (74, 75) and suggest that therefore early assessments can be helpful identifying children at risk. Wolke, Johnson and Mendonça (76) note that for preterm children,

**“Substantial deficits in achievement are still evident at the end of compulsory schooling”.**

A number of studies have also identified increased risks in a range of social and emotional difficulties for children born preterm including

- friendship difficulties (77)
- behavioural and emotional problems (78-80),
- anxiety disorders (81),
- poorer self-concept (82)
- poorer quality of life (83).
- bullying (84)

A recent review (85) describes a preterm 'behavioural phenotype', suggesting children born preterm may frequently present with characteristics of ADHD, autism spectrum disorder and anxiety. The authors suggest that if these symptoms are better understood and are recognised early, then interventions can



be targeted more successfully. Bullying has been increasingly recognised as a problem for children born preterm. Research suggests that preterm children are more than three times as likely to report bullying in school than their full-term peers (84, 86). This has been reported by research teams in the USA, Norway, Canada, Germany and the UK (84). The social, emotional, and executive functioning challenges for children born preterm may well make managing peer relationships more difficult. Furthermore, children born preterm often grow up to be smaller and lighter than their peers (12, 87). This may be another factor leading to increased targeting by bullies. Bullying, especially chronic bullying, was found to predict high rates of emotional problems, including anxiety and depression in preterm adolescents (84).

Development in infancy and early childhood provides the building blocks for continuing progress in learning throughout the school years.

## The parenting context

Alongside the development of babies and children, parents too are growing into their roles as parents of a child or children born premature. As seen above, even before the premature birth or even conception occurs, epidemiological data (2) suggests that pregnant women who experience a range of challenges, including stress and social deprivation, are more likely to have a premature birth. Substance use and early teenage pregnancy are also risk factors. The higher rate of twin or other multiple pregnancies which do not progress to full term also increases the risk of possible loss of a foetus for some women during the pregnancy. For some parents, a premature birth may come after difficulty conceiving and sometimes lengthy and arduous treatment for fertility problems. This suggests that before

the birth, there is a greater likelihood that the mothers of premature babies may be more vulnerable.

The early delivery of an infant may engender fear and sometimes trauma in parents. Many parents will be unprepared and may well be unfamiliar with the appearance of a preterm infant. The NICU environment, its people, its language, its technology can be overwhelming and anxiety provoking.

*In the first few months, parents have to manage both the worry of having a baby whom they may have thought would not survive, followed closely by the challenge of trying to engage with a new baby in an environment which they may find alien.*

As we have seen, the baby born preterm may well be 'hard to reach' both physically and psychologically. The brains of babies born preterm, unlike full-term infants, are not ready to respond to the soothing behaviours which parents typically use to engage with their full-term newborns. This may undermine from the outset the positive development of a 'sensitive or attuned' relationship – that is a relationship in which both partners are responsive to each other (see box page 22). For parents, learning how to use 'preterm appropriate' soothing and care takes time. In addition, parents bring with them their own capabilities, mental well-being, attitudes, cultural norms and belief systems which will have varying impacts on their relationship with their infant (88). For some parents, working alongside experienced and efficient health care professionals on NICU may feel disempowering. Though not an issue specific to premature infants, the current phenomenon of pervasive cell phone use is another barrier to developing responsive dyadic interactions (89, 90).

*In general, parents of premature infants as a group have a greater risk of coming into parenthood with health, social, psychological and economic vulnerabilities.*

## Loss of parental role

Woodward and colleagues (91) examined experiences of Ōtautahi Christchurch mothers with babies born preterm in NICU. They reported that mothers found the most stressful aspect of having a baby in NICU was losing their maternal role, followed closely by worries about being separated from their infants and not being able to protect them. The authors note that pregnancy is a time of growing attachment between baby and parent, and this is cut short by a preterm delivery resulting often in shock, grief and worry.

Women may be at work one day and go into premature labour the next, with little time to prepare for the new role.

Emma\* says...I really wanted to put her back in my tummy and she looked so small and I felt really guilty. I felt like I hadn't done what I was supposed to do as a mum. I hadn't kept her safe in there. It hadn't been a good place to grow in there, because she obviously had to come out. (\* Name changed)

Studies have shown that mothers and fathers of babies in NICU report high rates of clinical symptoms of depression and anxiety (15, 92-94). Young parents were found to be particularly at risk of stress in NICU (95)

Research has found that the children of mothers who have mental health problems during the early postnatal period, are more likely to have emotional and behavioural

problems during childhood (15, 96).

Contrary to expectations, mothers have not been found to be more stressed if their babies were especially sick or small, but rather parents tended to be more stressed, if their baby was unsettled and dysregulated (91)

Dysregulation might make infants more difficult for mothers to engage with.

Thus, healthy relationships are the result of complex bio-psychosocial interactions and early hospitalisation may disrupt optimal development of the relationship process.

As noted above, parents living in adverse social and economic circumstances are more likely to have a baby born early, but they are also more likely to find the NICU experience stressful as well (97). There may be economic barriers to travelling and staying with their baby or caring for older children; educational or language difficulties in understanding the process or relating to staff. For parents from New Zealand's rural areas, the stress of managing a baby a long way from home will be an additional burden. As seen above, parents on the South Island's West Coast and the North Island's MidCentral district and the Tairāwhiti coast are most likely to have premature babies, all areas with high numbers of remote and rural communities. Mothers who are Māori are most likely of all ethnic groups to have babies born premature. Inequities in healthcare for Māori are well-documented (98). Racism and discrimination are reported across health care settings in New Zealand and maternity services will not be exempt (99).<sup>8</sup> Whānau Māori are also more likely to experience social and economic hardship.

<sup>8</sup> Recently published guidance on anti-racism from Manatū Hauora/ Ministry of Health can be found at- <https://www.health.govt.nz/publication/position-statement-and-working-definitions-racism-and-anti-racism-health-system-aotearoa-new-zealand>

## Double jeopardy

A combination of stresses for vulnerable parents may begin a process of an increasingly downward spiral for families from the most at-risk sectors of the community.

Research showing the clear association between an increased number of adverse childhood events (ACEs) and poor health, education and social outcomes is well-documented (100).

Some babies who are born premature will therefore be exposed to a 'double jeopardy' of insult to their brains from their early birth, as well as adverse influences from the family/whānau environment in which they are growing up (16, 79, 101). For babies, who are both very premature and are also discharged from NICU into disadvantaged family/whānau environments, the risks are very significant. There is some evidence that a preterm birth can put infants at greater risk of non-accidental injury (102). Certainly, children with disabilities have been shown to be at higher risk of non-accidental injury (103). Furthermore, having a child who has a disability or who is preterm will further compound the economic hardship facing the family/whānau (104). Socio-economic risks tend to cluster, and the effects of social adversity are often multi-faceted. Mainstream studies have found parenting difficulties to be associated with social disadvantage (105). The transition home from the specialised and high-tech neonatal intensive care unit environment, where intervention and advice is provided 24 hours a day, can be difficult.

A number of studies have examined the relationship between prematurity and parenting. Recently, Treyvaud and colleagues (106) have suggested that sensitive (see box) parenting in toddlerhood is associated with

positive changes in brain structure and growth which was found using magnetic resonance

## Sensitive parenting

Sensitive interactions are defined as those in which the adult responds appropriately to an initial communication from the infant or child. The Centre on the Developing Child uses the metaphor of a tennis match ('Serve and Return') to explain this. In a sensitive interaction, the baby makes an initial 'serve' (i.e. a communication of some sort), which the parent 'returns' by responding, then the baby might again communicate a reply, and the parent responds in return. In this way, it is seen that the baby or child takes the lead in a back-and-forth series of 'sensitive' communications. These positive interactions may also be referred to as 'attuned' or 'responsive'. On the other hand, parent/child relationships where interactions are largely parent-led have been found to be more often associated with less positive long-term outcomes. The term 'insensitive or intrusive' may be used for these adult-led interactions. Further information and videos can be found at <https://developingchild.harvard.edu/science/key-concepts/serve-and-return/>

imaging scans at age 7 years. Sensitive, attuned parenting has been found by a number of studies to be related to preschool children who were born premature, having more secure attachments, more self-control, fewer behaviour problems, better language and cognitive development (76, 107-109). On the other hand, other studies have found that children who were born very premature were negatively affected by parenting which was insensitive (110). We acknowledge that principles of sensitive parenting are derived from attachment theory which has largely been developed by western researchers from societies where nuclear families are the norm. There is little equivalent research from collectivist societies, where child care may be more communally organised. In this light, knowledge is lacking around what may be best for infants/pēpē from Māori and Pasifika families, and also for the children of migrants to Aotearoa New Zealand.

## Bi-directional influence

On a positive note, Wolke and colleagues reported that mothers of children who were very preterm were as likely to parent as sensitively as mothers of full-term infants; nevertheless, babies born preterm who were

dysregulated or delayed were found to be more likely to have poorer attachments with parents (111). A third of children born very preterm showed these poorer attachment patterns despite sensitive parenting.

**Wolke and colleagues suggest premature infants are prone to a cluster of social relationship problems, neurodevelopmental in nature, which put them at long-term risk.**

This suggests that the effects of prematurity may be bi-directional; that is babies born preterm may have developmental challenges which negatively influence the style of parenting they receive. Parents may develop an adaptive response to the infant's interactions, which could in fact be maladaptive (106). It appears that premature body and brain systems can lead to infants being dysregulated and difficult to engage, which particularly when combined with stressed or dysregulated parenting, may lead to long-term challenges for children and their families.

**The contributions of both baby and parent need to be considered and a dyadic understanding of the parent/baby context is key. Sensitive and responsive interactions from parents give infants the best possible chance of more positive long-term outcomes.**



## So what does the science mean?

During the course of pregnancy, the growth of the baby in the womb is influenced positively or negatively by a range of factors. These processes set the infant within each family or whānau context on a unique developmental track. A premature birth, rather than a full-term birth, appears to more often negatively prime the infant. The neonate begins life with a mismatch between the environment he or she needs (i.e. a uterine environment) and the environment he or she receives in the external world. This external environment does not provide the infant with the ideal conditions for continued organ and brain growth. It also challenges the baby's ability to cope with arousal and accept soothing from caregivers. The long-term consequence of this has effects for those born premature, their parents and the dyadic relationship between them. For the individual born preterm, the effects can be lifelong and may affect their health and mental health, learning and relationships; for parents, there may be effects on mental health, with developing a confident parental role and on whānau income. Research suggests that sensitive, responsive parenting is associated with positive outcomes for children. Resilience is built on positive early relational experiences. Sensitive early relationships can provide an adaptive organising framework for the way children grow up experiencing the world. On the other hand, family dysfunction and additional adverse childhood events, especially trauma, will negatively affect the life course for children born premature. Relationships, where infants are dysregulated and parents are insensitive or unresponsive, put children at significant risk.

The implications of the New Zealand and international evidence have not been widely and consistently applied to practice and policy and funding decisions in this country.

Theory to practice:

# Intervention for babies and children born premature and their caregivers.

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Around the world, intervention programmes have sought to mitigate the impact of prematurity on children. These programmes address the needs of children and/or their families at varying developmental stages. Guralnick (112-114), a leader in this field of research, promotes the case for intervening early.

Guralnick suggests that early childhood provides a ‘unique window of opportunity to alter children’s developmental trajectories, with the potential to generate long-term benefits in many aspects of an individual’s quality of life’, (114).

This aligns very well with the First Thousand Days programme of Te Hīringa Hauora, New Zealand’s Health Promotion Agency<sup>9</sup>. The programme focuses on the importance of early relationships and infant wellbeing. Many intervention programmes for individuals born premature have been trialled with babies and young children.

## NICU services – philosophy, practice and resources

Many neonatal intensive care units (NICU), both in New Zealand and overseas, are considering ways to engage families in the care of their newborns, support parent-infant bonding, support parent and infant mental health and implement strategies to reduce adverse sensory stimulation for babies. Models of family-centred care and ‘developmental supportive care’ have been proposed widely (28, 115). The Newborn Individualised Developmental Care and Assessment Program (NIDCAP) was at the forefront of changes in the 1970s<sup>10</sup>. Als and colleagues (116) showed multiple improved outcomes for neonates cared for under the NIDCAP system including shorter NICU stays, improved feeding, weight gain and longer-term development. Family-centred care seeks to actively involve the participation of parents in the infant’s care. ‘Developmental’ or sometimes ‘Neurodevelopmental’ care

<sup>9</sup> <https://www.hpa.org.nz/programme/first-1-000-days>

<sup>10</sup> <https://nidcap.org/en/about-us/nfi/mission/>

(for example the Developmental Supportive Care model proposed by Altimier (117)) focuses NICU care on the developmental needs of the infant, trying to minimise toxic stress by, for example, the clustering of care activities to reduce the adverse effects of handling experienced by babies and increasing the number of positive touch experiences. The model also seeks to support all sensory systems of the baby, by considering the handling of the baby, as well as positioning, protecting skin and safeguarding sleep and so on. This approach also involves whānau in helping to buffer against stress responses in the baby, by using skin-to-skin care for example. There is therefore significant overlap in family-centred care and developmental care.

Studies have noted that implementing hospital practices known to improve outcomes for infants and parents in NICU is complex and uptake of new methods by staff can be variable (118, 119).

On the South Island, services in Christchurch and Dunedin are actively working to introduce Family Integrated Care<sup>11</sup>. The model is a 'whole system' approach to NICU care, designed to engage whānau in real partnership with the team and empower parents to feel confident and comfortable in the care of their infant. However, adopting new approaches in existing systems can be challenging (120). In Auckland, a 2018 survey reported that NICU parents continued to feel disempowered during their infant's NICU stay and progress was still needed in the implementation of family-centred care (121). The New Zealand Manatū Hauora/Ministry of Health commissioned Malatest International to review neonatal care (122). Their report concludes that "all levels of NICU consistently operated at above resourced capacity in the 2012-2017 time period" (page 5) and notes that a high proportion of the workforce felt

they were overworked. Fourteen percent of staff questioned stated that the development of family integrated care was a priority for the sector and 12% of staff surveyed believed that developmental care was a priority (page 65). It is possible that when staff are rushed and over-worked, aspects of care including support for infant sensory systems or talking to families may be compromised.

Nurse behaviour was observed in a New Zealand NICU and data suggested that nurses engaged in less vocal soothing with infants during painful procedures than during routine nappy changes (123). The research team suggest that maintaining sensitive interactions with the baby during a painful procedure is difficult when the nurse may be already stressed. Funding for professionals with expertise in parent and infant well-being and relationships is often lacking in New Zealand NICU services. In Auckland, researchers, Penny and colleagues found that when a psychiatric consult team was available to mothers of infants in NICU, 69% of mothers were referred to the team with 29% of mothers requiring continued follow-up after discharge (124). These studies suggest high levels of stress amongst NICU parents and NICU staff and indicate a need for greater support. Best practice guidelines suggest 'mental health specialists should also be an integral component of the transdisciplinary team' in NICU services (124). Their absence suggests that supporting early dyadic relationships may not be prioritised in budgeting for New Zealand services.

A 2021 national survey by the Infant Mental Health Association of Aotearoa New Zealand showed that perinatal mental health and infant mental services are not available in all areas and are significantly under-resourced across New Zealand.

11 <http://familyintegratedcare.com/about-ficare/>

Treyvaud and colleagues (125) recommend that best practice in NICU services should involve a multi-layered approach to parent support which includes having specialist psychologists and/or psychiatrists who can both work with parents when needed, but who can also work with staff, so that they can better support whānau. The U.S. National Perinatal Association has facilitated a National Network of NICU Psychologists (NNNP), who propose that psychology services should be integrated into all NICU services<sup>12</sup>. In Canterbury, a new service offering group Eye Movement and Desensitization Reprocessing (EMDR) therapy for parents who have experienced a traumatic birth is a positive development but is available to very few<sup>10</sup>. Talking to parents about the effects of prematurity on their infant is a complex issue in itself; research has reported that what is important to professionals may not be the same as what is useful information for parents (126, 127).

**Hussey-Gardner and colleagues point out that developmental interventions in NICU have the potential to offer ‘inexpensive, effective and feasible’ approaches to improving long-term outcomes for preterm infants (128).**

Other than the ‘whole systems’ approaches of developmental and/or family-integrated care, specific add-on programmes have also been trialled and evaluated, including using music (129), infant massage (130), sensory enhancement (131-133), pain management (134), maternal voice (135) and providing single family rooms (136). NICU parenting programmes have included Triple P for parents of preterm infants (137), a Family Nurture Intervention programme (138) and parent-to-parent support (139). A 2018 review (140) of the effectiveness of NICU interventions around the world concluded that Skin to Skin contact (141) (sometimes called Kangaroo Care) showed the most frequent positive impact on infant and parent outcomes. The use of the Newborn Behavioral Observations (NBO)<sup>13</sup> system is

being introduced at several sites across New Zealand to help strengthen and increase sensitivity in the parent/infant relationships during the newborn period. Informal feedback suggests it is well regarded by professionals who have trained in its use, but research evidence confirming its benefits is limited as yet (142).

## Transition to community-based care

Community-based follow-up services have been found to be slow to engage with families once they leave hospital (131). Research has noted that parents may not understand why follow up may be needed (126)<sup>14</sup>. The U.S. National Perinatal Association is developing guidelines for comprehensive discharge planning (144). As noted above, especially when infants are returning home to very disadvantaged environments, a discharge plan which considers the needs of both children and whānau is important. Pineda and colleagues have trialled a pilot ‘Baby Bridge’ programme in St Louis, Missouri to strengthen links between NICU and community follow-up (132, 145). The Baby Bridge pilot programme was well-received by parents and staff. The follow-up therapist visited families in hospital before discharge, both teams collaborated on a single therapeutic approach and decreased time between discharge and community follow-up.

**The transition between NICU and follow-up care is also an important time for whānau.**

Improving hospital services to be more accessible for Māori is currently on the agenda for the government. Changes to the management of health services in Aotearoa New Zealand were introduced in July 2022 with the establishment of Te Aka Whai Ora/ Māori Health Authority. The new body aims to improve health outcomes for Māori and

12 <https://www.nationalperinatal.org/psychologists> 10 <http://resiliencepsychologychristchurch.com/emdr/> 13 <https://www.newbornbehaviorinternational.org>

14 The Champion Centre has developed two booklets to smooth this process - “Understanding Your Baby” and “Prematurity and Your Infant’s Learning” freely available to parents through the Champion Centre website.



embed the principles of Te Tiriti o Waitangi. Iwi-Māori partnership boards will be involved in decision making. It is hoped that this new partnership can address inequities in care, design and improve services to use more holistic kaupapa Māori models of care. The issue of taking time and care to communicate with parents is even more important when there are cultural or language differences between parent and professional.<sup>15</sup>

## Follow-up in Early Childhood

Comprehensive medical follow-up is crucial and is required to address the long-term medical challenges for children and adults born early, reviewed above. Developmental follow-up after NICU and into early childhood for children born premature has also been recommended in a number of regions around the world. The UK's National Institute for Health and Care Excellence (NICE) recommended in 2017 follow up until 2 years for all children born at less than 30 weeks gestational age and children

born 30-36 weeks who have further risks. It also recommends assessment at 4 years for children born at less than 28 weeks gestational age with results being shared with education providers, if needed (146). In Europe, the European Foundation for the Care of Newborn Infants (EFCNI) (147) recommends follow-up care for those born less than 32 weeks gestational age and also for those born later than 32 weeks, if they have other risks. Reymundo and colleagues note that services also need to be alert to the possible follow-up needs of children born late preterm (148). EFNCI point out that follow-up should be structured and coordinated to start in NICU and then support families through the transition process from hospital to home and into continuing care through early childhood. Both NICE and EFCNI note that follow-up should be multi-disciplinary, with EFCNI stating that care should shift focus 'from medical, including feeding and growth, to psychological development and educational issues such as behaviour and emotions interactions with peers and siblings as well as schooling and transition to school'.

## International recommendations for follow-up of infants born premature

<b>UK NICE</b>	Until 2 years for all children born less than 30 weeks. Follow-up to 4 years for all children born less than 28 weeks. Liaison with education providers.
<b>European EFCNI</b>	Until school age for all children born less than 32 weeks and any others with additional risks. Liaison with education providers. Multidisciplinary follow-up is recommended with attention to psychological, emotional
<b>USA Division for Early Childhood</b>	Early intervention should be provided to all children born less than 37 weeks or less than 1500g.

15 The following reports highlight the importance of equity in addressing perinatal mental health support in New Zealand. Holly Walker's report *Āhurutia Te Rito | It takes a village* can be found here: <https://helenclark.foundation/publications-and-media/ahurutia-te-rito-it-takes-a-village/>. Kelly Feng co-authored: *Supporting Equitable Perinatal Mental Health Outcomes for Asian Women*: <https://www.asianfamilyservices.nz/resources/resource-items/supporting-equitable-perinatal-mental-health-outcomes-for-asian-women-20200615/>. Jacinta Fa'alili-Fidow co-authored *Equitable Perinatal Mental Health Outcomes for Pacific Women*: <https://www.moanaresearch.co.nz/equitable-perinatal-mental-health-outcomes-for-pacific-women/>

Recent research suggests that though there are wide variations from country to country, on average the development of 30% of European infants is followed up to age four years (149). Van Beek et al concluded from their longitudinal research that follow-up to school age is 'essential' (101). A position statement by the Division for Early Childhood in the USA (150) states that all children born less than 37 weeks and/or children born less than or equal to 1500g should be considered for early intervention services, even if no 'full-blown delays or functional deficits' are evident. The evidence for delays and difficulties in a significant number of this group of children, they argue, is adequate to justify preventative intervention for all premature children.

Wallois and colleagues (151) also point out that cognitive and executive function difficulties, which are the most common difficulties for preterm children, cannot accurately be diagnosed until the late preschool, if not the school age period. A paper by Doyle and colleagues (152) based on a workshop held in 2011 in Melbourne for New Zealand and Australian health professionals and parents of infants born premature concluded that follow-up beyond two years should be based on circumstances, including the development of the child, but also based on the report of parents, as well as an assessment of family or whānau functioning. Even so, they suggest that many problems occurring at school age will be missed and that children will be failing in school before action is taken.

In New Zealand, ongoing follow-up for children born premature has been routinely offered by many paediatric, child development services and in some cases, NGOs. In 2018, Gledhill and colleagues (153) surveyed 24 paediatricians (100% of New Zealand hospital services were represented by respondents) and 17 child development services (85% of DHB services

responded). All services provided some follow-up care for children born at less than 32 weeks gestational age until two years of age, but 44% respondents added that they were unable, due to funding constraints, to provide desired levels of care'. New practice recommendations for New Zealand have been developed by the Paediatric Society of New Zealand/NZ Newborn Clinical Network (Practice Recommendations for 2 year follow-up of infants, at high risk of developmental disability, 2022). These will be available on the website of Starship Hospital. The NZ Cerebral Palsy Network has also published new guidelines. The new guidelines stress the need for services to be available nationally to children born preterm and their families. The guidelines also highlight the need for culturally-sensitive care and care which pays attention to family relationships as well as early growth and development. However, the recommendations propose that in general, routine developmental checks (e.g. B4School check at 4 years), primary care, early education and parents will be relied upon for noticing and addressing any follow-up needs for children beyond two years corrected age. If primary care and education providers are to provide this safety net, it highlights the need for further training and dissemination of information about prematurity for these services, as well as adequate funding for the training and service provision.

**A NZ survey reported that there is disparity in the care received by preterm children across New Zealand. Most children are not followed-up after two years. In New Zealand most moderate or late preterm children are not followed up.**

In New Zealand all children born premature will be seen in the community by primary care services and tamariki ora/well-child services, including Plunket, Tamariki Ora and Pasifka well-child providers and general practitioners. A review of New Zealand's Well Child Tamariki

Ora (WCTO) programme has recently been released online (154). The report identifies preterm birth as a risk factor for neurodevelopmental disorder but does not propose that children born preterm should be a top screening priority.

The report nevertheless confirms the need for early identification of developmental and behavioural difficulties and notes that 4 years of age when the national B4 School Check takes place is too late for intervention programmes to have the best chance of success.

## Well-child and Tamariki Ora Services

Knowledge in universal Well Child Tamariki Ora services about the developmental risks relevant to children born premature is not believed to be widespread. Over recent years, in Canterbury, the Plunket Parent and Infant Relationship Services (PPAIRS) has developed an intensive home-based programme for infants born preterm.<sup>16</sup> The programme focuses on the complexities of preterm cues, behaviour and infant states and seeks to support caregiver sensitivity and responsiveness to each infant's unique verbal and non-verbal communication. The PPAIRS team are of the view that it is vital that primary care providers are able to make assessments of the dyad, not just of the infant or parent. The review of the Well Child Tamariki Ora (WCTO) programme also notes that universal services need radical change to be adequately responsive to whānau Māori and Pasifika parents, who are more likely to have children born preterm (155). Smith notes that true kaupapa Māori services would provide a holistic support for whānau Māori, supporting emotional well-being for pēpi/tamariki and the whole whānau. Smith contrasts this with typical western concepts of health and wellbeing, where the focus tends

to be on physical health and growth. In this respect, it would appear that a kaupapa Māori service, as described, is better aligned with best evidence-based practice for tamariki born preterm than the traditional health care services offered and is an approach which would benefit all children requiring follow-up.

## Early childhood education

Many children will also come into contact with generic early childhood education services in their first few years. Liberty (156) points out, there is an increasing need in the early childhood education sector for resources and supports for children with early intervention needs, especially for tamariki Māori. She argues for greater integration of cross-sector services and national coordination. Transition to child care can be stressful for preschool children (157). Babies born preterm, who may have extra needs particularly with regard to self-regulation challenges, may need more individual support than full-term babies and they may find the noise and 'busy-ness' of a group care situation more stressful. As such, very early admission to group day-care for babies born preterm may be problematic. Furthermore, the risks from exposure to illnesses spread by other children, can also cause more problems for infants born preterm than other more robust babies. At-home care with a home-based carer may reduce some of the potential problems for babies born preterm. An online article by the Brainwave Trust NZ reviews the literature around childcare choices.<sup>17</sup> The Brainwave report suggests that centre-based early education becomes arguably more beneficial for children from around three years of age. For mothers with babies who wish to, or who are required to return to work by Work and Income New Zealand (WINZ), finding appropriate childcare for infants born preterm can pose challenges.

<sup>16</sup> <https://www.plunket.org.nz/plunket-near-me/christchurch-plunket-family-centre/plunket-parent-and-infant-relationship-service-ppairs/> <sup>17</sup> <https://brainwave.org.nz/article/our-literature-search-into-childcare-how-are-the-children-doing/>

## Early Intervention

It is clear that while ongoing monitoring is clearly indicated for children born very or extremely preterm, more importantly, targeted intervention is required for many children in this group.

As we have seen above, there is evidence supporting preventative intervention for children born preterm and their whānau starting in infancy. Evaluated preventative intervention studies have shown positive long-term effects on the cognition, behaviour, language, peer relationships and motor skills (50, 77, 143, 158-160) of children born preterm.

As noted above, strong research evidence now supports the finding that sensitive, responsive parenting promotes healthy brain growth and makes positive outcomes more likely for all children, including those born preterm. Sensitive communication styles may be more difficult to establish with some children born premature.

Providing effective interventions, which begin in NICU or soon after, can address the risks of developing unhelpful patterns of parent-child interaction which may result from a preterm birth. Wolke reported that in the UK, early follow-up for infants born preterm was led predominantly by physiotherapists who found themselves ill-equipped to deal with the largely emotional and relationship concerns with which the parents of infants born preterm presented (161). Alderdice and Redshaw make the case for the important role of psychologists in the care of infants

born preterm and their families (162).

Professionals supporting early relationships need to understand and address the minutiae of interactions, since causal pathways are being formed from birth. Post-NICU, early childhood programmes were reviewed by van Wassenaeer-Leemhuis and colleagues (163). They concluded that a combination of elements is needed in programmes to increase the likelihood of positive outcomes. They argue that intervention should focus on supporting reliable and sensitive parent-infant relationships, as well as reducing infant and parent stress and supporting self-regulation in the parent and in the child. They cite the Mother-Infant Transaction Programme and the Infant Behavioural Assessment and Intervention Programme (IBAIP) (164) in particular, as having positive long-term outcomes on a range of measures. Both programmes included elements of supporting sensitive parenting. On the other hand, educational programmes which sought to teach parents activities for promoting their child's development did not find positive results. They noted that successful programmes trained their professionals to use non-directive counselling skills. A review of studies by Benzies and colleagues found that parent psychosocial support was a key element of a successful early intervention programme (165). The UK's NICE also recommend that best practice includes providing follow-up care using professionals who have the skills to support parents with issues of feeding, sleeping and helping parents or carers to interact with their baby (66, 146). The Well Child Tamariki Ora (WCTO) programme report also notes that "interventions for at risk parent/child dyads can occur right from birth, fit within a strengths-based and whānau ora approach, and are economically more viable and effective delivered early in the life cycle" (154).



## Successful early intervention programmes should include: –

- a focus on supporting sensitive, playful parent-child interactions
- a professional team who together have expertise in all aspects of the neuro-biology of child development
- an understanding of the unique characteristics of each child
- team members who are trained in non-directive intervention techniques
- trusted professionals who can support parents with sleeping, feeding, regulation issues
- strengths-based, 'whānau ora' style, whole family approaches
- a focus on strengthening family competencies
- culturally sensitive and appropriately responsive interventions

Early intervention services for children with disabilities across New Zealand are often not available to children born premature who do not present in early childhood with evident neurodevelopmental disorders. Where follow-up is provided, many services rely on home visiting. Whilst this may be more convenient to families, there can be the risk that each visiting professional delivers unrelated pieces of advice to whānau. It is crucial that professionals understand and embrace the whole child in context and apply approaches which go beyond the boundaries of individual disciplines, from birth onwards. When professionals practice in isolation and visit families alone, it is more difficult and costly to offer a truly integrated intervention service. Feedback from 971 surveys of parents of children born preterm in Europe, suggested that parent dissatisfaction with follow up was most frequent when there was poor communication and poor coordination of services (166).

Babies are born social beings. Language begins in the first weeks - as babies share eye gaze, touch and reciprocal interactions. These shared behaviours form the early building blocks for language and communication. If these foundations are lacking or shaky, then communication and eventually speech and language will be delayed. Intervening with some sessions of speech therapy when the child is three years old is failing to understand the nature of the problem. The intervention needs to happen when these early behaviours are first missing. Assigning a speech therapist to a child, three years later is not good enough and is not based on developmental brain science.

As we have seen above, prematurity is more prevalent amongst whānau facing socio-economic challenges. Infant neurodevelopmental challenges often coincide with family disadvantages in health, welfare and financial stability. This 'double jeopardy' puts children born preterm at very high risk of ongoing problems with learning, behaviour and wellbeing. It is critical that family and whānau support services who specialise in providing early intervention for children and families at high social risk understand the extra demands that prematurity brings to parents.

All early intervention services working with young children and their families, especially those families facing multiple disadvantages, would benefit from having additional expertise in vulnerabilities, including interactional and regulation challenges, relating to prematurity.

In some cases, children may be referred to both a service for children with developmental risks and another service for whānau with social risks, but the practice for services to work together with families and integrate their intervention is crucial, but not often achieved. As noted above, parents are often frustrated by poor communication and coordination of services.

For whānau living in New Zealand's rural areas, access to early intervention services for preterm children is significantly reduced. Whilst internet services are still notably poorer in rural New Zealand, improvements are occurring<sup>18</sup>. This ought to open possibilities for increased use of e-health strategies for follow-up. Several recent studies have demonstrated some success using telehealth techniques to follow up infants born preterm on discharge (167-169). Telehealth services have become more widespread since the COVID pandemic and would work equally for remote communities. A number of studies note there are still practical difficulties to overcome. Garfield et al (170) reported some success using a smartphone application to support parents during the transition home from NICU. Baggett and colleagues trialled an internet-based early intervention programme for babies born preterm and their parents at very high social risk in Chicago, USA (171). They reported practical difficulties in recruiting and maintaining contact with their participants. However, the programme was based on a successful trial of internet-based early intervention with infants born full term (172). Tele-practice is being increasingly promoted in Australian health services. Hines and colleagues have produced guidelines for allied health practitioners working in internet-delivered early intervention for children with disabilities (173). In the Gledhill survey noted above of New Zealand providers of follow-up care for children born preterm, several respondents (12%) noted there is a need for outreach or mobile teams to serve the rural

populations. The use of liaison networks for rural health professionals to link to specialist professionals around the country could also be effective and inexpensive.

## Intervention during the school years

Despite the best efforts of early intervention providers, it is likely that some of the neurodevelopmental challenges described in the first half of this paper will continue to cause problems when children born preterm reach school (74).

*As we have seen above, children born early are mostly challenged by subtle difficulties in a number of areas, which can nevertheless significantly impact their learning, behaviour and peer relationships.*

Research in the UK and the USA (174, 175) suggests teachers in general have little knowledge about prematurity and its implications for learning. Carpenter and colleagues (176) suggest that prematurity, at least in UK schools, is under-identified as a significant risk factor for learning. Given the number of children born early, nearly every teacher will be responsible for supporting the learning of a child born preterm and teachers will be the professional group most commonly working with them (175). In New Zealand, the extent of awareness about prematurity amongst teachers is unclear. A summary of relevant research for educators was provided in 2009 by Hornby & Woodward from the University of Canterbury (177). To a large extent in this country, children born premature will be managed by classroom teachers with support from school-based Special Educational Needs Coordinators (SENCOs) and Resource Teachers for Learning and Behaviour (RTLb). New Zealand research reported that of around 100 children born

<sup>18</sup> <https://www.mbie.govt.nz/science-and-technology/it-communications-and-broadband/fast-broadband/quarterly-updates-on-broadband-deployment/>

very preterm assessed in Christchurch, 43% needed remedial support at age 6 years and 39% at age 9 years (65).

Few children born preterm will qualify for individualised funding provided by the NZ Te Tāhuhu o te Mātauranga/Ministry of Education for children with moderate to high levels of learning support needs.

Carpenter and colleagues (176) propose that all schools should a). identify children born premature on school entry, b). understand the learning, social and behavioural needs of this group of children, c). proactively maintain links with other agencies and professionals working with these children and d). intervene early. Consideration should also be given to the timing of school entry. For some children, an early birth will bring them into a school year ahead of the school year in which they were due. Pettinger and colleagues (178) argue that this puts children at further risk. Whilst this is arguably less of an issue in New Zealand, which traditionally takes a more flexible approach to starting school at age 5 years than in the UK for example, it is still a matter for consideration once school year groups become settled for individual children.

Wolke notes that despite improved neonatal care, rates of cognitive and educational difficulties in preterm children have not improved (76).

Indeed, Cheong and colleagues report that achievement in reading, spelling, and mathematics was significantly poorer in extremely preterm children born in 2005 in Victoria, Australia compared with those born in the 1990s (53). The reasons for the deterioration in academic performance are not known.

it is clear that improvements in neonatal care need to be paralleled with improved teacher training and educational support for children born preterm (175, 178).

Bryce Coleman, President of the Mana Principals Association commented that New Zealand teachers are inadequately trained in neuroscience and are under-resourced to respond positively to children with learning difficulties, especially those who do not qualify for individualised funding (179). UK expertise about prematurity has been developed into an online resource for teachers. An evaluation of this resource found 97% of teachers said they would recommend it (180)<sup>19</sup>. Of interest for New Zealand schools and preschools who adopt a Māori immersion or other bilingual approach to teaching, some research now suggests that bilingual experience for children is helpful in building executive function skills (181). It is thought that learning two languages may help in practising skills that support flexible thinking.

We have seen above that being the target of bullying is much more likely for children born premature. Bullying was found to predict high rates of emotional problems and poorer self-concept, including anxiety and depression, in preterm adolescents (82, 84). However, Wolke and colleagues point out these vulnerabilities may be modifiable by intervention. Greater teacher and school counsellor awareness of the problem would be a first step.

Services for school age children and young people, including mental health services, Oranga Tamariki and other social work or whānau support services and youth justice services again may not be familiar with the specific needs and challenges of preterm children and adolescents.

The persistent difficulties for premature children with emotional self-regulation and impulse control may well increase the chances for this group of children to need extra support from mental health services, youth justice and other family/whānau services.

As we have seen above, children born preterm are more likely to experience social adversity growing up and thus are more likely to come into contact with a wide range of support services. A good understanding of the implications of prematurity for professionals working in these fields will be vital to providing adequate support. Currently training for teachers, school counsellors, social workers, mental health workers and youth justice professionals in New Zealand does not, to our knowledge, include specific training around the needs of children born premature.

## Everything exists in context

"Science tells us that early experiences are built into our bodies and shape lifelong learning, behaviour and health. Brains are built over time, and the strength or weakness of its evolving architecture in the first few years influences all later development. Twenty-first-century science underscores our shared responsibility to provide all young children with a strong foundation of responsive relationships, positive learning experiences and health-promoting environments as early as possible so they can grow into resilient adults with the skills to successfully manage the responsibilities of work, citizenship and parenting of the next generation. We cannot let this critical opportunity slip by. The time to invest in the future strength of our nations, our economies and our communities is in the earliest years of life. The clock is always ticking and the time to act is now."

Jack P. Shonkoff, M.D., Director of the Center on the Developing Child at Harvard University from "Early Moments Matter", [www.unicef.org](http://www.unicef.org), 2017.



## Conclusion:

# Implications for New Zealand policy and services

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Children's well-being is vital for the continued social and economic prosperity of our communities. We cannot achieve equality in outcomes without equity in opportunities. For many children born premature, the playing field is not level from before birth. Economic hardship, racism, illness, domestic abuse or violence, addictions and rural isolation increase the risk of prematurity, but then further increase the slope of the playing field as children grow up. These underlying conditions make it harder for parents to form responsive relationships with their newborns. This in turn leads to the increased risk of stress activation, affecting the infant's brain from the earliest weeks. Furthermore, this then gets in the way of healthy psychological and physical development. When we level the playing field, by attending to these risks, our investment will be returned by strong and healthy development and as a result, greater productivity and decreased demand on health, education, mental health, social and justice services.

Thus to be successful, services need to be better informed to understand both the lifelong consequences of prematurity for the child and for family relationships; then address

both the needs of the child and the whānau. It is essential that services are not silo-ed but offer 'joined-up', integrated professional services, which understand and attend to the social, learning, emotional and health needs of the whole child and the whānau in which he or she is growing up. Acting early and preventatively can help to deflect the negative longer-term outcomes and mounting costs associated with health, education and social welfare challenges (182). To do this, practitioners in health, education and social services need a specialised skill set and knowledge. Msall and colleagues (39) note that in the U.S.A., the costs associated with prematurity in 2005 were around US\$ 51,600 per child. (This included the costs for medical care, early intervention, special education and lost household and productivity costs). Early intervention costs increase for preterm infants the earlier in gestation that they are born (183). Furthermore, economic modelling in 2016 projected that comprehensive intervention services in early childhood saved US\$ 2.60 on later special education costs for every dollar spent (184). In the UK in 2015, data suggested that for moderate and later preterm births the average cost to society was an extra £4657, compared to controls

between birth and age 2 years (185). To our knowledge, no equivalent research on prematurity exists in the New Zealand context. An evaluation of the social impact of Ngā Tau Miharo – the Incredible Years Programme for Māori parents (of presumably mostly full-term children) delivered by Te Whānau o Waipareira in Auckland suggested a social return on investment ratio of 3.75:1, that is, for every \$1 invested into the programme, \$3.75 of value is created (186). Hughes

and Tallboy in a 2018 report for the NZ Ministry of Justice suggest that there is ‘clear international evidence’ that early intervention has a range of benefits (187). They estimated the cost at that time to be NZ\$5,700 per child for an intensive home visiting programme and concluded, “As such, there is an investment case for both the justice sector and broader social sector to invest in at-risk children”.

## 1 Services for babies born preterm and their whānau

As Weber & Harrison (28) write in a paper about minimising the effects of toxic stress in NICU services, ‘Hospital systems need to proactively develop innovative solutions for promoting and supporting parental presence’. Reports suggests that NICU services in New Zealand are starting the process but need to be better resourced to continue to fully and effectively develop developmental supportive care and family-centred care, which will minimise stress for the infant and support the

primacy of parent-child relationships. Implementation of Family-Integrated Care requires the resourcing of the four pillars of parent education, nursing education and support, environmental adaptations and psychosocial support<sup>20</sup>. The funding of more mental health professionals to work with and alongside NICU staff to develop integrated practices which engage and empower families, especially those at greatest risk is urgent. This requires professionals with a dedicated focus on the

## 2 Services for toddlers and pre-schoolers born preterm and their families

As best practice overseas suggests, monitoring and intervention including assessing the risks for the dyad and caregiving relationship, should be routine for all pēpē born less than 32 weeks gestational age, as well as tamariki born in the moderate to late preterm period, who are at risk or showing difficulties. Follow-up needs to be multi-disciplinary and allow adequate resourcing for supporting dyadic relationships. True multi-disciplinary, or indeed interdisciplinary, best practice requires professionals to provide a

seamless, high-level integrated delivery of care; to do this, practitioners need together to be able to offer wide-ranging but specialised skills. Monitoring should continue until school age and liaison with education systems should be routine. New 2022 Practice Guidelines for New Zealand do not make this provision and need updating inline with accepted international best practice. An interdisciplinary group of health, education, and social service professionals with expertise in prematurity should be asked to provide best practice

guidelines for an integrated, multi-agency response to the challenges of children and adults born preterm.

As well as specialist follow-up, primary health care professionals and mainstream early educational practitioners would benefit from understanding the extra challenges for children born preterm and their whānau, know when to refer on and know to whom to refer for more specialist help. This is especially true if primary health care and educational professionals will play a key and central role in assessing and addressing challenges of tamariki over two years born premature in their care. We have

seen that children who are both preterm and grow up in highly disadvantaged family circumstances are at most risk. There are likely to be a higher proportion of tamariki born premature in services for high-risk families than would be typical. As a result, specialist services for families, including those services supporting whānau with greater social challenges need to understand the further risks that prematurity brings to the context. Children born preterm in the Oranga Tamariki care system will also have special needs which must be considered when planning care and transitions.

### 3 School-age children born preterm and their families

Teachers may well not be familiar with the learning needs of children born premature. Self-regulation and other executive function vulnerabilities can combine to have a significant impact on children's learning in the classroom. Teachers need to be well-trained and have adequate support from specialist staff to recognise the best ways to promote the success of children born preterm in school. Te Tāhiuhu o te Mātauranga/Ministry of Education Te Kete Ipurangi webpage provides useful guides for teachers on many of the issues for facing children in our schools<sup>21</sup>. A guide for teachers about prematurity should be added and made available.

Also, at this stage of life, increasing use will be made by children and families of services for behaviour support, emotional problems and mental health difficulties. Services from Manātū Hauora/Ministry of Health; Te Tāhiuhu o te Mātauranga/Ministry of

Education and Te Manatū Whakahiato Ora/Ministry of Social Development which include counselling, behaviour support, mental health and social support services would all benefit from greater knowledge about the vulnerabilities and challenges of prematurity. Training for teachers and other professionals should include an introduction to typical and atypical neurodevelopment. Again, an integrated response to the issues of prematurity across multiple agencies is required. Professionals with expertise in prematurity should be available to work collaboratively with schools and other services to enable appropriate responsiveness to the developmental profiles of individual children born premature. This way professionals could work towards a collective understanding of children's challenges in different environmental contexts. This would include developing an understanding with educational professionals about the drivers of bullying.

21 <https://www.tki.org.nz>

## 4 Support for whānau Māori and Pasifika families

Ongoing efforts to provide services which are designed with and for whānau Māori, as well as Pasifika and migrant families should be pursued urgently. Kaupapa Māori and Pasifika services should be available for families by choice. Current hospital services and the Well-Child Tamariki Ora programme require radical change to enable pae ora (healthy futures) for pēpi/ tamariki and their whānau. A consumer advisory group drawn from whānau Māori, Pasifika and migrant families affected by

prematurity should advise and recommend changes to current practice, where needed. Expertise from the delivery of whānau ora services could be applicable more widely for families in New Zealand. Obligations for culturally-safe practice by professional bodies involved in the care and education of children must be promoted. Attention should be paid to documents including the Manatū Hauora's Position Statement on Anti-racism referred to earlier.

## 5 Other considerations

Gledhill and colleagues (153) point out that there is no national parity in New Zealand services for infants and children born preterm. Funding and resourcing needs to support follow up for all children at risk across New Zealand, whether in urban or rural areas. Innovative use of

telehealth services is now within reach. For all children, especially those growing up in adversity, joined-up and integrated services which understand the need to individualise intervention for children and families, are vital. The cost of doing nothing will be greater than funding support.

"The opportunity to align new science and the lived experiences of families and decision makers across a diversity of sectors, cultures, and political values offers a powerful pathway forward. The need for shared leadership along that path is urgent."

Jack P. Shonkoff, M.D., (2022) Director of the Center on the Developing Child at Harvard University in Re-envisioning Early Childhood Policy and Practice in a World of Striking Inequality and Uncertainty. <https://developingchild.harvard.edu/re-envisioning-eed/>

# Recommendations for Urgent NZ Action on Prematurity

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The evidence is clear, a premature birth can lead to significant challenges for many children and their whānau. Early life experiences and upbringing shape the people we become and consequently shape our society. All learning is based in relationships - it is what the human brain requires. In order to minimise the risks for infants born preterm, we need to support infant-caregiver relationships whilst at the same time providing targeted, individualized, developmentally-integrated interventions. We have the epidemiological and neurobiological evidence to know that we must intervene in ways that can shift early risk factors. We know now what to prioritize, what to do when and why, and by whom;

beginning with NICU care and going forwards through early development, pre-school and school. We know we must work to protect tamariki from adverse early experiences and act preventatively to minimize the risks of social disadvantage. Services need to be adequately funded to allow this important work to be implemented. Further research could evaluate, inform and support services, but further research is not a reason to delay implementation. New Zealand policy and practice needs to be urgently brought up to date with developmental science. Recommendations include:



- Across the age-range, developing services in conjunction with whānau Māori, Pasifika and migrant families which better meet the needs of their people.
- Prioritising the growth of developmental and family integrated care in New Zealand NICU services. Providing funding for NICU-based mental health professionals to develop integrated practices which engage and empower families within a bio-psycho-social model of development.
- Establishing a national multi-disciplinary advisory group of professionals with expertise in prematurity from across sectors to develop best practice guidelines for integrated multi-disciplinary follow-up of high risk children born preterm and their families.
- Providing services for children born preterm and their whānau where practitioners, collectively, have the skills and experience to support the medical, developmental, social and early relationship challenges faced by survivors of a preterm birth and their families. These services need to be nationally available and should be long-term, comprehensive, and integrated across sectors.
- Using telehealth and primary care liaison to support children born preterm and families living in rural areas.
- Establishing better training for educational, mental health and social work professionals about the needs of children born preterm. Neurodevelopment should be included in basic training programmes. Prematurity information should be added to the Te Tāhuhu o te Mātauranga/ Ministry of Education Te Kete Ipurangi (TKI) webpage. This, alongside further training across sectors, would prioritise neurodevelopmental knowledge and understanding and the impact of context. Knowledge and intervention need to be integrated across school and caregiving environments.

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**“It is essential to determine which policies and programs can do most to enable families to perform the magic feat of which they alone are capable: making and keeping human beings human“**

- Prof. Urie Bronfenbrenner in Ecology of the Family as a Context for Human Development: Research Perspectives. Developmental Psychology, 22(6), 723-742. 1986.

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# Meet the authors



**Dr Alison Davie-Gray  
PHD.**

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Alison trained as a clinical and child psychologist in the UK. For the early part of her career, she practised in Cumbria in the fields of child and adolescent mental health, working with specialist teams and primary care, child development services and paediatrics. Moving with her family to New Zealand in 2002, she began work with Canterbury District Health Board with the Mother and Baby Mental Health Service and then completed a PhD at The University of Canterbury, which examined the developmental outcomes of a group of toddlers exposed to methadone in pregnancy. Most recently, Alison worked at the Champion Centre, leading the follow-up programme for premature children and their whānau for nearly 10 years. Alison continues to practise as a clinical psychologist with children and families, from her home on a farm in rural Canterbury. Alison is a member of the executive committee of the Infant Mental Health Association of Aotearoa New Zealand.



**Dr Patricia Champion,  
MBE, PHD.**

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Patricia has practised in the field of developmental and child psychology for 40 years. She is the founder of the Champion Centre, New Zealand's longest running early intervention programme. Her experience includes in-depth clinical work with children and infants with special needs and with their families/whanau. Patricia has taught and lectured both in NZ and internationally across early intervention, developmental psychology, child development, human issues and family processes. She currently holds teaching positions as honorary senior lecturer at the University of Otago Medical School and Adjunct Associate Professor in the School of Health Sciences at the University of Canterbury. Patricia is active in research and has been published internationally in a number of articles and texts.



