

PREMATURE BIRTH

SUPPORTING PARENT AND INFANT ATTACHMENT

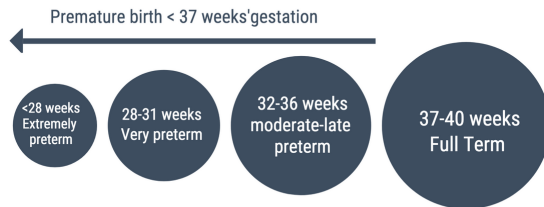
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CHALLENGE MAPPING

According to the World Health Organisation (WHO), 15 million infants are born prematurely (before 37 weeks' gestation) each year. In well-developed nations the rate of premature birth ranges between 8 to 10%.



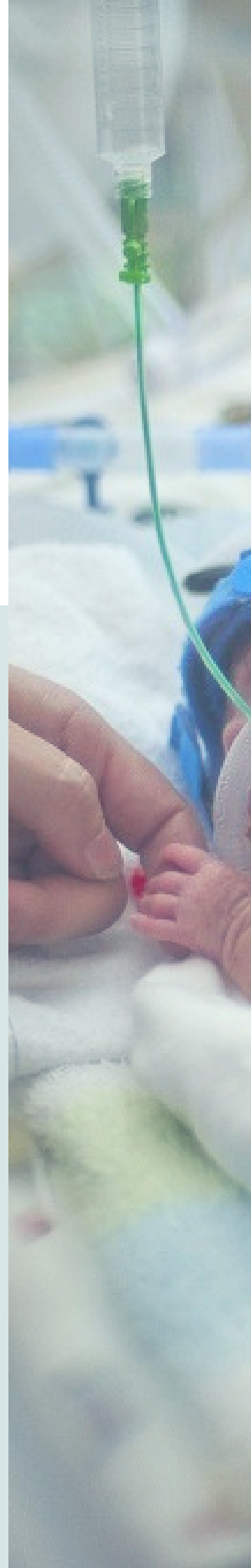
In Australia, almost 27,000 infants are born premature each year, accounting for approximately 8% of all births, yet contributing to more than two-thirds of all perinatal deaths (1).

DESCRIBING THE CHALLENGE

Premature birth creates a situation where critical stages of brain and central nervous system development occur in an environment that is at complete odds with what's needed for healthy brain development. The events a premature infant experiences in their perinatal care is commonly associated with pain and stress to a system that is in the midst of rapid growth and organization (2). The early and prolonged physical separation that often occurs between a parent and their premature infant compromises the parent-infant attachment relationship (3), the connection formed between a parent and their baby, which is integral to a child's healthy development (4).

The birth and hospitalisation of a premature infant is a stressful experience for parents. In exploring mothers' first reactions to having an infant in the neonatal intensive care nursery (NICU), many reported feeling like a stranger, visitor, or outsider in the neonatal nursery; feeling ambivalent about the relationship with their infant; and having a sense of "borrowing their infant" (5).

The development of the parent-infant attachment relationship in the neonatal nursery and beyond is the challenge.



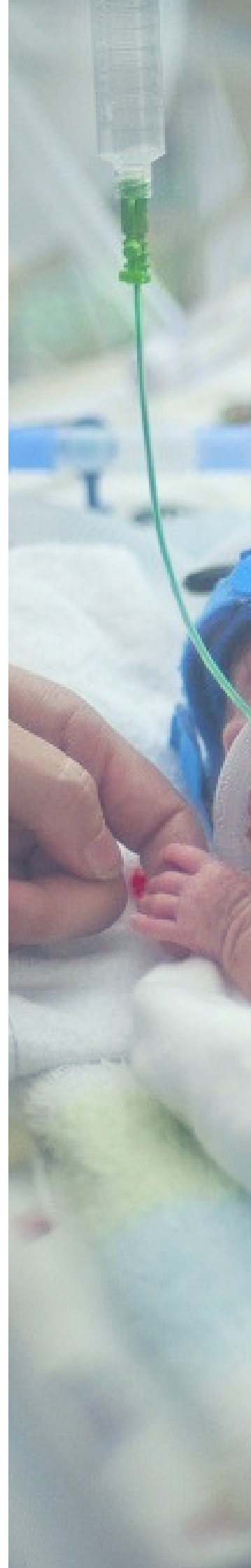
IMPACT OF THE CHALLENGE

Those impacted by this Challenge include the infant, parents and extended family, healthcare professionals, and society as a whole.

Birth before 34 weeks increases the risk for impairments in neurosensory, physical, social-emotional and academic functioning (6-10). In addition to the impacts on infant development, premature birth can have an ongoing negative influence on parent mental health, family functioning (11) and the parent-infant attachment relationship (12). Parents of premature infants experience significantly higher rates of depression and anxiety compared with parents of term born infants with up to 63% of mothers of infants born <34 weeks' reporting symptoms of depression in the first few months post birth (11, 13, 14). These symptoms of psychological distress often persist beyond hospital discharge with approximately 25% of mothers reporting significant symptoms of psychological distress up to two years post birth, double the rate reported by parents of term born infants (14, 15). Furthermore, research has documented Post-Traumatic Stress Disorder (PTSD) in mothers who have had an infant in a NICU with a prevalence rate of up to 41% and persisting for as long as fourteen months post birth (16).

It is vital to address the effect of premature birth on parent wellbeing and family functioning, as parental mental health problems are also associated with poorer developmental outcomes for premature infants (15, 17-20).

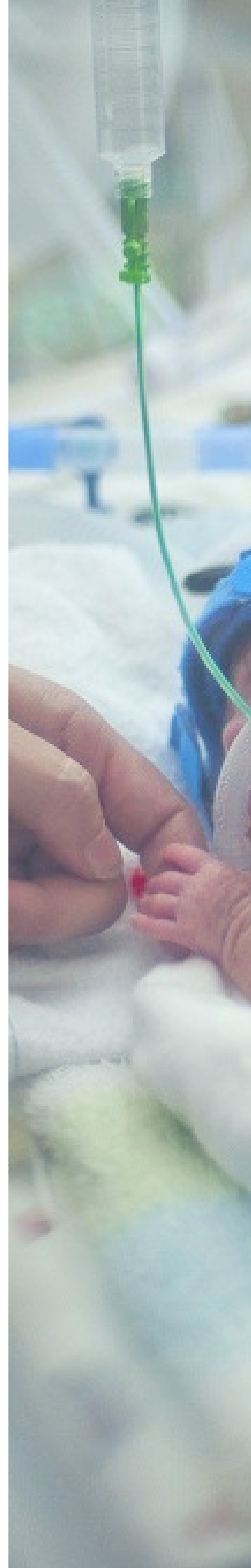
Placing an increased demand for early intervention, educational support, and mental health services, the impact of premature birth on both parent and infant well-being has an enormous cost to our society (21) and the annual direct cost in Australia related to post-natal depression is estimated at \$78 million (22).



CAUSE OF THE CHALLENGE

There are multiple reasons why this Challenge persists. At the macro level, little or no nationally agreed clinical practice guidelines appears to be the source of significant inefficiency, waste and duplication. Currently, Research Institutes, State and Federal Governments, Public and Private Hospitals and other Professional Bodies are commissioning guidelines on the same topic. This lack of coalition and bilateral and multilateral collaboration subsequently results in poor research translation. Two examples of this fragmented environment include over 20 socially innovative Not For Profits, most of which are not informed or sophisticated and lacking governance (23), and the development of state guidelines (Queensland) that lack peer review and have not been approved by the National Health and Medical Research Council (NHMRC) under Section 7 or 14A (1) of NHMRC Act (1992) (24).

At the micro level, those that exacerbate the Challenge include health professionals, in particular the neonatal nurse. They are one of the biggest predictors of a parent being able to establish a connection with their infant (25), however, not all nurses are comfortable with a change in model of care from what was historically a paternalistic approach towards parents, to regarding them as equal partners in the care of their infant (26). In a systematic review of parent participation in the care of hospitalised infants, health professionals expressed both positive and negative attitudes towards parents being actively involved in the care of their infant (27). Parents also reported difficulties in finding a balance between their role and the nurse's role in the NICU due to lack of information and ambiguous boundaries.



HISTORY & FUTURE OF THE CHALLENGE

There has been a significant decline in the mortality rate in infants born prematurely, however this has not been matched with a decline in the morbidity rate, which remains fairly constant (28). This, in addition to the 2% annual rise in the incidence of premature birth in Australia (29) will continue to have a significant financial impact as demand for early intervention and support services increase. There is a growing awareness of the positive effects that nurturing the parent-infant relationship has on parents and their premature infants well being, however this requires greater attention and remains a challenge.

SOLUTIONS MAPPING

Due to the plasticity of the developing brain (Figure 1) and its responsiveness to the environment, preventative early interventions have the greatest potential to permanently alter an infant's developmental trajectory and reduce the associated financial burden of special education and mental health services (30). A recent Cochrane review supports the use of early intervention with premature infants to improve cognitive development (31). Larger improvements in cognitive outcomes were reported when programs focused on strengthening the parent-infant relationship rather than focusing on infant development or parental support alone (32, 33).

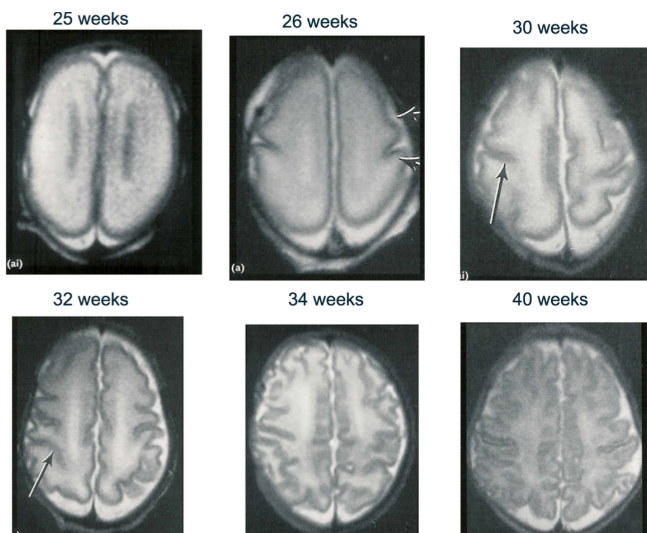
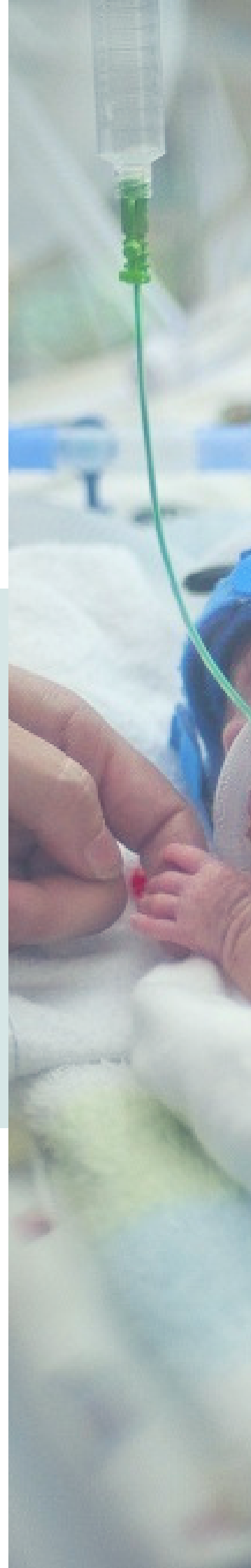


Figure 1:

Brain changes over time. MRI images of infant brain from 25 weeks' gestation to 40 weeks' gestation (full term).



LOCAL SOLUTIONS

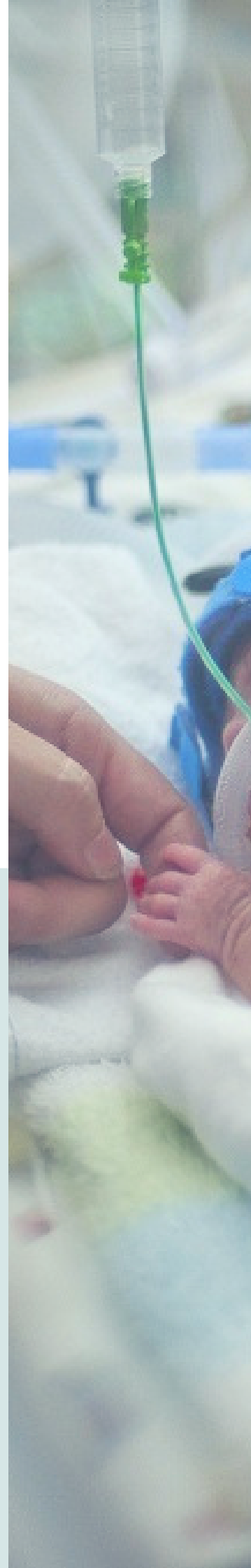
Intervention with parents and infants in the early years is one of the most cost-effective strategies to improve future outcomes and productivity (37).

The lack of programs to support a solution to the Challenge has resulted in the creation of multiple models and initiatives that focus on close collaboration with parents. This includes, but is not limited to, the Neonatal Individualised Developmental Care and Assessment Program (NIDCAP) (34), Close Collaboration with Parents Program (35), Family Integrated Care (FiCare) (36), and VIBeS Plus (37).

Specifically, they explore interventions with parents and infants, but also maternal care, address the Challenge causes, the physical and social environment, and how to improve support to all those effected. Unfortunately, these solutions are not being treated as a system, and therefore siloed due to IP, miscommunication and limited or mismatched Commonwealth and State funding.

GLOBAL SOLUTIONS

Organisations such as BLISS and Tommy's in the UK, the Neonatal Network in Canada, March of Dimes in the US, Canguro Foundation in Colombia, and the Neonatal Trust in NZ are consistently identifying that a focus on parent and infant vs infant or parent alone is vital to improving health outcomes. They are focusing on Family Integrated Care (FiCare), improving academic collaboration, and reducing barriers to parenting in the neonatal nursery to improve parent mental health and the social-emotional and cognitive development of children born premature.



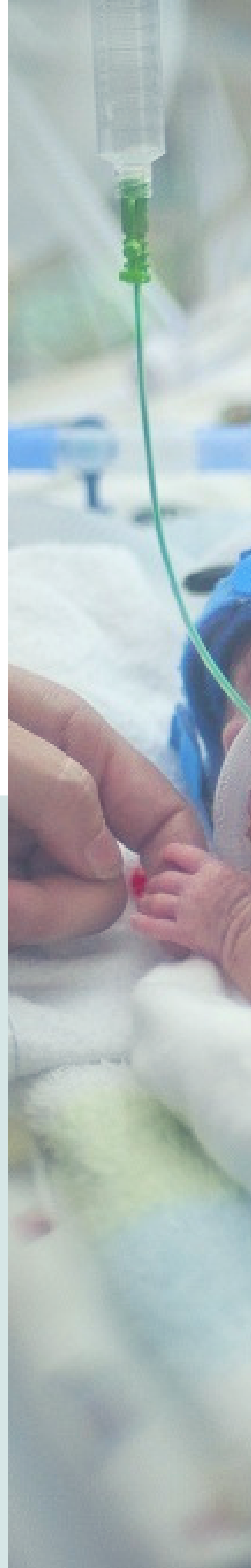
WHAT'S WORKING & WHAT'S NOT

In recognising the importance of the parental role in neonatal care, units worldwide have shifted their philosophy of care to a more family centred model where parents and families are encouraged to participate in their infant's care, with the aim of developing parental sense of confidence, control, and growing independence (38). Consistent application of methods such as improved communication, skin-to-skin care (Kangaroo Mother Care) (39) and investing time in the development of collaborative relationships between staff and families appears to be the most cost effective model.

Amidst such efforts many parents continue to report feeling disconnected from their infants in the neonatal nursery, unable to contribute meaningfully to their infants' care and lacking confidence in caring for them post discharge (40).

THE FOCUS & THE FUTURE

FiCare appears to be the most cost-effective solution, with specific efforts focused on the development of the infant, parent mental health and health care costs. This involves improving communication with parents and actively involving them in the care and decision-making process around their infant. Moreover, improvements in education firmly revolve around developing connection and attachment between parents and the infant, with an end result of reducing parent distress and discharging a healthier infant earlier. Unfortunately, what is currently not being investigated is financial support and culturally and linguistically diverse approaches for families.



IMPACT GAPS

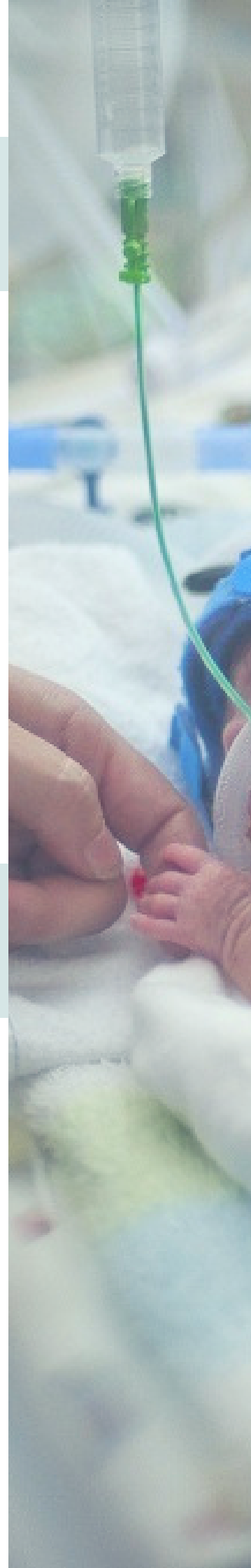
GAPS BETWEEN THE CHALLENGE AND THE SOLUTION

Crucial macro gaps include the lack of Commonwealth Clinical Practice Guidelines for the Care around Preterm Birth and National Standards, resulting in those effected not being served holistically.

At the micro level, gaps include funding for allied health services and education programs specifically designed for premature infants and their families. Other gaps include inconsistent engagement of professional associations and academic institutions, a lack of professional development resources to train and support neonatal nurses in their role of supporting the emotional wellbeing of parents and facilitating the parent-infant relationship, insufficient GP mental health treatment plans, and a lack of development of innovative technology systems.

GAPS WITHIN THE SOLUTION

A key gap within the solution is the inconsistent guideline for the developmental follow up of 'high risk' infants. Eligibility criteria for follow-up are often based on gestational age or birth weight cut-off (e.g. infants born <28 weeks' or weighing <1000g) and are determined by individual hospitals and their available staffing and resources. This creates inconsistent parent support post discharge, greater exposure to neurodevelopmental delays, and missed opportunities to maximise early brain plasticity through timely early intervention access.



IMPACT GAPS

GAPS WITHIN THE SOLUTION

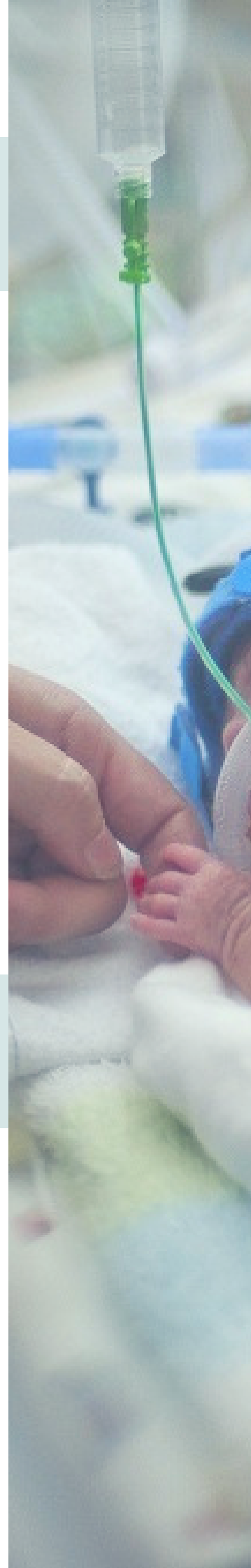
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What is also missing is financial support to families during hospitalisation of their infant. Furthermore, there is limited educational products for parents of premature or sick newborns that have been specifically developed to empower parents to modify their infant's physical, social, and emotional environment so that brain growth is optimised and overall wellbeing is improved.

NHMRC has a responsibility to reinforce the need for better coordination to ensure that Australian clinicians and consumers have access to current, high quality, relevant guidelines in areas of identified need (41). Unfortunately there has been no nationally endorsed clinical guideline around premature birth since it was withdrawn in 2005. This contradicts their statutory responsibilities to provide national leadership in the development and promotion of high-quality clinical practice guidelines that help them foster consistent health standards across Australian states and territories (42).

UNADDRESSED OBSTACLES

Poor parent mental health, inconsistent developmental surveillance and intervention, and education of maternal and child health nurses on preterm specific development continues to be overlooked, as do the social welfare cost increases associated with poor child development outcomes. Key opportunities that could unlock future impact would include the Commonwealth Government prioritising and funding researching, identifying and implementing solutions to the Challenge. Furthermore, psychosocial research outcomes would also reveal other innovative solutions.



LESSONS LEARNT

The Challenge of premature birth and supporting parent and infant attachment contains the elements and characteristics of a complex adaptive system. Because of the complex nature of healthcare delivery, solutions to this challenge are difficult to implement.

Levers for change include:

- Guideline funding and research translation. This has positive outcomes for the health and wellbeing of premature infants and their families, resulting in significant financial savings for the Australian community (43).
- Wider implementation of models of care that support collaboration and partnerships with parents in the nursery. This empowers families through ownership and control of their circumstances and environment.
- Improved research collaboration of early intervention programs.
- Addressing staff attitudes and culture are fundamental to success.
- Improved health professional education on relationship-based care and supporting the parent-infant relationship

