Submission No 27

IMPROVING ACCESS TO EARLY CHILDHOOD HEALTH AND DEVELOPMENT CHECKS

Organisation: The Grace Centre for Neonatal Intensive Care

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Grace Centre for Neonatal Intensive Care submission to [NSW Legislative Assembly Committee on Community Services inquiry]

28/02/2024

To the Committee,

RE: **Submission – Improving access to early childhood health and development checks**

Dear Secretariat,

The Grace Centre for Neonatal Intensive Care welcomes the opportunity to provide this submission to the Legislative Assembly Committee on Community Services' inquiry into improving access to early childhood health and development checks.

The Grace Centre for Neonatal Intensive Care at The Children's Hospital at Westmead is an integral service within the Sydney Children's Hospitals Network (SCHN). It comprises the Neonatal Intensive Care Unit (NICU), Grace Research Unit, the Grace Development Clinic and the Australasian NIDCAP Training Centre. As a major quaternary referral unit for babies with surgical and cardiac conditions, the Grace Centre is a unique component of the NSW Pregnancy and Newborn Services Network. It works in close collaboration with the High Risk Feto-Maternal Unit at Westmead Hospital in the management of mothers whose babies have been identified with birth defects and are referred for delivery to enable early transfer to the Grace Centre. The NICU also accepts babies from across New South Wales, interstate and from New Caledonia (Noumea), who have congenital malformations which have been diagnosed in-utero and who require major operations within the first few days of life.

In recent years, the Grace Centre for Neonatal Intensive Care has seen a sustained increase in the survival of babies with congenital heart disease, surgical and complex medical conditions to 97%. The priority now is a reduction in the rate of neurodevelopmental disability to enable more survivors of our neonatal intensive care to fulfil their potential and lead productive lives.

We seek to achieve this through the ongoing work of the Grace Research Unit, the Grace Development Clinic and the Australasian NIDCAP Training Centre. The importance of neuro-developmentally supportive care in the NICU is well recognised with caregiving occurring during a unique period of neuroplasticity in the 'First 2000 days' of life. Improving health and developmental outcomes within this critical time has far reaching effects on educational attainment, productivity, social interaction, future earning potential, and mental health outcomes. Our Australasian NIDCAP Training Centre promotes sensitive cue-based care and our staff have trained 2000 health professionals around Australia and New Zealand.

The Grace Research Unit is a leading neonatal clinical and academic research unit with a commitment to multi-disciplinary research. Our vision is to lead practice through research and knowledge translation that improves clinical care and outcomes. The program has a strong neurodevelopmental focus with research aiming to diagnose neurodevelopmental risk as early as the first few weeks of life, identify the best ways to protect the developing brain and thus to prevent and reduce subsequent disability. Research has resulted in sustained changes to clinical practice within the NICU and beyond, focussing on early detection and neuro-promotion.

We implement a collaborative, multidisciplinary program of research to support families and target factors that we know are associated with a stressful neonatal admission: understanding and managing neonatal pain; involving fathers in the NICU; researching the best assessment tools for early detection of disability; measuring long-term infant outcomes; targeting infant language outcomes and infant-parent bonding via reading; capturing data on physiological and behavioural stress; and providing education on developmentally supportive care.

Our team have gained international expertise and published widely on a range of topics and are actively involved in supporting other NICUs to implement evidenced based programs. The Grace Centre was awarded the prestigious NSW Health Research Award in 2023 for our submission, ‘Research based care through neonatal admission and beyond’.

The insights from the work by the Grace Research Unit and the Grace Development Clinic are relevant to this inquiry, particularly in addressing Terms of Reference 4: *“Funding for early intervention programs and screening to ensure children are given support for developmental issues.”*

Grace Development Clinic

The Grace Development Clinic currently provides specialised, multidisciplinary developmental assessment for infants at three months, 12 months and three years of age, which enables the early identification of infants at risk of developmental delay or disability.

Research has identified time critical assessments for the early detection of neurodevelopmental disability, such as cerebral palsy (CP). The detection of CP requires a specific assessment approach including magnetic resonance imaging (MRI) combined with two other tests – the General Movement Assessment (GMA) and the Hammersmith Infant Neurological Examination (HINE)[1]. In particular, the GMA requires a high degree of training and skill, with clinicians assessing the spontaneous movements of infants at 3-4 months to identify the presence and quality of movements that are highly predictive of CP. The Grace Development Clinic screens all infants using the GMA as we have shown in our research that is able to accurately identify risk of CP in the neonatal surgical population as early as 3 months of age[2].

Further research on longer term neurodevelopmental outcomes identified the need for ***longer***, regular and targeted multidisciplinary neurodevelopmental follow up for our surgical population. This demonstrated that children who required neonatal surgery for both cardiac and non-cardiac related conditions had poorer neurodevelopmental outcomes, with higher rates of motor impairment and higher rates of developmental coordination disorder, poorer behaviour and emotional well-being and poorer attention and cognition compared to healthy controls and the reported population prevalence respectively. These groups should be considered a high-risk population for longer-term neurodevelopmental sequelae, and their development should be systematically followed up until at least eight years of age[3].

This need is confirmed by the recently published scientific statement from the American Heart Association[4] which states that congenital heart disease is the most common birth defect, with an estimated prevalence of 9 per 1000 live births worldwide, affecting all racial, ethnic, and socioeconomic groups. Approximately 25% of people with congenital heart disease require surgical or catheter-based intervention in infancy, and these infants are categorised as the most high-risk for developmental delay or disorder according to current scientific evidence. Due to increased survival there is a growing population with developmental delays and disorders and a greater need for societal resources over time. The Australian Standards of Care for Childhood-onset Hear Disease state that early identification of, and intervention for developmental concerns is critical to the wellbeing of children with congenital heart disease and the responsibility of health professionals as an integral function of health care as impairments in motor, language, and cognitive skills are common and are evident in the first months of life[5].

The Cardiac Neurodevelopmental Outcome Collaborative recommends that young children with congenital heart disease at high risk for developmental delay or disorder participate in developmental evaluation at key developmental stages: infancy, toddlerhood, preschool and before the transition to formal schooling (at approx. 5 years), with further neurodevelopmental evaluation at key transition points such as late primary school, high school entry, and transition to adulthood[4]. We also know that poverty and lower maternal educational attainment are associated with worse neurodevelopmental outcomes in children with congenital heart disease, highlighting the need to ensure a comprehensive follow-up service is in place.

In addition to this, there is the risk of cerebral palsy (CP) in this infant surgical population. An estimated 34,000 Australians have CP. It affects 1 in every 700 births and is caused by a brain injury during pregnancy or shortly after birth and is the most common physical disability in childhood. The recent decrease in the incidence of and severity of cerebral palsy demonstrated by data from the Australian cerebral palsy register demonstrates that improvements in outcomes are feasible and indeed probable with targeted health interventions. Being born with a congenital anomaly, such as a cardiac defect, places an infant at risk of CP.

CP is a lifelong condition with no cure. However, CP-specific evidence-based therapies and interventions provided at the right time can improve a person's wellbeing, quality of life and functional capacities. Early intervention, delivered in the first 1,000 days of an infant's life, is proven to give children the best chance of overcoming developmental disabilities[6]. Access to this early intervention requires a robust system for early detection and developmental monitoring.

Despite this critical need for early detection of developmental issues and subsequent early intervention to optimize these high-risk babies neurodevelopmental potential, we are not able to follow-up all infants at risk. Follow-up services have limited places, are only short term and are often funded by donations from the community. Babies from regional or rural areas or those from Aboriginal and Torres Strait Islander families, non-English speaking families or from lower socioeconomic groups are particularly disadvantaged and are slipping through the cracks despite them having the most to gain from follow up developmental programs.

The follow-up service provided by the Grace Development Clinic is largely unfunded and is dependent on donations by parents and benefactors in the community. Unfortunately, there is no permanent funding for the occupational therapist and physiotherapist who have specialised training and expertise in infant development and interventions. It is ironic that the developmental outcomes following surgical operations and neonatal intensive care admissions, which cost hundreds of thousands of dollars, are not adequately monitored.

Follow-up can only currently be offered until children are 3 years of age due to a lack of funding. However as described above, the evidence shows us that infants born with conditions such as heart disease requiring early surgery are at risk of longer-term disabilities.

Summary and recommendations

Despite the high risk of neurodevelopmental disability for infants following surgery in the neonatal period, for conditions such as congenital heart disease, we do not have a permanently funded, or comprehensive follow-up service. ***Permanent*** funding for ***long-term*** developmental follow-up is urgently needed, as per the recommendations by the Cardiac Neurodevelopmental Outcome Collaborative. This includes funding for:

- Specialised Allied Health professionals, i.e., Occupational Therapists and Physiotherapists, to conduct evidenced based assessments to screen all infants following neonatal surgery or with complex medical conditions admitted to Grace NICU.
- Funding for longer term follow-up including psychological assessments by a Developmental Psychologist and developmental/behavioural evaluation by a specialised Developmental Paediatrician.

We thank the committee for providing us the opportunity to share our insights in the early diagnosis and detection space and would welcome the opportunity to provide further details.

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