Submission No 60

INQUIRY INTO FOUNDATIONAL AND DISABILITY SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE IN NEW SOUTH WALES

Organisation: NSW Nurses and Midwives' Association

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NSW NURSES AND MIDWIVES' ASSOCIATION

Inquiry into Foundational & Disability Supports Available for Children & Young People in New South Wales

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NSW NURSES AND MIDWIVES' ASSOCIATION
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Introduction

1. The New South Wales Nurses and Midwives' Association (NSWNMA) is the industrial and professional body for nurses and midwives in New South Wales, representing over 80,000 members across the full spectrum of health care services in NSW, including public and private hospitals, midwifery, corrective services, aged care, disability, and community settings.

2. NSWNMA strives to be innovative in our advocacy to promote a world class, well-funded, integrated health system by being a professional advocate for the health system and our members. We are committed to improving the quality of all health and aged care services, whilst protecting and advancing the interests of nurses and midwives and their professions.

3. We work with our members to improve their ability to deliver safe and best practice care, fulfil their professional goals and achieve a healthy work/life balance.

4. Our strong and growing membership and integrated role as both a trade union and professional organisation provides us with a complete understanding of all aspects of the nursing and midwifery professions and see us uniquely placed to defend and advance our professions.

5. Through our work with members, we aim to strengthen the contribution of nursing and midwifery to improving Australia's health and aged care systems, and the health of our national and global communities.

6. The NSWNMA thanks the Select Committee for the opportunity to provide feedback on Inquiry into Foundational & Disability Supports Available for Children & Young People in New South Wales.

Overview

7. The *First 2000 Days Framework*[22] is a strategic policy document which outlines the importance of the first 2000 days of a child's life (from conception to age 5). Nurses and midwives provide care during this time and are instrumental in early identification and referral for possible disability from conception through to childhood.

8. Our members working in disability, paediatric, maternity, child and family health, and community and primary health care provide clinical support at different stages of the infant, child and young person's healthcare journey.

9. Care of children and young people living with disability is multifaceted, encompassing advocacy, care coordination and specialised support. Nurses and midwives bridge gaps between healthcare services and child welfare systems, ensuring that children with disabilities receive comprehensive care that addresses both their medical and social needs, including conducting thorough assessments from conception and beyond which identify their specific needs and allow for tailored interventions. Ongoing evaluation is crucial for developing individualised care plans that address immediate health concerns and consider the broader social determinants of health that affect children and young people with disabilities[7].

10. Nurses and midwives are pivotal in facilitating communication and collaboration among various stakeholders caring for children with disabilities, including social workers, educators and other healthcare providers. This interdisciplinary approach creates a cohesive support network that can effectively address the complex needs of these children in a timely manner, ensuring that they are not overlooked in the healthcare, education or welfare systems[7, 24].

11. Nurses and midwives advocate for the rights and agency of children with disabilities, promoting a strengths-based, client-centred approach that recognises the competencies and agency of these children.

12. The challenges faced by families of children with disabilities are significant, often exacerbated by systemic barriers. Nurses provide support to these families by offering resources, guidance and emotional support. This support is essential, as families navigating complex service systems may experience stress, isolation and frustration[5].

Summary of Recommendations

13. All children and young people with disabilities must have timely, tailored, local and culturally safe nursing and midwifery services, regardless of their location. Services must be based on consultation and collaboration with health, education, government and non-government organisations to provide cohesive person-centred care and early intervention.

14. The role of nurses and midwives must be recognized as a vital part of the foundational & disability support system of care available for children & young people in New South Wales , their role must be clearly defined, without ambiguity.

15. An urgent review of service gaps is required to ensure that regardless of location, all children and young people receive adequate care and support.

16. Further development of multisectoral, multipurpose hubs is needed to improve and simplify care for children and young people living with disability and support for their families.

17. NSW nursing and midwifery wages must be commensurate with other states and territories and reflect the vital contributions of nurses and midwives. Wage disparity is leading to loss of workforce to other states and territories where wages are higher, and cost of living is lower. Workforce shortages put service provision at risk as does de-skilling through replacement workforce initiatives.

18. Improve funding and incentives to attract nurses and midwives to rural and remote locations to reduce service accessibility disparities.

19. Urgent investment to address the aging nursing and midwifery workforce and related nursing and midwifery workforce shortages and service gaps, and increased promotion and incentives for education and training to encourage sustainability of the workforce.

20. Introduce further measures to increase training and numbers of Aboriginal and Torres Strait Islander people in nursing and midwifery including increasing the numbers of Aboriginal Health Workers and Aboriginal Health Practitioners, and improving collaboration with nurses and midwives.

21. Placement of Nurse Practitioners, or the creation of a specialist role in maternal and child family health similar to the UK Health Visitor model[11] which values their additional training, expertise and leadership and allows prescribing rights to a limited formulary[28]. Nurses in this space should be afforded increased referral rights to reduce burdens on the healthcare system and to increase system efficiencies to the benefit of children and young people living with disabilities.

22. Increase administrative support for clinicians, particularly in community health contexts, to free up time for clinical care and multisectoral collaboration.

(a) The role of such services and supports on a child's overall development, health and wellbeing

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"Lack of ANY administration help is added to the clinician's time when they could otherwise concentrate on a quality service."- NSWNMA Member

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Services and supports available for children and young people with developmental concerns are essential for their overall development, health and well-being. These include medical, community-nursing, allied health, NDIS and other service delivery providers and models that address the diverse needs of this population in New South Wales[12].

23. Nurses working with people with disability demonstrate a breadth and depth of practice reflective of their diverse needs. Evidence around poorer health outcomes of people with disability and the growing need for preventative healthcare will increase demand for nurses and midwives providing care to this cohort. Under the NDIS, people with disability can access services across several disciplines, through a variety of service providers, and delivered by workers with a diverse range of skills. The nurse's role in the NDIS appears ambiguous and limited in nature. According to the National Disability Insurance Agency (NDIA), nurses may be required for the provision of care, training and supervision of a delegated disability support worker to respond to the complex care needs of a participant where that care is not the usual responsibility of the health system; nursing care may only be claimed as a capacity-building support. The intended rationale for this limited scope for nursing care is to maximise client independence. The nurse teaches the client or support worker healthcare skills and all other nursing services are provided by state and territory health departments. The needs of many people living with disability cannot be met by the NDIS nurse training or consultation model. Nurses should have a larger role in the provision of care coordination and delivery through the NDIS.

24. Nursing services and supports for children with disabilities not only address the immediate medical needs of children but also significantly enhance their quality of life and facilitate their integration into society.

25. A key function of disability services is to alleviate the stress and burnout experienced by families of children with disabilities. Support can significantly enhance life satisfaction and reduce parental burnout, fostering a more nurturing environment for children. Nurses can contribute to this by offering clinical, emotional and practical assistance, which helps families cope with challenges[6].

26. The involvement of disability nurses in the care of children with disabilities can lead to improved health outcomes. For instance, nurses trained in telehealth can provide ongoing monitoring and

support, which is particularly beneficial for children with complex needs[23]. This approach enhances access to care and ensures that interim interventions align with the child's specific requirements.

27. The continuity of care provided by disability nurses fosters trust and allows for a more comprehensive understanding of the child's health and developmental needs[8]. Families prefer to work with the same health professional over time. This relational continuity is critical in community-based settings where disability, MCFH (Maternal Child and Family Health) nurses and midwives can engage with families in their home environments[25].

28. Nurses facilitate play and recreational activities vital for the emotional and social development of children with disabilities. Playing helps children build resilience and develop effective coping strategies, contributing to a positive self-image and emotional health[17].

29. Effective diagnostic services are crucial for identifying developmental concerns early and ensuring timely access to appropriate interventions. Gaps and barriers in accessing these services can significantly impact a child's development, health, well-being, and that of family or caregivers[26].

30. MCFH nurses and midwives are the first point of contact for families navigating concerns about their child's development. These professionals deliver crucial early intervention by conducting developmental screenings during routine health checks to identify developmental delays early; educating families on child development milestones, health and wellbeing strategies; and offering support to parents, equipping them to better care for their child's unique needs[1].

31. NSWNMA members working in the MCFH sector provide developmental assessments at regular health visits to detect development delays early. Early and timely intervention can dramatically improve the outcomes of children with developmental problems[15]. MCFH professionals provide parents with information about child development, enabling them to care for and feel empowered to advocate for their child[27].

32. The use of standardised screening tools and the universal service offered by MCFH nurses and midwives during *Blue Book* checks means that nurses and midwives are best placed in managing child health and development checks.

33. However, our MCFH members face obstacles to care delivery via health care system inefficiencies, including an onerous referral system. By increasing the scope of MCFH nurses and midwives in conducting child health checks and referring families directly to specialists, care for children and their families will be streamlined and more efficient. Standardised screening tools, such as the Ages & Stages Questionnaire[2] (ASQ), have long been used to facilitate the transfer of information in referrals. The MCFH nurse or midwife is well trained in the use of screening tools such as the ASQ, the NSW State Wide Infant Screening Hearing Program (SWISH)[21] and vision assessments. Increased referral rights to reduce burdens on the healthcare system and to increase system efficiencies to the benefit of children and young people living with disabilities will go a long way in addressing the obstacles our members face in healthcare delivery.

Our MCFH members report that there remains a lack of administrative support that impacts upon their ability to provide clinical care. The burden of administrative work means that our members have less time available to provide clinical care, meaning less clients can be seen in a given day. The erosion of clinical time also leads to less availability to provide aspects of nursing care including assessment and care planning. Additionally, less time available for clinical care adds to waiting lists and availability of appointments, delaying the timeliness of client assessment and interventions.

(b) The types of services and supports available and measures to improve effectiveness, availability and access of such services and supports in metropolitan, regional, rural and remote New South Wales, including medical, community-nursing, allied health services, NDIS services and other service delivery models

34. The NSWNMA and our members have significant concerns regarding the scarcity of nurses and midwives in rural and remote NSW communities, depriving many children of specialised healthcare and early intervention. Lack of awareness among parents about available programs and next steps is also an issue. Nurses and midwives help mitigate these challenges by acting as trusted advisers, guiding families through intervention options, and building relationships within local communities to raise awareness about intervention services.

"The government cannot continue to stand by whilst children with social and emotional delays are denied this crucial service to improve holistic healthcare outcomes. These communities are in crises, which is putting unnecessary stress on isolated, vulnerable families who are trying to advocate for their child and feel helpless within a broken system."- NSWNMA Member

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One of the most significant barriers to accessing services is the geographical disparity in service availability. Families in rural and remote areas often face difficulty accessing specialised services due to a lack of local providers and long travel distances. This can lead to delays in diagnosis and intervention, which are crucial during the early developmental years[10, 29].

35. Fragmentation of services can create obstacles for families. Often, diagnostic services, therapeutic interventions and educational supports are provided by different agencies, making it challenging for families to coordinate care effectively. This lack of integration can lead to gaps in service delivery and delays in accessing necessary interventions.

36. Lower health literacy may be a barrier to knowledge of available services and/or how to navigate the complex systems involved in accessing them.

    Families from low-income backgrounds may struggle to afford necessary services, even when available. Financial constraints can limit their ability to seek timely interventions, exacerbating developmental delays and negatively impacting the child's long-term outcomes.

    Families from culturally and linguistically diverse (CALD) backgrounds may encounter difficulties understanding the services available and accessing competent care[16]. This can result in mistrust of the healthcare system and reluctance to seek help, ultimately impacting the child's developmental trajectory[14]. Discrimination experienced by CALD healthcare workers increases psychosocial burden, which impacts quality of care delivered[9].

Increasing the number of nurses and midwives in rural and remote areas through incentives for healthcare professionals can help bridge the access gap through improved staffing. Telehealth services can also provide remote consultations and support, making it easier for families to access necessary services without the burden of travel. Telehealth services should not replace the option of face-to-face services; however, they can be utilised as an effective adjunct.

37. Financial assistance for low-income families should be improved to alleviate economic barriers to accessing services. Additionally, awareness campaigns can educate families about available services and how to navigate the system effectively.

38. Providing cultural competence training for service providers can improve the quality of care for families of children with disabilities from diverse backgrounds, foster trust.

39. Developing integrated service models that coordinate care across agencies can enhance the effectiveness of intervention services. This approach ensures that families receive comprehensive support tailored to their child's needs[19].

    NSWNMA members are ideally placed and specifically skilled to address health inequities and improve outcomes for families and communities. The scope of practice of disability, MCFH nurses and midwives facilitates referral processes to GPs and subsequent paediatric or specialist services; however, timely and accessible follow-up is also essential.

40. Rural and remote communities deserve access to health services commensurate to those in urban areas. Neither place of residence, nor remoteness, should hinder healthcare accessibility and outcomes.

41. Our members assert that investment at the beginning of life will reduce poor health outcomes later in life and is therefore beneficial relative to health outcomes, but also fiscally, through the life span.

"If we do absolutely nothing in this space, we will have poorer health outcomes, poorer educational outcomes, poorer job opportunities and a financial deficit for the region. Shame on us, this will be felt for generations to come. Every child deserves the right to healthcare, no matter where they live."- NSWNMA Member

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42. Our members report that referral processes in some rural and remote NSW communities are being disrupted due to lack of paediatric and specialist supports. The inability to refer to appropriate specialists means that GPs are left with no alternative but to refer these children back to MCFH nurses and midwives to try and manage their ongoing care. The MCFH nurses and midwives are then left to try and find alternatives where service gaps exist. Often the only option is in distant locations, and at cost, which are prohibitive for the families. Solutions to improve local access to specialist medical and allied health services must be implemented.

43. The NSWNMA is aware that some rural and remote communities have resorted to flying metropolitan-based paediatric supports in on a fortnightly or monthly basis to assess referred children. An urgent review of service gaps is required to ensure that regardless of location, all children receive adequate care and support. With adequate funding, paediatrics and other

specialties can be brought into these local communities, to provide ongoing input for these often-desperate families.

(e) Opportunities to increase engagement across sectors and improved collaboration across both government and non-government services, including Aboriginal Community Controlled Organisations, early learning services, educational settings and health services

44. Approximately 6.0% of First Nations people live in remote areas, whilst 9.4% live very remotely[3]. The proportion of the total population who identify as being Aboriginal and/or Torres Strait Islander increases with remoteness. The NSWNMA acknowledges the profound connection to land and Country in First Nations culture. This connection not only shapes identity but also encompasses responsibilities, spirituality, social kinship and emotional well-being. In these communities, reliance on local GPs practising westernised medicine, travelling to nearby towns or implementing telehealth services for early childhood health and development assessments is not always conducive with the provision of culturally safe care in rural and remote communities.

    Culturally safe healthcare is imperative in improving access and addressing the gaps in health outcomes for First Nations children and families in rural and remote NSW communities. Disability, MCFH nurses and midwives are well placed to work collaboratively with Aboriginal Health Workers (AHWs) and Aboriginal Health Practitioners (AHPs) to foster trustworthy and compassionate professional relationships with children living with disability and their families[20].

"I worked side by side with the most amazing Aboriginal Health Worker who also identified the massive gap in the children's development."- NSWNMA Member

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45. Upon the identification of significant MCFH service disengagement in Warren in Western NSW, the *Bellies and New Life* program was established through collaboration with Warraan Widji Arts, a local Wayilwan language and cultural community group. Funded by the NSW Department of Aboriginal Affairs, *Bellies and New Life* utilises cultural dance, language, and music to encourage First Nation's pregnant women to paint belly castings and yarn with Elders, whilst simultaneously being linked into MCFH services with the support of an AHW. The program highlights the importance of MCFH services working in partnership with AHW to address service gaps. It has successfully established trust to facilitate access to healthcare by families who are not only vulnerable but were previously disengaged.

46. The NSWNMA supports Aboriginal and Torres Strait Islander community control in health as a means of reducing health inequalities. To adequately identify and address the unique needs of vulnerable First Nations children, consultation and collaboration with each local community is fundamental. Tailored implementation of appropriate and localised services without a need to travel off-Country is paramount for early intervention. Specifically, increasing engagement across sectors and improving collaboration amongst agencies, including Aboriginal Community Controlled Health

Organisations (ACCHOs), early learning services, educational settings and health services, is essential for enhancing outcomes for children with disabilities and their families.

47. The NSWNMA acknowledges the preference of Indigenous Australians to receive care from Indigenous health professionals due to enhanced cultural safety. Presently, there is a stark underrepresentation of Aboriginal and/or Torres Strait Islander nurses and midwives within the workforce, comprising only 1.3% nationally[4]. This lack of representation poses barriers to service access and results in a significant deficit in culturally appropriate care, exacerbating health disparities. The NSWNMA emphasises the importance of addressing this under-representation as the benefits are two-fold: Firstly, improved engagement with children and families in Aboriginal communities in NSW, due to enhanced cultural awareness and safety. This facilitates engagement and subsequently improves early identification and intervention for children with disabilities. Secondly, employing more Aboriginal and/or Torres Strait Islander nurses and midwives will assist in addressing current workforce shortages, rebuilding a more sustainable workforce.

48. The NSWNMA acknowledges that whilst telehealth services have emerged as a viable option for increasing access to health and educational supports, particularly in rural and remote areas, they are not necessarily culturally relevant and accessible for Aboriginal and/or Torres Strait Islander children and families.

(g) Workforce issues in the child development and early childhood intervention sectors, including workforce demand and the availability, quality and capacity of existing workers

49. The demand for MCFH nurses and midwives is high, but the sector faces workforce shortages. Some potential solutions have been outlined in paragraphs 17, 19, 47 and 50. There is an urgent need to grow and maintain the nursing and midwifery workforce to support children and young people living with disability. NSW remains behind the rest of the country, particularly regarding pay and conditions for nurses and midwives. This leads to loss of new and experienced nurses and midwives to other states. Our experience has been that the Government has implemented an informal wages cap restricting the ability to address issues such as workplace shortages in bargaining. Due to the restrictions the Government has made to bargaining, the NSWNMA needs to lodge special cases to seek the assistance of the IRC in delivering pay increases that addresses issues such as workplace shortages. These types of cases are costly and lengthy. A decision is unlikely to be given until the end of 2025 at the earliest, which will mean that any effect of relief granted to address workplace shortages will be delayed.

"Over the course of my nursing career I have had an increase in pay that equates to $1 per year over 40 years... If any government wants to get serious about improving outcomes, then renumerate nurses accordingly."- NSWNMA Member

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50. Our members report that workforce issues in the child development and early childhood intervention sectors present significant challenges that impact the quality of services provided to children and families. The shortage of skilled personnel in MCFH is compounded by a lack of funding and training programs that cater to children and families. To counter these obstacles, training programs that

support specialisation in child and family health, particularly in rural communities, should be increased. Additionally, monetary incentives will attract and retain healthcare workforce in underserved areas[13]. Efforts across sectors, and a focus on cultural competence, will be essential in building a robust and responsive workforce that meets the diverse needs of children and families.

51. MCFH nurses and midwives often travel long distances, particularly in rural and remote areas, to undertake assessments. Increased or targeted staffing is required to mitigate risks associated with travel. Although telehealth provides an adjunct to face-to-face appointments, our members report that many at-risk and disadvantaged families do not attend online appointments, meaning an emphasis should remain for home visiting. Home visiting programs have been found to improve socio-emotional, cognitive and language development in the developing infant and child as well as benefits to parenting practices including improved breastfeeding rates and enhancements to parenting styles. Improved maternal physical and psychosocial health are additional outcomes, along with increases in maternal self-sufficiency[18]. Supporting parents in the parent-child relationship and interaction provides positive developmental outcomes to the child and young person.

Conclusion

52. This submission highlights shortfalls impacting our members who deliver care to families of children and young people living with disability across all jurisdictions, particularly rural and remote NSW communities. These shortfalls must be addressed as a matter of urgency. No one living with a disability should fall through service gaps due to funding or geographical location or due to workforce insufficiencies. The NSWNMA hopes that this submission will provide guidance for this Inquiry and that optimal life is actualised for all people living with a disability.

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