Royal Far West's response to NSW Parliament Committee on Community Services Inquiry into improving access to early childhood health and development checks

August 2024

Late submissions can be provided to the Committee via email at:
communityservices@parliament.nsw.gov.au

Terms of reference:

1. Barriers that affect parents' access to routine health and development checks that track their child's progress against developmental milestones.
2. Recruitment and retention of health professionals to address workforce shortages.
3. Funding for early intervention programs and screening to ensure children are given support for developmental issues, including telehealth and other models.
4. Any other related matters.

General Comments

This submission is based on Royal Far West's (RFW) extensive experience working with schools, early education centres and families in rural and remote communities across NSW. This submission addresses the terms of reference in regard to barriers to accessing routine developmental checks, workforce issues and funding for early intervention.

The importance of early development checks for children in rural and remote NSW has been highlighted significantly in recent years because of a compounding set of circumstances. The effects of COVID, natural disasters (such as bushfire, drought and floods), as well as increasing cost of living pressures have all contributed to a significant increase in child behaviour and mental health issues reported in schools and by paediatricians in rural NSW. Coupled with a shortage in specialist workforce (developmental paediatric allied health services as well as paediatricians) in these areas, this has resulted in the problem compounding. This means children are often not being seen by a specialist until they arrive at school, by then many children are presenting with significant speech or behavioural challenges. Teachers are not equipped or resourced to deal with these issues and the child is then deemed "difficult" and the pattern is set. This can precipitate wide reaching issues both at school and longer term, including attendance, learning and social-emotional wellbeing. Teachers and early educators in rural areas consistently report to the RFW team that following COVID lockdowns there are greater numbers of children they worry about, and these children are increasingly younger and more complex in their needs. They also report increased educator stress and burnout.

The latest Australian Early Development Census (AEDC) research shows that children living in rural and remote NSW continue to have a far greater likelihood of developmental vulnerabilities or delays compared to their city counterparts – which in turn is linked with poor educational outcomes, disability, chronic mental health problems and a higher risk of unemployment, personal relationship difficulties, contact with the criminal justice system and homelessness. The physical, emotional and social development attained in childhood sets a trajectory for long-term outcomes in health, education and wellbeing.

Research shows nearly 70% of regions with the highest rates of child development vulnerability are located in rural and remote areas of NSW.

Further to this, the highest levels of developmental vulnerability on two or more domains in NSW include:

1. Bourke 40% (Western LHD)
2. Cobar 31.95 (Western LHD)
3. Coonamble 31.6% (Western LHD)
4. Griffith 26.7% (Murrumbidgee LHD)

Recognising the significant need, in 2022 the NSW Government announced the Brighter Beginnings initiative, which included $111.2 million to bring health and development checks to all children in NSW preschool settings in partnership with health professionals. These checks are for 4-year-olds before they start school.

Prior to this, Royal Far West ran a philanthropically funded screening program in rural and remote NSW called the Healthy Kid Bus Stop (HKBS). This program ran for eight years (2014-2022) and ceased in 2022 as a result of the announcement of the Brighter Beginnings initiative. The HKBS was a free mobile developmental screening program for 3–5-year-olds living in rural and remote NSW. The health screening was undertaken by a multidisciplinary team of nursing and allied health staff from RFW, working with staff from other agencies such as the Local Health District (LHD), the Primary Health Network (PHN), Aboriginal Health Services and other local health service providers.

Over the eight years of its operation, the HKBS delivered screening to over 5,000 children living in rural and remote NSW who otherwise would have carried unidentified and untreated issues into school, risking their academic and life progress. A significant 80% of these children were referred to at least one other health service as a result of the screening. Children with complex developmental needs who were unable to access local services were referred to RFW's Paediatric Development Program (PDP), where they received a multidisciplinary assessment. The HKBS provided an integrated assessment service, delivered by a multidisciplinary, allied health team (speech and language, hearing, dental and behaviour). It also worked with other local services – such as community-based health and education organisations – in supporting children identified with developmental needs.

It is RFW's understanding that the Brighter Beginnings screening initiative currently underway in the most remote areas of NSW is a far less comprehensive screening process than the HKBS. From feedback RFW understand that the check, focusing more on basic developmental milestones, includes only a blue book checklist, basic hearing and vision screening and weight, height etc. Under the KPIs of the program, the clinicians do not need to provide any treatment program, and only provide simple strategies to preschool teachers, further increasing the educator's workload. Given it is a universal check for 4-year-olds, and not staffed appropriately, it is our concern that the same disadvantaged children, a high per cent indigenous, will continue to fall through the cracks and not receive the ongoing healthcare that they require.

1. Barriers that affect parents' access to routine health and development checks that track their child's progress against developmental milestones.

1. Limited or no screening available

The most vulnerable children live in the most remote locations where screening services typically have not been available. Many families do not have access to transport, nor are they aware of screening services available. The same locations often do not have access to early education services, where developmental issues can also be identified.

Royal Far West (RFW) understands that in Western LHD, there is one nurse, one speech pathologist and one occupational therapist to undertake the Brighter Beginnings screening for the entire area. Given there are approximately 4,000 4-year-olds in this LHD – it is not realistic that all children can be properly assessed. Four years of age is also a very late stage of development to determine if a child needs further support when this could have been implemented much earlier in a child's development.

RFW also understands the screening underway, due to staffing issues, is not a full multidisciplinary team (MDT) assessment but a tick the box weight and height screening test. What is needed is a proper MDT assessment, which is a comprehensive process that includes: case history, family interview, integration of assessment results from other disciplines/sources, standardised and/or non-standardised measures specific to the concern and integration and interpretation of all gathered information to formulate diagnosis and develop a treatment plan, including referral on to other relevant services.

To significantly compound the issue, once screening is complete and a child is referred for specialist support, there is either a wait time or lack of services to help with the identified developmental issue.

In its own submission to this Inquiry, NSW Health states:

"Through the Brighter Beginnings Health and Development Checks in Early Childhood Education and Care program, multidisciplinary health teams including a range of allied health disciplines are now being established across NSW to provide health and development checks for 4-year olds in early childhood education environments. This program has been established to increase the number of 4-year health and development checks being completed in response to the evidence of the importance of identifying children's needs prior to their commencement of school. .....Children and families are referred to allied health services by GPs, paediatricians/specialists, child, and family health services or directly by parents if they have concerns about their child. Education providers may encourage parents to seek services. The types of allied health professions employed through NSW Health vary across districts in NSW, but predominantly include speech pathology and occupational therapy services, with some also providing dietetics, orthoptist, physiotherapy, psychology, and/or social work services. Children may also be referred to other public or private allied health services as required, including audiology, exercise physiology, optometry, podiatry, or orthotics/prosthetics. Many districts experience high demand for their allied health services and children can experience long waiting times to access therapy and early intervention services. Allied health services are also not available in some regional communities."

2. Limited access to GPs and paediatric specialists for assessment and follow-up.

The 2023 report, "Evidence base for additional investment in rural health in Australia", released by the National Rural Health Alliance (NHRA) and conducted by the Nous Group, identifies that in the Australian healthcare system GPs are the common referral pathway for services. Low GP access results in flow-on impacts to accessing allied health and specialty services. It is recognised that where primary care access is low, patients access emergency departments at higher rates.

Additionally, compounding the issue of a lack of GPs for referral, is the lack of paediatric specialists for follow-up. This is covered under the workforce terms of reference.

In a recent survey of parent participation for our Paediatric Development Program (PDP) assessment service (residential service in Manly), covering the past 18 months, over 80% of parents/carers surveyed said they experienced difficulties in accessing local speech therapy, occupational therapy or psychology services. The main difficulties faced were:

- Over 70% said waiting times for local services were too long
- Nearly 60% said local services were inconsistent
- A third said local services were too expensive
- 35% said travel time and no local services were the main difficulties

3. Limited access to early learning – rural areas miss out

Adding to the existing disadvantage for children living in rural and remote areas, is the issue of access to childcare – where many developmental issues are identified and referred to health specialists. The Mitchell Institute's report released in 2022, "In the Deserts and oases: How accessible is childcare in Australia?", shows that shortage of early childhood education and care increases in regional and remote locations. About 30% of people living in major cities live in childcare deserts, compared with around 87% and 80% of people living in remote and outer remote neighbourhoods.

While the large numbers of rural and remote children missing out on early learning may not be a surprise, research shows it could have life-long impacts on young children. The importance of early learning and access to childcare in addressing developmental vulnerabilities is key – it is all about early intervention and picking up challenges before children start school.

Royal Far West's own data analysis has found over 190,000 children across rural and remote Australia need some form of developmental support.

4. Challenges accessing support under NDIS

Children from rural and remote Australia face substantially less positive outcomes from the NDIS due to a number of compounding factors. These factors are at play from the moment a child is identified as requiring additional support.

Scheme access

Families face delays from the outset in accessing Scheme due to lack of paediatricians or allied health professionals who can diagnose or assess their children (outside of the early childhood pathway), as well as a lack of access to early childhood partners for those under the age of six.

Choice

When on Scheme there are substantially fewer providers available to rural families, which means families have less choice, and may feel pressured to utilise a provider that is not a great fit for their child. Where providers are available, they generally have long waitlists. There is also a great deal of confusion with state-run Community Health services, who are exiting children from therapy once they have NDIS plan approval. This may mean that families are left with no therapy while they wait for a NDIS provider. Essentially, these families may have been better off without plan approval if they had access to Community Health.

Providers

NDIS providers in rural and remote areas may have to rely on inexperienced and junior staff, and often cannot provide a continuity of care due to a very high staff turnover. As a result, families may not be able to access any services that are operating under best practice guidelines. The lack of development of the Allied Health Assistant model is extending these issues.

Not-for-profit organisations are continuing to provide services but are not adequately supported to operate in thin markets, where transactional funding is unsustainable. There continues to be a lack of support for community service that are struggling to exist and operate a sustainable business.

Distribution of active participants by remoteness 30 September 2023 - intellectual disability and all participants

Remoteness	intellectual disability	All participants	Percentage of all intellectual disability participants	Percentage of all participants
Major cities	57,931	432,047	64%	68%
Popln > 50k	10,172	68,321	11%	11%
Popln 15k - 50k	9,154	52,229	10%	8%
Popln 5k - 15k	5,005	28,706	6%	5%
Popln < 5k	5,978	40,627	7%	6%
Remote	1,027	5,791	1%	1%
Very Remote	740	3,765	1%	1%
Missing	<11	43	0%	0%
Total	90,014	631,529	100%	100%

Ime: NDIS Dashboard – remoteness and participants

Plans

Small plans do not take into consideration the distances that providers need to travel to reach remote families. Travel costs for rural families are often at least double that of metropolitan

services, and there have been multiple examples of providers taking advantage of excessive distances and engaging in price gouging. It is not uncommon for families to pay up to $500 per session by the time travel and report writing is included. Due to the lack of choice and competition, families are forced to accept this and see plans eaten up by additional costs.

If plans are not able to be fully utlilised due to a lack of providers, then they may be reduced in subsequent years. In order to avoid this, some families exhaust their plans through getting reports to support an increase, only to then have the new plan denied.

Guidelines

Rigid operational guidelines don't take into account unique factors for regional families – such as longer waiting lists, longer travel distances and less choice – increasing stress impacts on the parents mental health. Many families are absorbing the travel costs themselves if providers are unable to travel to them.

First Nations participants

The above issues are often exacerbated for remote First Nations participants, who face additional barriers to entry. RFW supports the Coordinated Funding Proposal approach that can be used when the supports not available locally, are too expensive or are not good quality. However, this approach will only be successful if there is a local representative driving the proposal – such as a school or early childhood educator worker who has an excellent understanding of the NDIS.

2. Recruitment and retention of health professionals to address workforce shortages

The lack of public paediatric services in all rural areas of NSW, coupled with an increased need for services, has resulted in many closing their books to children with developmental issues and focusing solely on critical or emergency presentations. The result is waitlists of between 18 months and up to six years in some centres, for children ~~r~~eferred for language delay, ADHD, autism, anxiety and learning difficulties. The alternative is to see a private practitioner, which is often a prohibitive cost factor for many families, with reports of up to $3,000 being charged for an assessment.

RFW regularly receives phone calls from GPs across the state, reporting a lack of paediatric access and assessment support for children who are developmentally vulnerable. Paediatric waitlists have been an ongoing and worsening situation in many major rural centres.

To the best of our knowledge – this is the situation today:

Dubbo and Orange: have closed their books for developmental or behavioural referrals

- Coffs Harbour: 24 month wait to see paediatrician
- Bega: 18-24 month wait to see paediatrician
- Tamworth: long wait times, with local families being told they will be waiting "up to six years" for an appointment and to try elsewhere

- Wagga: two year waitlist

It is now widely recognised within rural health services that the most vulnerable, complex children in remote NSW may not be properly assessed, a situation that is not equitable and serves to replicate a cycle of disadvantage.

At RFW's PDP development assessment service at Manly, the average age of a child being seen is now 10-years-old. They are coming to us at this age often because of delayed referrals from paediatricians, however the issues that they face as a 10-year-old are much harder and more expensive to address.

At a RFW event in Sydney in April 2024, two paediatricians based in Wagga, Dr Theresa Pitt, and Dr Leah Maree-Finney, talked about the crisis emerging in this sector.

Event link here: https://www.youtube.com/watch?v=M6858rrEIQc

The main issues raised included:

- A significant increase in referrals for behavioural issues and mental health over the past few years, including physical and verbal violence issues, and higher rates of diagnosis of ADHD and autism.

- The Wagga Base public paediatric clinic is receiving between 20-30 referrals per week. Two thirds are for emotional or behavioural issues, with a waitlist of up to two years.

- A shortage of rural GPs means a child may wait weeks or months to be seen. GPs previously managed many developmental issues immediately, however these are now being referred to paediatricians.

- A shortage of allied health services – particularly speech therapy and occupational therapy –with many closing their books. In addition to this, the services are expensive and a lack of NDIS services accentuates the issue.

The paediatricians said other avenues are needed to alleviate the waitlists and lack of services on the ground. If this doesn't happen, there will be a continuing cycle, for example: a child that doesn't speak well at 2-3 years of age and is missed, arrives at school with developmental delays, is bullied, becomes the 'naughty' kid, gets into trouble, behaviour gets worse, leaves school early, can lead to crime, unemployment or drugs and then the cycle begins all over again.

Similar to the shortage of paediatricians in rural and remote areas, there is a shortage of allied health services – speech, occupational therapy and clinical psychology. All these specialised skills in supporting children's development have long wait times, are long distances away or cannot see clients regularly enough to have an impact.

Recruitment and retention of allied health staff, who are critical in addressing developmental health, remains a critical issue in rural and remote NSW. Allied health practitioners working in rural and remote areas have populations spread over vast geographical areas, serve a wide range of clients and clinical presentations, are often isolated and typically, are not paediatric specialists. The serious shortage of allied health professionals in country NSW, especially psychologists, along with a lack of paediatric and diagnostic services is creating exceptionally long waiting lists in some locations.

Despite the pressing demand for allied health services in these areas, attracting and retaining staff remains difficult. The NHRA/Nous report shows that this workforce pipeline will not change anytime soon. A survey of final year medical students in 2021 demonstrates graduates' strong preference to work in capital cities with less than 5% wanting to work in a small town or rural community.

3. Funding for early intervention programs and screening to ensure children are given support for developmental issues, including telehealth and other models.

Across both health and education, early intervention services remain significantly underfunded. NSW Department of Health bureaucrats report that their discretionary budgets are exhausted and that current fiscal conditions mean there will be no additional funds to supplement or fund new or existing services. Local Health Districts (LHDs) want to retain funding and workforce but cannot fill vacant workforce places in paediatrics and allied health and remain reluctant to outsource or rely on visiting medical officers to fill gaps. This is not sustainable and does not allow for continuity of care.

Schools are expected to fund early intervention as part of their operating budgets but cannot cope with increased demand which arises from the increasing mental health issues and complexity of children in the classroom. Classroom teachers are not sufficiently trained to support children with developmental vulnerabilities, or the increasing trend of child protection concerns.

4. Any other related matters

The physical, emotional and social development attained in childhood can make the difference between kids flying or falling behind, not just in school but across their lifetime. The 2021 AEDC figures highlight that those children who are already disadvantaged, the majority of whom live in rural and remote areas, are slipping further behind, especially those with two or more developmental vulnerabilities. In its 2021 national report, the AEDC said: "These changes can appear to be small, but they are significant, with real impacts at the community level..... This highlights the fact that substantial support is still needed for these children to have the best chance of thriving through their school years."

RFW recommendations:

1. Fund place based early intervention and assessment programs in both the early years and early to middle school years. This will result in a long-term, positive impact for children, yet remains significantly underfunded by government. Funding for these services often falls between education and health portfolios; health and education departments do not fund services centrally; and hence NGOs or NFPs are often left to provide philanthropic services.

2. Address workforce issues with a combination of outreach, telehealth and locally based staff, leveraging the gains made in the acceptance of telehealth during COVID.

3. Engage and support educators in the screening process through capacity building workshops. This would help identify when children need referral and/or assessment, and to which discipline they should refer.

4. Increase knowledge and awareness in rural communities about development milestones and the need for screening. Families and educators report value in spending time with clinicians and learning more about child development.

Distribution, supply, and need for speech pathologists

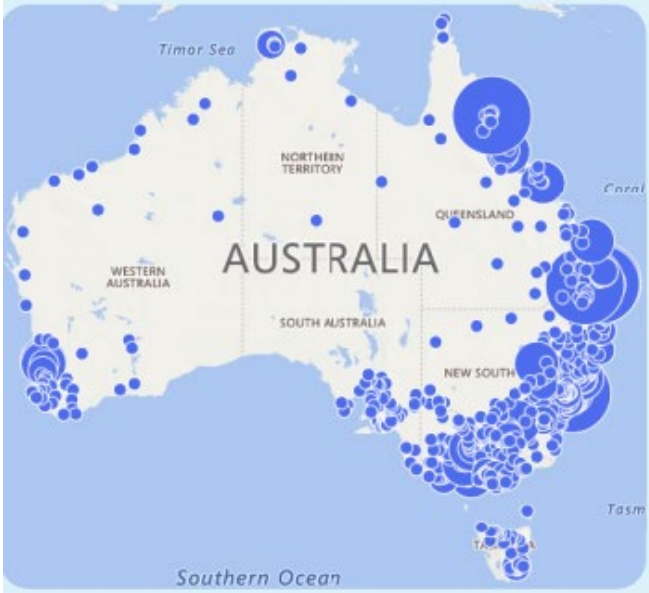


Figure 3 illustrates the overall distribution of speech pathologists nationally, with larger circles representing greater numbers of speech pathologists.

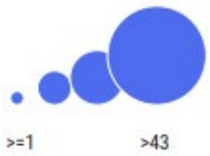


Figure 3. Distribution and number of speech pathologists across Australia.

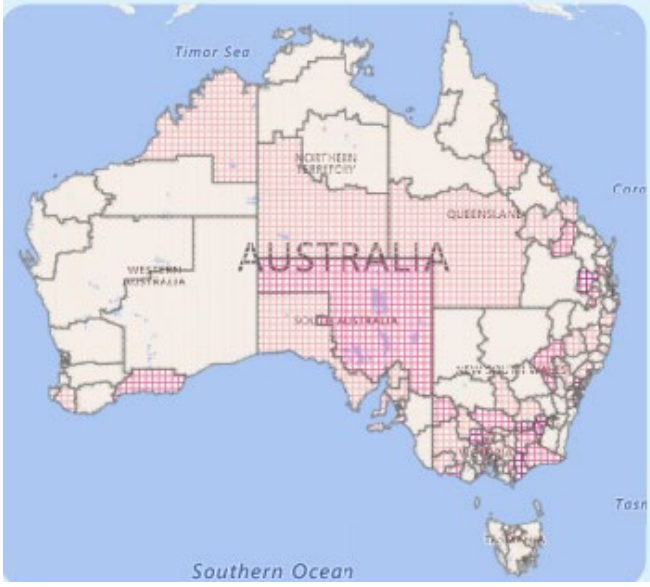
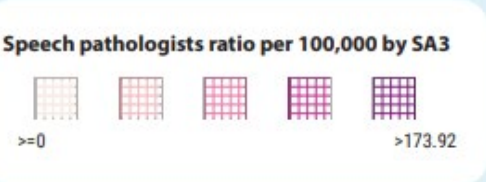


Figure 4 shows the ratio of speech pathologists per 100,000 population. The darker colours represent higher ratios of speech pathologists. Most speech pathologists were located in areas of higher population, particularly the Australian eastern seaboard and capital cities. Fewer speech pathologists were distributed across rural and remote areas.



Speech Pathology Workforce Analysis – Speech Pathology Australia, March 2023

Feedback from rural and remote stakeholders (Feb-April 2024)

"You are likely well aware of the escalating waiting times faced by both general practitioners and paediatricians across the state in recent years. Within my region, countless families encounter formidable obstacles in accessing a paediatrician for developmental assessments, particularly if they cannot locate a bulk-billing service."

A/Professor Head of Paediatrics, Maxwell Hopp, Griffith Base Hospital

"As a referring doctor, I've witnessed firsthand the growing strain on both general practitioners and paediatricians across New South Wales, leading to extended wait times. Having served as a paediatrician in the Murrumbidgee Local Health District for over seven years, I heavily relied on Royal Far West's services. It's a privilege to have such a valuable resource in NSW, and I consistently emphasise this to my patients and their families. Unfortunately, accessing a paediatrician and psychologist, especially for developmental assessments, remains a significant hurdle for many families in rural and regional areas. While the situation isn't ideal in metropolitan areas either, at least there are more options available."

Dr Khalil Soniwala, Specialist Paediatrician

Royal Far West

Royal Far West (RFW) is a specialist child development service providing vital supports to improve the health and wellbeing of country children. In 2024 RFW will turn 100 years old and throughout its history its mission has remained unchanged. Its bold ambition is to ensure every country child has access to the services they need to support their early development and enrich their lives

RFW offers multidisciplinary allied health, mental health and wellbeing services for children up to 12 years of age living in rural and remote Australia. Our team of 150+ trauma-informed, paediatric allied health and medical staff support country children with their developmental health needs, including speech and language delays, behavioural and learning difficulties and mental health needs. Last financial year, we supported over 3,000 country children with complex needs and over 21,000 total beneficiaries including parents, carers, educators and health professionals across three states, 161 schools and 50 early childhood centres in more than 364 rural communities.

Our Services:

Schools and Early Years Services

We partner with schools, early childhood centres and families to support country children's behavioural, mental and developmental health in their own communities so they can belong, learn and grow. Our services are delivered by dedicated multidisciplinary allied health teams

virtually and in-person into schools and early childhood centres.

Community Recovery Services

A multidisciplinary and community-based service providing psychosocial support to children and key adults supporting children (parents, carers, teachers and professionals) with recovery, wellbeing and resilience following natural disasters like bushfires, droughts and floods. This service is delivered in-person through schools and early childhood centres in areas affected by natural disasters.

Child and Family Services

A holistic multidisciplinary assessment, referral and treatment service for country children and their families in NSW with complex developmental, mental health and behavioural needs. This is a residential program, based in Manly, with follow-up services provided locally or via telehealth.

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