Royal Far West

Children's health, country-wide

Remote, Rural and Regional Health Inquiry into the implementation of Portfolio Committee No. 2 recommendations relating to the delivery of specific health services and specialist care in remote, rural, and regional NSW

April 2024

Royal Far West's response to the Inquiry into the implementation of Portfolio Committee No. 2 recommendations relating to the delivery of specific health services and specialist care in remote, rural, and regional NSW. This response addresses the terms of reference regarding paediatric and allied health specialist services. It builds on our previous submission in September 2023 and our attendance at a Committee hearing at Parliament in November last year. Royal Far West is happy to provide more detail if required, and extends an open invitation to the Inquiry Committee to visit us in Manly or see our team working on outreach visits in rural and remote locations across NSW.

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About Royal Far West

Royal Far West (RFW) is a children's charity, turning 100 years old later this year. Our mission is to improve the health and well-being of children who live in rural and remote communities across NSW and nationally. We believe every country child should have access to the services they need to support their early development and enrich their lives.

We offer 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 3000 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 pre-schools in more than 364 rural communities.

Our Services:

1. Schools and Early Years Service

We partner with schools, pre-schools, 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 years settings.

2. Community Recovery

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 pre-schools in areas affected by natural disasters.

3. Child and Family Services

A holistic multi-disciplinary 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.

General Comments

This submission is based on Royal Far West's extensive experience working with schools, pre-schools, and families in rural and remote communities across NSW. This submission focuses on the specialist areas of allied health and paediatric services, and addresses two questions:

Q1: What are the challenges facing the delivery of speciality services in rural and remote areas of NSW (paediatrics and allied health)

and

Q2: Have they improved in recent years? Has there been any change to the issues raised since recommendations were released in 2022?

The effects of COVID; and natural disasters (bushfire, drought, floods) as well as substantive cost of living pressures, is starting to play out in rural communities with a significant increase in child behaviour and mental health issues reported in schools and by paediatricians throughout rural NSW, over the past few years. Coupled with a shortage in specialist workforce in these areas, this has resulted in the problem compounding – meaning children are often not being seen by a specialist until they arrive at school – by then many 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 which can precipitate attendance and even truancy issues. Teachers and early educators on the ground in rural areas consistently report to our RFW teams 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.

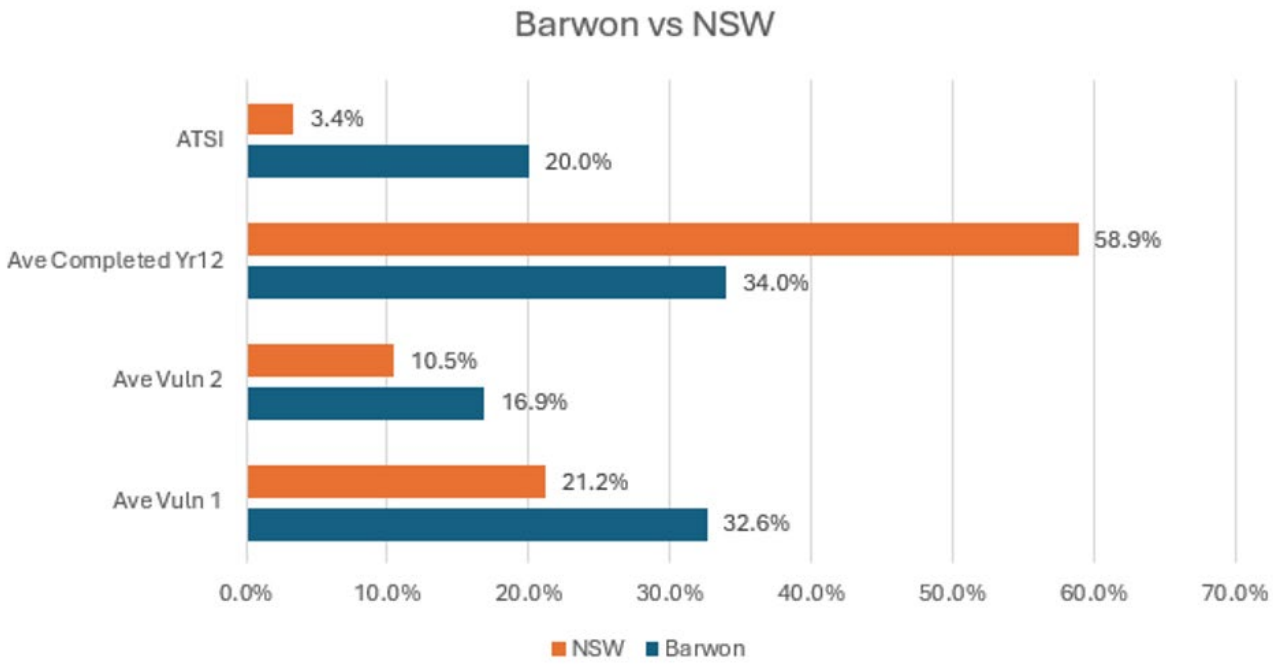
Latest research shows that children living in rural and remote NSW continue to have a far greater likelihood of developmental vulnerabilities or delays compared to their city counterparts – which in turn are linked with poor educational outcomes, disability, chronic mental health problems and a higher 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 well-being.

In our submission in September 2023, we highlighted how 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)

The following table highlights the context and need facing NSW's most remote electorate of Barwon – in comparison to the rest of the State.



1. Challenges accessing paediatric services

There is a crisis in paediatric services in many rural and remote areas of NSW. A shortage of specialists coupled with significant, increased need for services has meant many paediatric specialists working at public hospitals have closed their books to non-emergency patients, particularly those with developmental and mental health conditions. The result is waitlists of between 18 months and up to six years in some centres, for children referred 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 $3000 being charged for an assessment.

This situation has worsened in the past 18 months.

Royal Far West 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.

In our submission in September 2023, we included, to the best of our knowledge, waitlists for paediatricians seeing behavioral/developmental issues in major regional public hospitals:

This situation has further deteriorated in six months. This is the state of play, to the best of our knowledge 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 has long wait times – local families have been told they will be waiting "up to six years" for an appointment and to try elsewhere
- Wagga: two-year waitlist

Other cases reported to Royal Far West clinicians recently:

- GPs are writing acute paediatric conditions such as headaches or respiratory problems on referrals to paediatricians, to ensure kids with developmental problems are seen sooner, only mentioning their developmental problems in passing.
- At least a 2 week wait for a GP in Narrabri even if your child has a fever – only choice is to go to the hospital placing further pressure on that system.
- A family in Tamworth have been told don't bother going on a waitlist for a paed as people on the waitlist are being told it is a 6-year waitlist and advice is to go to Coffs Harbour that has a two-year waitlist.
- There is no public paediatrician in the Eurobodalla LGA, families need to travel to Bega or Wollongong. As mentioned, the wait time in Bega is approximately 18 months. Bega is about a 2-hour drive from Batemans Bay
- Mudgee client said "Our doctor, speech therapist and occupational therapist have said our child needs to see a paediatrician, but we can't get into anyone. My sister lives in Sydney so have asked around but they have all said they aren't taking on any new patients outside of Sydney."
- "I have tried Orange Bathurst Cowra and Wagga for an ADHD assessment for my son with no luck"

In 2022, the NSW Health Agency for Clinical Innovation completed a review of diagnostic services and emphasised the importance of a tiered system for diagnosis with tier 4 services available for the most complex patients. Tier 4 services are available in metropolitan areas only, and, as they are only accessible with a paediatrician's referral, regional patients may be waiting up to four years.

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 Royal Far West's Child & Family development assessment service at Manly, the average age of a child being seen is now 10 years - often because of delayed referrals from paediatricians. 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 2023, 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=M6858rrElQc

The main issues raised included:

- A significant increase in referrals for behavioural issues and mental health including physical and verbal violence issues over the past few years with 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 – speech and OT – many have closed their books plus they are expensive, and 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: a child that doesn't speak well at age 2/3 years and is missed; arrives at school delayed; is bullied; becomes the 'naughty' kid; gets into trouble; behaviour gets worse; leaves school early; can lead to crime; unemployment; drugs and the cycle begins all over again.

2. Challenges facing delivery of allied health services

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 also have long wait times, are long distances away or cannot see clients regularly enough to have an impact.

In the most recent survey of parent participation for our Child & Family Manly development assessment service, covering the past 18 months, **over 80% of parents/caregivers 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 of parents surveyed said local services were too expensive and 30% said travel time and no local services were the main difficulties

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.

Mental health services for children in NSW rural and remote communities is an ongoing area of great unmet need. So too, with increasing stress for many families, child protection and family wellbeing issues are anecdotally increasing, however there is a persisting shortage of

child protection workers in many rural remote areas, which compounds effects of allied health shortages.

Children in regional areas and remote communities have severely limited access to services that support healthy development, such as medical and allied health services. Our previous submission outlined the significant discrepancy between the availability of allied health clinicians in metropolitan areas compared to country areas.

Another recent report from Wagga Wagga is that Occupational therapists in the area have also closed their books.

A 2023 report released by the National Rural Health Alliance (NHRA) by the Nous Group: "Evidence base for additional investment in rural health in Australia" – provides data on the annual health spending deficit in rural Australia compared to metropolitan Australia. It demonstrates that rural Australia has a health access spending deficit of $6.55b annually, equating on average to $848.02 less expenditure annually per rural person compared to their city counterparts. The report highlights a triple disadvantage for rural Australians: negative social determinants of health, poor service availability, and higher cost of access and delivery have resulted in poor health outcomes. The report 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 recognized that where primary care access is low, patients access emergency departments at higher rates.

Research shows the prevalence of health professionals on a per capita basis, including allied health professionals is also reduced in rural areas. Inadequate supply and uneven distribution of the allied health workforce impedes rural communities access to essential allied health services, particularly in remote areas. Despite the pressing demand for allied health services in these areas, attracting and retaining staff remains difficult. The 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.

At the same time, demand for clinical allied health services into schools and pre-schools continues to grow as educators attempt to deal with significant increased levels of complexity amongst children living in rural and remote areas.

Improvements

Over the past 18 months, there has been greater collaboration and discussion around these significant health issues affecting rural and remote NSW. However, data remains hard to access in terms of official waitlists and need.

Similarly, 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.

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 remain 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. Greater collaboration between the Department of Health and the NGO sector to ensure a joined-up approach to escalating complexity and access issues.
3. Address workforce issues with a combination of outreach, telehealth, and locally based staff, leveraging the gains made in the acceptance of telehealth during COVID.
4. Provide greater transparency on waitlists and data sharing to ensure there is not duplication occurring across districts and with NGOs.

Royal Far West has a current Budget ask with NSW Government to expand our developmental assessment and treatment service, with the establishment of two new rurally based paediatric assessment clinics in Wagga Wagga and Dubbo in collaboration with the LHDs. This would provide assessment and support to an additional 1000 children with developmental delays across Western LHD and Murrumbidgee LHDs, (where 60% of our current referrals come from) and offer professional development for local health professionals, training and education for teachers and parents.

While the proposal is focused on health outcomes, it also has positive long term economic impacts. A substantial evidence base shows that if you start school developmentally vulnerable this will not change without an adequate assessment and treatment pathway. Not addressing these disadvantages has long term economic and social impacts. Additionally, the program will also focus on growing the rural health workforce, and capacity building with local clinicians, educators, and family workers

International cost benefit analysis shows that for every dollar spent on effective early childhood intervention, there is a $13 - $25 return to society.

In terms of government services, better coordination and planning between health, education, and child protection/family services locally, would provide better support to the most vulnerable children and families.

ENDS ###

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 7 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 emphasize 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

"I expect you are aware of the increasing waiting times for both general practitioners and paediatricians across the state in recent years. In my region (the Mid North Coast) many families face significant challenges in accessing a paediatrician for developmental assessments, particularly if they cannot find a bulk-billing service."
Dr Stephanie White, Consultant Paediatrician

"MPHN currently funds a range of programs across the region to encourage equitable access to timely and professional paediatric care. While these activities all work towards increasing the capacity of general practitioners to support children with developmental and behavioural concerns, long waiting times for clinical services in our region continues to be an ongoing challenge to ensuring timely access to required interventions that align with the First 2000 Days Framework. It is therefore MPHN's opinion that Royal Far West's proposal for Rural Paediatric Assessment Clinics will assist in addressing these access challenges and will offer additional options for families requiring support and assistance."
Narelle Mills, Acting Chief Executive Officer, MPHN

"The AWC is a group of thirteen Councils stretching from Mudgee (Mid- Western) in the East to Central Darling (Wilcannia) in the Far West. We largely comprise the northwest corner of NSW and our footprint covers 32% of the State. We have the highest need for this service with the largest Indigenous population in NSW. We suffer the worst health outcomes and early intervention programs such as this will go a long way to helping bring us into line with the rest of the State. Dubbo is our largest population centre and even it is located 570 kms from Wilcannia. There is a dire need for this service to be made available to residents most in need. There is currently no opportunity for appointments in Dubbo and without this service the situation across Western NSW will continue to deteriorate leading to poverty/crime outcomes for the youth of this vast area."
Cr Craig Davies, The Alliance of Western Councils NSW