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

**Organisation:** Marathon Health

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### **Marathon Health Submission**

NSW Legislative Council Select Committee – Inquiry into foundational and disability supports for children and young people in New South Wales

April 2025

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#### **Introduction to Marathon Health**

Marathon Health was established in Western NSW in 2015 to address gaps in high quality, community-based health and wellbeing services for people living in regional, rural and remote areas. We now deliver face-to-face services across 75% of NSW and a virtual service Australia-wide. We are a non-profit organisation with a vision of empowering these communities to thrive through equitable health and wellbeing.

During the past 10 years, we have grown to become the largest not-for-profit employer of allied health in regional NSW. In 2023-24, our multidisciplinary teams supported 22,404 people – 25% identifying as First Nations.

In 2024 we were named NSW's Outstanding Community Organisation in the Business NSW Awards, with a reputation for establishing and developing evidence-based, person-centred care, with a focus on equity of access and early intervention.

We deliver face-to-face support to 60 regionally-based Local Government Areas (LGA) from our regional service hubs at Bathurst, Dubbo, Albury and Wagga Wagga. We are a large provider of headspace services in Australia, providing wrap-around mental health and wellbeing services to young people aged 12 to 25 through our centres at Dubbo, Orange, Bathurst, Lithgow, Cowra, and Queanbeyan. We also deliver one of Australia's first headspace outreach First Nations-focused services to 10 rural communities in Western NSW.

Our purpose is to collaborate with communities to create the services they need to improve their quality of life. Our services cover four key domains:

- Early intervention and disability supports person-centred allied health services for children and people with a disability. We also deliver Australia-wide after-hours crisis support for NDIS participants on behalf of the National Disability Insurance Agency (NDIA). This domain represented 18% of our work in 2023-24.
- Mental health a range of services spanning the stepped-care spectrum, including psychology, headspace services and psychosocial support for people with severe mental illness. This represented 54% of our work in 2023-24.
- Preventive health and chronic disease –supporting people to navigate the healthcare system to keep them well, including care coordination, chronic disease management, prevention allied health supports and after-hours GP services. This made up 16% of our work in 2023-24.
- Place-based health person-centred programs focused on bespoke models of care based on community need. This represented 12% of our work in 2023-24.

We applaud the Select Committee's focus on delivering quality care in child development, early childhood intervention services and other foundational and disability supports available for children and young people with developmental concerns, delays, differences or disabilities.

Thank you for acknowledging the central importance of foundational and disability services and supports in helping families and communities to thrive. As a key provider of community-based early intervention supports to children across regional NSW, we welcome the opportunity to provide insights and recommendations that will support equitable access for families, no matter where they choose to live.

## TOR 1.a – child development early childhood intervention services

It is well documented that early intervention allied health services are crucial for children, as they promote development, learning, and social skills, ultimately leading to improved long-term outcomes and greater independence. Yet, access to allied health services is not universal or affordable for families living in regional, rural and remote NSW.

Despite one in five children in rural and remote areas being developmentally vulnerable in two or more domains, compared to one in 10 children in metropolitan areas (2021 AEDC National Report), data from our Marathon Health early intervention services and feedback from local communities highlights that children across regional, rural and remote NSW are starting school without the relevant supports in place. Barriers include:

- Low health literacy families are not aware that their children require additional support.
- Limited access to GPs, Paediatricians and other specialists families are not able to access the services and supports they need, when they need them.
- Limited access to community-based assessment services access to key initiatives such as the Brighter Beginnings universal screening program is not equitable across rural communities due to workforce shortages in the Local Health Districts (LHDs).
- Lack of community-based supports for families there are limited community-based supports for families to navigate the NDIS system. For example, the NDIA has withdrawn community-based Planners from remote communities, resulting in no local supports to help families navigate access to the NDIS, particularly before children start school.

For families living in regional, rural and remote NSW, difficulties in availability are common, compounded by the fact that clinicians may not work in areas close to them. There is now only limited access to community allied health for children, and limited opportunity to gain funding for supports for early intervention or preventive health. We see a complete cohort of children who do not have an NDIS plan missing out on early intervention that would support their smooth transition into school and help them achieve optimal learning outcomes.

Prior to the NDIS, Marathon Health had a network of Allied Health Assistants based in preschools and schools across Western NSW working under the delegation of our team of outreach Occupational Therapists and Speech Pathologists. Under this universal access model, our Allied Health Assistants supported families to engage and implement their child's goal-based therapy plan between outreach visits of the clinical team to address developmental therapy.

Under the NDIS, it was no longer cost effective to maintain this enabling workforce in community. This significantly increased demand on an already stretched clinical workforce and placed additional pressure on LHD community health services.

**Recommendation 1:** The NSW Government invest in a community based, primary health-focused VET trained workforce to increase the capacity of clinical services in regional, rural and remote communities.

#### TOR 1.b – services and supports available

Marathon Health's focus is on collaborative primary care models, with the GP at the centre of a patient's wellness journey. Our models of care are evidence-based and designed to take pressure off an already stretched hospital system.

Our success in embedding services within communities is underpinned by our priority on building strong local relationships, acknowledging that person-centred care is only achieved when services are integrated and working together for a common purpose. This is often challenging where there is a disconnect between federal- and state-funded services.

#### Our key models of care for children and young people

Our Flying Start Paediatric Service and WARATAH for Kids highlight our integrated approach to paediatric services in primary care and the benefit to families and the wider health system.

#### Flying Start Paediatric Service

The Flying Start Paediatric Service provides families living in rural NSW free access to a Paediatrician in their local community – unlocking access to ongoing health, education, carer and social supports.

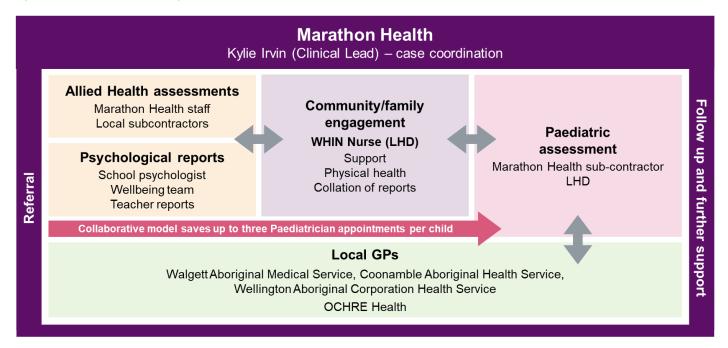
Flying Start is an evidence-based, best practice Tier 4 paediatric model designed by our allied health team for children aged 2-18 years. This community-led program provides a solution to local service gaps and barriers in accessing foundational supports. It also increases the health literacy of local communities about services and referral pathways.

As the program has evolved, we have secured a mix of funding from Rural Doctors Network (RDN); Variety – the Children's Charity; and MBS; with in-kind support from Western NSW LHD.

- To date, more than 55 children and young people (80% First Nations) from four Western NSW communities have accessed a holistic paediatric assessment, individualised care plan and linkage to ongoing health, educational and social supports in their local community.
- Flying Start is successfully addressing the critical shortage of paediatric services in rural and remote
  areas the nearest paediatrician can be more than three- or four-hours' drive away and
  appointment waiting times can blow out beyond 700 days (around two years). Some children and
  young people who have accessed Flying Start were referred to a Paediatrician more than five years
  prior.
- The service brings together a multidisciplinary team of local and visiting clinicians, including Paediatricians, Local Health District Wellbeing and Health In-reach Nurses, Clinical Psychologists, Speech Pathologists, Occupational Therapists, GPs, Practice Managers, school Psychologists, Aboriginal Education Officers, and local allied health providers to deliver in-community support to families.
- As demonstrated in Figure 1, local services and the allied health team undertake multidisciplinary assessments and case conferencing with the Paediatrician before the community-based clinic – meaning families do not need to visit a Paediatrician two to three times before accessing a holistic paediatric assessment.
- Data shows 72% of children and young people who accessed Flying Start had two or more diagnoses. Common co-existing conditions include autism spectrum disorder, anxiety, depression,

- specific learning difficulties (literacy / numeracy), obsessive compulsive disorder, sensory processing disorder and oppositional defiant disorder.
- All children and young people who have accessed the Flying Start service have received an
  individualised care plan, have been supported to access the recommended supports and have been
  linked back to their GP for ongoing care under a shared-care arrangement with the Paediatrician.
  More than 60% of children and young people now have ongoing access to the NDIS.

Figure 1: Overview of the Flying Start Paediatric Clinic Model



#### Flying Start key success factors

Place-based, community centred

- Flying Start provides tailored services focused on the individual needs of children and young people, where they are at, where they live. Unlike other providers, the Flying Start model is community centred, providing face-to-face care and enduring local support pathways.
- Our model aligns with key NSW and national strategies and priorities for community health, education and social determinants.

#### Multi-disciplinary collaboration

 Flying Start brings together Marathon Health's allied health team, local General Practice, Aboriginal Medical Services, local pre-schools and schools, and the Western NSW LHD. Joint case conferencing and care planning delivers strong outcomes for families.

#### Efficient, ongoing wrap-around supports

Dedicated, culturally appropriate wrap-around support, before, during and after children and young
people are seen by the Flying Start Paediatrician. With such a strong foundation of collaborative
support in the Flying Start model, we are successfully delivering a comprehensive service, while
saving what could be three extra Paediatrician appointments per child.

Figure 2 - Flying Start outcomes since 2024





## Children and young people highly engaged

10 clinics held in Walgett, Lightning Ridge, Coonamble and Dubbo

100% face-to-face with 55 children and young people

99% attendance

80% First Nations children

### Wrap-around supports from care team

72% of children have high-level complexity with two or more diagnoses

100% of children under a shared care plan between local GP and Paediatrician

More than 60% now have ongoing access to NDIS

## Place-based community centred approach

Targeted educational support unlocked for children, eg. one school received funding and established an additional Multicategorical Class

Focus of capacity building by Paediatrician to GPs, families and care team

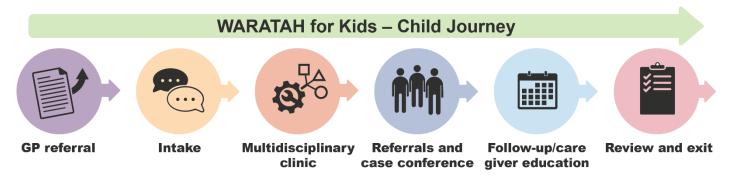
#### **WARATAH for Kids**

WARATAH for Kids is a free service for children aged 0-7 years, living in the Murrumbidgee, who have a developmental delay or behavioural concerns. Since commencement in 2023, we have supported more than 144 children in five regional communities.

We co-designed and conducted a pilot paediatric early intervention allied health service, delivering monthly multidisciplinary clinics in the community:

- Funded by the Murrumbidgee Primary Health Network (MPHN), we worked with local GPs and Aboriginal Medical Services across the region to coordinate community-based multidisciplinary clinics.
- As demonstrated in Figure 3, the WARATAH for Kids service includes screening clinics; provision of screens and detailed allied health reports to support the GP in developing the child's individual care plan; and participation in case conferences and Community of Practice.
- Referral pathways include access to a Paediatrician or ongoing funded early intervention allied health supports, such as a Speech Pathologist and/or Occupational Therapist.
- Through additional funding, in 2025 the program is expanding to a further five communities (nine in total). A new element is the provision of short-term early intervention therapy services to build the capacity of families to support their child's journey through parent-led therapy.
- The service model resourcing is also being broadened to include a Paediatric Linker to follow up referrals, complete check-ins and support the GP and the family to ensure a seamless experience and address any gaps between healthcare providers, families, and educational settings. This will ensure families meet their healthcare goals and children do not fall through the gaps in healthcare.

Figure 3: CARE pathway WARATAH 4 KIDS



#### WARATAH for Kids key success factors

#### Multi-disciplinary collaboration

- WARATAH for Kids supports the management of children with behavioural and developmental issues through holistic and multidisciplinary care. This includes collaboration with local GPs participating in the Enhancing Paediatrics in Primary Care (EPiPC) Program; MPHN; LHD and community Paediatrician; Aboriginal Medical Services; and other local health services.
- An evaluation of the WARATAH for Kids model found the pilot was highly successful. The program
  has been co-designed over time and continues to respond to community needs. It is evidence
  informed but is working in an area requiring innovation and adaptation.
- Benefits include greater support and information provided to families; children receive the right support at the right time; collaborative upskilling of local health practitioners; more coordinated support; and better health workforce utilisation.

#### Family-centred care

- WARATAH for Kids has a strong focus on family empowerment and capacity building. Parents and caregivers gain practical skills to manage challenges, reducing stress and foster stronger family dynamics.
- Family-centred care interventions are tailored to the child's developmental stage and specific needs.
- Service flexibility WARATAH for Kids is a flexible and responsive model, enabling us to pivot to meet the needs of families in new communities, GPs and other care partners.

#### Timely, ongoing wrap-around supports

- All children who access WARATAH for Kids have received an individualised care plan from their GP, based on collaboration with WARATAH for Kids screening and recommended supports and referrals, including Speech Pathologist and Occupational Therapist.
- Enhanced access the provision of the Paediatric Linker will reduce barriers to services by coordinating and streamlining access to care, while the blended service delivery model will provide more touchpoints for families, without significant cost increases.

**Recommendation 2:** The NSW Government provide sustainable funding for existing, proven community-led models of care that enable access to paediatric services.

**Recommendation 3:** The NSW Government invest in community-based allied health assessment clinics and Paediatric Linkers to work in partnership with local GPs and other local services to support families living in regional, rural and remote communities to access early intervention services to address development vulnerability.

# TOR 1.c-d – diagnostic services; and gaps and barriers to accessing early childhood intervention and their impact on children, families and carers

#### Lack of diagnostic services

Currently there is no access to Paediatric Developmental Assessment programs through the Western NSW and Murrumbidgee LHDs for a child with developmental concerns. Also, referrals for places in metropolitan areas have very long waitlists. Many families, particularly those in rural and remote communities, do not have means to access private services.

There is a lack of integration between LHDs, private service providers, NGOs etc to collaborate and join resources. There is also a lack of skills and capacity in mainstream early childhood settings, such as preschools and daycare centres, to identify children who have developmental delays or to link them with appropriate referral pathways like early intervention NDIS plans.

The impact of this we have seen in communities across our footprint. Many children are first identified with very complex presentations when they start formal schooling in Kindergarten and have missed early intervention supports altogether. And, in our experience, many First Nations children and those from culturally and linguistically diverse backgrounds, do not have contact with the education system until later years.

Service models such as WARATAH for Kids and Flying Start Paediatric Service highlight the benefits of embedding assessment services into primary health rather than the Local Health District, and how the system can work effectively in rural NSW when local services are integrated and child-centred.

#### Lack of Medicare-billed services and the NDIS

Since the introduction of the NDIS, the availability of Medicare-billed services in regional, rural and remote NSW has practically disappeared from the market. The biggest disruptor to the supply side in rural communities is the pricing of NDIS. The NDIS is attractive to small sole providers, servicing less complex clients who are not required to travel, in order to make their business viable. The model is not viable to larger not-for-profit allied health providers operating at scale and doing outreach due to compliance, workforce development and travel costs.

There is now only limited access to community allied health for children, and limited opportunity to gain funding for supports for early intervention or preventive health. Fee-for-service is too prohibitive for many families to pay for services outside the NDIS.

Across regional, rural and remote NSW, a complete cohort of children who do not have an NDIS plan are missing out on early intervention that would support their smooth transition into school, help achieve their optimal learning outcomes and set them up for life.

The Department of Social Services' (DSS) recent changes to NDIS plan variation and reassessments this year mean more children are falling through the cracks. The result is some children who were receiving NDIS support are being reassessed and are no longer eligible; while others, such as those on the autism spectrum, no longer meet requirements. Often children and young people do not quite meet the thresholds of the NDIS but still face significant challenges. According to the disability advocacy and education group, DSC, the NDIA is now conducting an average of 1,200 eligibility reassessments a week – 78% of these affecting children.

**Recommendation 4:** The NSW Government enable flexible models of care that provide universal access and more targeted blocks of foundational support which includes clinical intervention and support from an early age.

# TOR 1.e – opportunities to increase engagement and collaboration across sectors, governments and non-government services, including Aboriginal Controlled Organisations, early learning services, education settings and health services

To achieve a blended funding model of childhood early intervention, we need health care professions to work more closely together, in a child-centred model, so that we can reduce the economic burden on the health care system and reduce the out-of-pocket expenses that are proving a significant obstacle for families accessing the therapies their children need.

#### **Evaluation of the Enhancing Paediatrics in Primary Care (EPiPC) program**

In 2018, the MPHN funded the development of the Maternal and Child Health Strategy. MPHN launched the strategy in 2019 in collaboration with the MLHD. The Strategy identified there was a need to strengthen the existing GP workforce by increasing the expertise and confidence in paediatrics to encourage the appropriate use of hospital-based resources and increase the uptake of child health screening.

The Evaluation of the Enhancing Paediatrics in Primary Care (EPiPC) program was established in 2021. EPiPC comprises three key components: a community Paediatrician, five Special Interest GPs, and Marathon Health's WARATAH for Kids. Working together, these components seek to overcome issues identified within the co-design of the program, including limited paediatric knowledge in primary care, inefficient use of specialists, and long wait times.

A 2024 evaluation of EPiPC found that the ongoing co-design of the program has meant that EPiPC has remained responsive and adaptive to the needs of stakeholders and communities:

- Health equity Special Interest GPs are seeing a considerable percentage of their community
  monthly, with practices seeing between six and 18 percent of their community's child population on
  an average month. Where appropriate, the EPiPC program supports these children to receive
  screening and identification of behavioural and developmental issues.
- Family-centred All of the parents / carers engaged in the evaluation spoke positively about the support they had received from their GP and WARATAH for Kids. They felt listened to, involved in decisions about their child, and had confidence and trust in health professionals treating their children.
- Flexible innovative program components WARATAH for Kids has pivoted their operation over
  time to suit the needs of the program. This has included creating more detailed reports back to GPs
  and parents; providing parents with referral recommendations and follow up instructions; being
  flexible around the location and cadence of clinics; and conducting follow up calls or assessments
  where there are low referrals.
- Developing rural workforce WARATAH for Kids has also built relationships with relevant
  organisations and specialists to increase referrals and to find creative solutions to issues (ie.
  simplifying referral pathways to the NDIS).
- Effective early intervention stakeholders perceived that EPiPC was decreasing wait times for paediatric services, including reducing the number of appointments a child required with a Paediatrician due to information gathered through EPiPC.

**Recommendation 5:** The NSW Government invest in scaling the EPiPC model across the state and provide sustained funding for this successful evidence-based early intervention program.

# TOR 1.g – workforce issues in the child development and early childhood intervention sectors – demand, availability, quality and capacity of existing workers

#### Recruitment and retention of workforce

One of the biggest challenges for the rural health sector is recruitment and retention of our allied health workforce. Organisations, such as Marathon Health, are committed to building and sustaining a strong health workforce for rural NSW; however, we receive very limited Government support to do so.

We employ the largest non-profit allied health workforce in regional NSW, contributing \$25.3 million in wages into regional Australia in 2023-24. We are focused on delivering high quality, culturally safe, evidence-based health and wellbeing services in partnership with communities. A key point of difference for our organisation is that our staff live and work in their local communities.

Our multidisciplinary workforce of more than 300 people includes more than 100 clinicians in speech pathology, occupational therapy, clinical psychology, psychology, social work, mental health, counselling, Aboriginal health, dietetics and diabetes education, and nursing. Fourteen per cent of our workforce identify as First Nations. We also engage 224 clinical subcontractors, including General Practitioners, specialists and allied health – further increasing our reach.

To support the growth of a skilled health and wellbeing workforce for regional NSW, we embed innovative workforce development models in our services. This includes a structured psychology internship program and a targeted graduate and student pathway through relationships and written agreements with 19 universities across Australia. In 2023-24, we hosted and provided clinical supervision for 61 clinical students from 14 institutions across 10 disciplines, with eight accepting offers of employment on graduation.

In addition, we are building an enabling workforce of VET-qualified professionals to support the work of our clinical workforce, including Aboriginal Health Workers, Aboriginal Wellness Workers and Peer Workers, designed to build and engage trust in community and enhance clinical service delivery.

To support the growth of the health workforce in rural areas, we advocate and work with our partners to ensure workforce development is embedded into service model design and commissioning. This ensures that rather than service delivery being focused on activities and outputs, the model is more focused on delivering strong outcomes.

**Recommendation 6:** The NSW Government provide funding for workforce development initiatives across the primary health sector, alongside NSW Health.

# TOR 1.h – measures to implement recommendations of the NDIS Review Final Report and the Disability Royal Commission Final Report in relation to foundational supports

The NDIS Review Report recommends creating a more unified and accessible system of support for people with disabilities, not just those within the NDIS. This includes establishing foundational supports for all Australians with disabilities, regardless of NDIS participation, alongside streamlining processes and improving access for all. The report also proposes changes to funding, regulation, and the workforce to ensure sustainability and improve outcomes for participants.

Marathon Health's experience supports many recommendations, but specifically:

- National Cabinet should agree to jointly design, fund and commission an expanded and coherent set of foundational disability supports outside individualised NDIS budgets.
- Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS.
- The NDIA, in partnership with the Department of Social Services, and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.

- Create a continuum of support for children under the age of nine and their families.
- Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports.

In our experience, there is a conscious effort happening in rural areas whereby mainstream supports and NDIS providers are working closely together to support children and families (refer 1.e). This is particularly so in relation to child and family health nurses with allied health practitioners.

When funding is not individualised, supports can be provided with more flexibility and this can include building capacity and supporting people to navigate systems and referrals. This is particularly relevant in the cohort of children aged under nine, when working in programs supported with Government funding. Marathon Health has skilled, willing staff; however, funding and time availability can sometimes be barriers.

We have strengthened relationships with First Nations organisations, including the Walgett Aboriginal Medical Service, the Coonamble Aboriginal Health Service and the Wellington Aboriginal Corporation Health Service, to be able to support access for families. Collaboration includes collocation of our staff, joint workforce development initiatives, hosting services at their practices and joint delivery of programs such as Flying Start and allied health services.

**Recommendation 7:** More flexible funding arrangements for children under nine be put in place to support sector collaboration and enhance service access for families in regional, rural and remote NSW.

#### **Marathon Health summary of recommendations**

**Recommendation 1:** The NSW Government invest in a community-based, primary health focused VET trained workforce to increase the capacity of clinical services in regional, rural and remote communities.

**Recommendation 2:** The NSW Government provide sustainable funding for existing, proven community-led models of care that enable access to paediatric services.

**Recommendation 3:** The NSW Government invest in community-based allied health assessment clinics and Paediatric Linkers to work in partnership with local GPs and other local services to support families living in regional, rural and remote communities to access early intervention services to address development vulnerability.

**Recommendation 4:** The NSW Government enabling flexible models of care that provide universal access and more targeted blocks of foundational support which includes clinical intervention and support from an early age.

**Recommendation 5:** The NSW Government invest in scaling the EPiPC model across the state and provide sustained funding for this successful evidence-based early intervention program.

**Recommendation 6:** The NSW Government provide funding for workforce development initiatives across the primary health sector, alongside NSW Health.

**Recommendation 7:** More flexible funding arrangements for children under 9 to support sector collaboration and enhance service access for families in regional, rural and remote NSW.

#### Conclusion

Thank you again for the opportunity to respond to the Select Committee on foundational and disability supports available for children and young people in New South Wales.

Based on our experience of 'boots on the ground' service delivery across rural, regional and remote NSW, we have highlighted opportunities for improving supports for children and young people with developmental concerns, delays, differences or disabilities. We trust that our experience and assessment of the barriers and gaps in services and workforce will inform the work underway by the NSW Government to develop this new tier of foundational supports.

At this stage, we believe there has been incremental and disjointed progress in addressing the inequities of health services in rural, regional and remote areas. In our experience, it is taking the initiative of providers such as Marathon Health to encourage and drive collaboration and service integration – outside the parameters of our Government funding. We recognise the need to develop the workforce, for example, but the time and effort we put into those undertakings are often at the cost of delivering services in local communities.

We will continue to address gaps and respond to local community needs and we look forward to seeing ongoing progress in achieving better integration of services, supports and in turn outcomes for children and young people living in regional, rural and remote NSW.