The Invisible **Children**

The state of country children's health and development in Australia

Based on research prepared by the Murdoch Children's Research Institute, Centre for Community Child Health

Royal Far West
Children's health, country-wide

Introduction

For 94 years, Royal Far West has been serving country children and communities. Whilst our approach has changed and evolved over this time to respond to the most pressing needs of country communities, we have remained relentlessly focused on the health and wellbeing of country children and their families.

Today, we are a service provider, capacity builder and advocate for country children and their developmental health. We work in partnership with families, schools and communities to create services and solutions that respond to the complexities of rural and remote environments. We use our specialist paediatric workforce, technology, and our understanding of country communities to help improve children's health outcomes and life trajectories as much as we can.

Our staff see the strength and resilience in country families and communities every day. However, there are signs that children's developmental health is worsening in rural and remote Australia. Demand for RFW's programs is growing, as is the complexity of the children and families who seek help from RFW. Anecdotally, behavioural issues in young country children are increasing and mental health issues are arising at a much earlier age. We know from our experience at RFW that childhood trauma is a growing factor, whether this is from the stresses of drought, family dynamics, poverty or tragedy.

In early 2017, in response to concerns about the growing vulnerability of country children, RFW commissioned a review of the state of children's developmental health in rural and remote Australia from the Murdoch Children's Research Institute's Centre for Community Child Health. Their report shines a light on "The Invisible Children" – the complexity and challenges facing country children and families, the gaps in and fragmentation of services, the growing disparities in outcomes between children in urban and rural and remote areas, and the critical role that the social determinants of health play in this picture. It reinforces the gaps that RFW sees through our work with country children and families, and highlights the need for united government leadership across health, education, disability and social services to reduce developmental vulnerability. It also shows large gaps in data and evidence, revealing the difficulty in being able to gain a true picture of the services available in local communities.

But there is hope - the report highlights a way forward, with strong cross-government strategy, improved information and telehealth providing significant and potentially transformative opportunities. However, this cannot be achieved by any one organisation. It requires many people and organisations to come together and raise their voices for country children, early intervention and prevention.

Continuing our proud tradition of advocating for country children and families, "The Invisible Children" launch is the first in a series of activities designed to raise awareness of the challenges country children and families face, their growing vulnerability, and the impact of this on regional development, prosperity and our society. Following this launch, RFW will engage with a number of rural and remote communities to see how the national picture plays out on the ground.

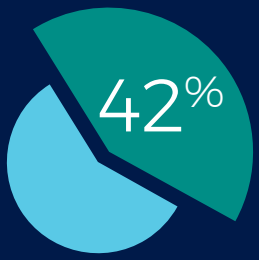
At RFW, we believe that all children have the fundamental human right to a high standard of health and wellbeing. Geography should not be a barrier to access or a cause for disadvantage for rural and remote children. We are convinced that one day soon, the "invisible children" can have the support they need to develop well and reach their full potential. We call on our friends in government, the corporate sector and other NGOs to commit with us to tackle developmental vulnerability in rural and remote communities as an investment in our future generations and the health and vibrancy of regional Australia.

Lindsay Cane, CEO, Royal Far West

1 in 5 22%

children in Australia are developmentally vulnerable on one or more domain in their first year of school

Children living in Very Remote areas are twice as likely as those living in Major Cities to be developmentally vulnerable



of Indigenous children are vulnerable on one or more developmental domains

More than 1 in 6 (16.2%) children and adolescents aged 4-17 in rural areas have mental health problems

This is closer to 1 in 5 (19%) in outer regional areas

*NSW Ministry of Health data

32%

of children in rural or remote NSW are unable to access the health services they need

*NSW Ministry of Health data

Children in rural, regional and remote areas are more likely to be developmentally vulnerable than children in metropolitan areas

27%

of all children in outer regional, remote and very remote areas compared to

21%

in towns and cities

Allied health workers in rural and remote areas service a population at least 5 times greater than their metropolitan counterparts

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In early 2017, Royal Far West (RFW) commissioned the Centre for Community Child Health (CCCH) to complete a systematic review of the state of children's developmental health across rural and remote Australia. Their report is available at royalfarwest.org.au/invisible-children.

The review highlights a number of important themes, challenges and opportunities for rural and remote Australia. It reveals the complex multi-layered challenge to creating meaningful and lasting solutions. RFW reflects on these here, in the context of our work and experience and we call for support and change on behalf of all country children and families.

Children in rural and remote Australia:

- **experience poverty at disproportionately higher rates**
- **are more likely to be Indigenous**
- **are more likely to live in unemployed households, with single parent families, and in families where the mother has a low educational attainment**
- **are more likely to be socially isolated**
- **are more likely to be exposed to family and domestic violence and have contact with child protection services**
- **are less likely to engage in early childhood education and care services**
- **have poorer access to early childhood intervention services, paediatricians, allied health and mental health services.**

Australian children living in rural and remote areas are more likely to be developmentally vulnerable.

Communities with the highest levels of childhood developmental vulnerability share common features of disadvantage including: higher family and domestic violence, low income and single parent households, greater social isolation, more contact with child protection services, and more children living in out of home care. Families are also more likely to be Indigenous, and less likely to have engaged with early childhood education and care services. All of these factors increase the risk of poor developmental outcomes for children as they grow up.

The 'vulnerability gap' between urban and rural children is widening, and complexity is increasing.

In many rural and remote communities, developmental vulnerability as measured by the Australian Early Development Census (AEDC) at around age five is growing, and the vulnerability gap between urban and rural children is widening.

For RFW, the experience of trauma amongst the children and families we work with is more and more apparent. Trauma factors include poverty, family violence, drugs and alcohol and parental mental health issues, and for Aboriginal families, includes the ongoing impact of inter-generational trauma. Trauma has a significant impact on development, particularly in the early years, as a result of its impact on the body's stress response systems. Childhood trauma both increases the risk of developmental issues, and increases the complexity of the response.

Higher levels of developmental vulnerability in rural and remote areas are compounded by limited access to services and less chance of early intervention.

The scarcity of services in rural and remote communities is undeniable. The CCCH review found systematic gaps in the availability of paediatricians, allied health and mental health professionals for children in rural and remote settings. Even for families who can access a suitable service, there are often long waiting lists. While there may be services on paper, providers are often covering a very broad region, and actual access is sporadic.

Recruitment and retention of allied health staff, who are critical in developmental health, is a well- established and significant issue in rural and remote Australia. 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.

RFW's clients normally experience long waiting lists and low service levels in their communities, with families reporting waiting lists of up to 16

months. Whilst this issue is not specific to children's services, the impact can be far more significant for developmentally vulnerable children, as by the time they are able to access support, the opportunity for early intervention has been lost.

This combination of greater need and poor service access is potentially catastrophic for some rural communities, contributing to the perpetuation of a vicious, multi-generational cycle.

Improving access to services is only one part of the picture – services also need to be appropriate and well integrated.

Investing in early childhood intervention and education services has proven effective in improving children's developmental outcomes, with the highest rate of return coming from investing early, in the first five years.

Services don't just need to be present, they need to be appropriate in quality and frequency, supported by parents, pre-schools and schools, and other community players. Children with more complex developmental issues require multi-disciplinary care that is integrated around their needs. This is particularly hard to achieve in rural and remote communities.

Ironically, while there are undoubtedly major gaps in services for rural and remote communities, there are also areas of duplication and overlap. There tends to be a lack of coordinated planning and delivery across regions.

Some Primary Health Networks, Local Health Districts/Hospital and Health Services across the country are piloting new models that may improve service integration for people with complex needs. However, few of these models focus on children, and they are far from systematic.

The National Disability Insurance Scheme (NDIS) provides many benefits for people with disability but proves challenging in country areas, especially for children.

Under the NDIS, children will be more likely to be identified earlier and be eligible for support. However, it is still an open question as to whether the right services – or any services – will be available to them in the country areas where they live.

We know that families are less likely to access disability services and funding in rural and remote communities, simply because such local services are fewer or absent. A previous survey by Hanft (2014) found that rural families of children with a disability are up to 23 per cent less likely to register with federal government's Helping Children with Autism (HCWA) and Better Start funding programs and that they access up to 60 per cent less funding than their urban peers. The individual funding model that lies at the heart of HCWA and Better Start, which is now at the heart of the NDIS, has been shown not always to work well for country children.

Not all children with developmental difficulties are likely to be eligible for the NDIS. Those with moderate to severe disabilities are likely to receive support, but there are many rural and isolated children with developmental delays that will present as mild to moderate, and whose issues could be resolved or mitigated through interventions, who may not receive support.

The NDIS also presents some real dangers to existing service levels if there is not a coordinated approach across health, education and disability – for example, where children's allied health services traditionally funded by the health system have been withdrawn on the assumption they will be picked up under the NDIS. This recently played out in Western NSW, where several communities have been left without any access to allied health rural services. While an interim solution has been found, most of the affected staff have already left their positions to seek work elsewhere, creating yet another recruitment challenge.

Indigenous children with disability face the greatest challenges of any population in the country.

Indigenous children have substantially higher rates of developmental vulnerability than non-Indigenous children, and face greater challenges accessing appropriate services.

Indigenous children are more likely to reside in remote and very remote areas, and face an even higher chance of being exposed to adverse concurrent social, economic and environmental conditions than their non-Indigenous counterparts. Consequently, Indigenous children continue to experience adverse developmental outcomes at disproportionately higher rates.

Not only do Indigenous families face the same lack of access to services as other regional families, but this is often combined with a lack of culturally appropriate services, particularly in remote areas. The largest difference between Indigenous and non-Indigenous children is in the language and cognitive skills domain, where Indigenous children are nearly four times more likely to be developmentally vulnerable (20.2 and 5.7 per cent respectively).

Indigenous children with disability face the greatest challenges of any population in the country.

RFW partners with remote Aboriginal communities to build local capacity and improve access to services for children with complex needs. We have seen first-hand the challenges that Aboriginal children and families face in accessing appropriate supports.

There remains a distinct lack of appropriate early intervention mental health services for children aged 0-12 in rural and remote communities.

In spite of recent investments in mental health nationally, the CCCH review found that mental health services for children aged 0-12 remain difficult to access across rural and remote Australia. Consistent services are predominantly located inside hospitals in major townships and require long distance travel for many people living in rural and remote communities.

The Australian Paediatric Society maintains that there is an alarming lack of child mental health services in rural and remote areas, making the provision of adequate mental health care tremendously difficult, noting that this will undoubtedly lead to a generation of "disturbed adolescents and dysfunctional adults". Child mental health services in these areas often operate without contact with other paediatric services, creating silos and disconnections between services.

RFW has observed a lot of positive developments in children's mental health services for rural and remote communities over the last 12 months, driven through Primary Health Networks and State Government initiatives. However, there remains a clear gap for these communities, and children's mental health services remain siloed.

Telehealth has the potential to be transformative in reducing developmental vulnerability in rural and remote communities.

It is not realistic to expect that all rural and remote communities will have access to a full spectrum of services that are physically available on the ground.

However, technology, in the form of telehealth can go a long way in providing access to those services virtually. The CCCH review highlights the increasing availability and acceptability of telehealth services, including for children, and growing evidence around their efficacy.

The benefits of telehealth for rural and remote families include:

- **conveniently finding high-quality services close to home**
- **decreasing time away from both work and school**
- **decreasing costs associated with traveling miles for care**
- **decreasing stresses of travel with a child with a behaviour disorder and siblings**
- **decreasing worries about navigating unfamiliar health care settings**
- **allowing additional supporters to attend and work together to coordinate care**
- **decreasing stigma by connecting to child friendly settings such as schools.**

In our experience at RFW, telehealth provides an opportunity for families to access consistent, regular and appropriate services by health professionals who are specialists in their field – and to resolve chronic local and regional workforce shortages. The CCCH review notes that, in addition to providing assessment and therapy services for children with developmental issues, telehealth can be used to provide specialist training and capacity building for rural communities, including parents, schools and health professionals. RFW actively uses telehealth across all these areas to achieve better outcomes for country children, through our 'Telecare for Kids' programs. These programs have been running for several years, and have been shown not just to improve access, but to improve outcomes.

While telehealth – or telecare – is not a silver bullet for rural and remote children, it does open up options for clever and innovative solutions that make better use of existing resources. RFW is resolute that telecare-based solutions are at the heart of reducing developmental vulnerability in rural and remote children and helping them to reach their full potential.

Why does all this matter?

Developmental vulnerability comes at a high cost to individuals, families and to society as whole. Vulnerable children are at risk of growing up to be vulnerable adults, with poorer educational attainment, higher rates of chronic disease and mental health, and greater tendency towards unemployment, homelessness and crime. At scale, this translates to significant costs in education, unemployment, health, social welfare and criminal justice. It has a significant impact on human capital and economic productivity and ultimately, Australia's growth and prosperity.

In an analysis undertaken by RFW in 2015, the economic impact of not halving Australia's childhood vulnerability rate of 22% would be a curbing of Australia's GDP growth by up to 10%, which is both material and significant.

At RFW we also believe that all children have a fundamental human right to expect to be able to enjoy a high standard of health and wellbeing, and we reflect this belief and commitment in all the services we provide and the activities we undertake.

Tackling developmental vulnerability is important for all Australian children, but particularly in rural and remote communities where vulnerability and disadvantage can be so much higher and outcomes frequently inequitable. Despite its critical importance however, this issue is not well understood and does not yet get the attention it deserves.

The way forward

The following recommendations build on the 2017 CCCH review and existing efforts across the country, offering direction for achieving a step change for rural and remote children and Australian society as a whole:

National leadership and stewardship:
Create a national target to reduce developmental vulnerability in rural and remote Australia from 22% to 10% by 2025 (as measured by the AEDC) - establishing it as a regional development priority - and develop a whole of government plan to deliver on it, prioritising the first 2000 days of life.

Early identification and intervention:
Invest in consistent, comprehensive pre-school developmental screening and school-readiness programs for children aged 3-5 years in rural and remote communities that integrate health, education and disability. Provide a priority focus on small, isolated communities.

Fund and scale innovative service models:
Prioritise funding for innovative approaches that provide rural and remote communities with ready access to paediatricians, allied health and mental health services to support childhood development. Give priority to service models that optimise and exploit technology and digital health and that focus on outcomes not just access.

Integrate health and disability services for children:
From the national level down, integrate the planning and delivery of health and NDIS services for children with developmental issues, developing an approach that will work for all country children who are developmentally vulnerable.

Adopt a broader approach to children's mental health:
Create a new paradigm that supports a broader, more multi-disciplinary, developmental perspective that looks at mental health in the context of the whole child and his/ her whole needs.

Promote school-based models that support transitions:
Mainstream the use of school-based models to identify and resolve developmental vulnerability, including mental health, and integrate this with health and disability approaches.

Teacher capacity building and support:
Improving access and funding for professional development and support services for early childhood educators and teachers in rural and remote communities to enable them to better support children with additional needs, including developmental and behavioural conditions.

Increase the 'health literacy" of parents and carers:
Increase access to information and resources that educate and empower parents/carers and other community members in rural and remote areas to identify and support their children's developmental needs at the earliest possible time and to navigate a path to diagnosis and treatment.

Improve access to data:
Invest in better data on children in rural and remote communities, including developmental vulnerability throughout childhood and access to services; encourage greater sharing of data between agencies, and build evidence on what is working in the long term.

Increase the use of telehealth models:
Provide funding, improve infrastructure and connectivity, and build and share evidence to drive a step change nationally in the use of telehealth models to improve outcomes for children with developmental issues.

Prioritise models for providing culturally appropriate services for Indigenous children:
Establish a national approach to co-designing and testing culturally appropriate service models for remote Aboriginal communities.

Target a reduction in developmental vulnerability from 22% to 10% by 2025.

About Royal Far West

Royal Far West is one of Australia's oldest and most respected charities. Established in 1924 as a summer holiday camp for country children, RFW has consistently adapted to meet the needs of rural and remote communities. Today we are dedicated to helping country children thrive. Our goal is to work in partnership with healthcare providers, Aboriginal Medical Services, schools, local government and community groups. We deliver multi-disciplinary services, build capacity and advocate in order to achieve sustainable outcomes for children most at risk.

Through our team of over 60 paediatric specialists and innovative use of technology, we support isolated and vulnerable country children aged 0-12, with developmental and health issues such as autism; attention deficit and hyperactivity disorders; behavioural and conduct disorders; speech and language delays; early life trauma and mental health challenges, anxiety and major depressive conditions. We offer services for country children and families at our dedicated centre in Manly, as well as via telecare and in community through targeted outreach programs.

Our specialist programs include:

Telecare for Kids

Connects country children with clinicians based in Manly to deliver specialist assessment, therapy and capacity building via video conference, often working through pre-schools and primary schools.

Paediatric Developmental Program

A unique, integrated health, education and social care service for children with more complex developmental needs, provided in Manly in a relaxed collaborative environment.

Windmill

As an NDIS approved provider, RFW offers an award-winning disability service dedicated to country children, providing intensive therapy blocks in Manly and a range of services via telecare

Healthy Kids Bus Stop (HKBS)

Supported by Ronald McDonald House Charity, the HKBS program provides a comprehensive, multi-disciplinary health screening and pathway to care for 3-5 year old children, aiming to improve their school readiness.

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