



# *Stories of* **The Invisible Children**



**Royal Far West**  
*Children's health, country-wide*

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**Charles Sturt  
University**

**The state of country children's  
health and development  
*in their own words.***

Based on information prepared for Project Catalyst - a joint  
Royal Far West / Charles Sturt University research initiative.



**Andrew Vann**  
**Vice Chancellor Charles Sturt University**

At Charles Sturt University, we believe in making a difference, and, that wisdom transforms communities. Our University ethos is described by the Wiradjuri phrase – *yindyamarra winhanganha* – translated as ‘the wisdom of respectfully knowing how to live well in a world worth living in’.

CSU has a heritage of high quality education for, and research and engagement with, Australia’s regional communities. We are very proud of the graduates we produce – we rated highest in the country for our rates of graduate employment. 59% of CSU’s students come from rural and remote areas, and we want to see these numbers grow. For that to happen, we must all seriously consider the implications of the disadvantages children and families face as they attempt to gain support for developmental challenges, and, ask how we can contribute to making change.

I am proud of our partnership with Royal Far West – an organisation also with a long history of service to regional, rural and remote Australians. I look forward to our future work together – enabling more children and families to live well in a world worth living in.



**Lindsay Cane**  
**CEO Royal Far West**

In 2017, Royal Far West commissioned a review of the state of children’s developmental health from the Murdoch Children’s Research Institute Centre for Community Child Health. This review formed the basis of *The Invisible Children*, a confronting report that highlights the growing divide in developmental health outcomes and access to services between city and country children. Challenged by the findings of this report, RFW partnered with Charles Sturt University to launch “Project Catalyst”, a partnership to assess the feasibility of developing a National Paediatric Telecare Service. The partnership aims to deliver a step change in health and social care services to children in regional Australia.

We also wanted to better understand the lived experience of rural families and communities and to record the real stories of the *Invisible Children*. With the support of CSU and the media partner Nine ACM, we travelled across regional NSW, met with hundreds of parents, teachers, health workers, and community leaders, and interacted with thousands more through social media, to discover the daily challenges faced by country Australians as they seek to find the best supports for their children. CSU’s Dr Tamara Cumming interviewed a number of families to discover what is working for them, and where the real gaps and opportunities are.

These stories have been supplemented with new data and insights from Project Catalyst on developmental vulnerability and community need, as well as observations from Professor Alex Martiniuk from the University Sydney, gathered through in-depth interviews with families, schools and health service providers through her National Health and Medical Research Council Fellowship.

# Introduction

There is irrefutable evidence that timely intervention for children's developmental challenges can make a significant difference to their life trajectory. Similarly, there can be lifelong disadvantages when children cannot access the help they need.

The lived experiences of families and service providers clearly demonstrate the need for more services for children's developmental health. It is much harder for rural and remote families to access and coordinate help than for city families.

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*We cannot alter the distance between some families and the help they need. What we must do is coordinate and deliver services that do not require people to be in the same place at the same time. Telehealth is one solution, and more education is required to build clients', educators' and clinicians' understanding of the benefits of telehealth.*

This report builds on the evidence presented through The Invisible Children research, bringing real life experience and perspectives to colour and amplify those findings. It tells the stories of The Invisible Children.

***The Invisible Children* report (2017) put forward several recommendations to tackle the growing developmental challenges facing Australian children. *Stories of The Invisible Children* examines the lived experiences of children, teachers and community members from rural towns across NSW between 2017 and 2018.**



# Developmental Vulnerability

**Children are benchmarked on five areas of development when they start school: physical health, social skills, emotional health, language and communication, by the Australian Early Development Census (AEDC).**

**If children at school age are vulnerable on two or more of these criteria, they are more likely to have** poorer educational attainment, higher rates of chronic disease and mental health, and greater tendency towards unemployment, homelessness and crime later in life. At scale, this translates to significant costs in education, unemployment, health, social welfare and criminal justice. **Children in remote and very remote communities - a large proportion of the Australian landscape - are far more likely to be vulnerable than kids in the city.**

While the greatest need for assistance is in regional and remote Australia, those geographies have the least access to health care. There are 2.5 times the number of clinicians per developmentally vulnerable child in the major cities compared to remote areas and 7.5 more compared to very remote areas.



## Physical health and wellbeing

Challenges that impact a child's ability to physically cope with the school day:

- Being dressed inappropriately
- Frequently late
- Hungry or tired
- Clumsiness and fading energy levels



## Social competence

Poor overall social skills:

- Not getting along with kids on a regular basis
- Not accepting responsibility for their actions
- Difficulty following rules and class routines
- Can be disrespectful of adults, children and property
- Low self-confidence and self-control



## Emotional maturity

Challenges relating to emotional regulation:

- Problems managing aggressive behaviour
- Prone to disobedience and/or easily distracted
- Inattentive, impulsive and reluctant to help others
- Can be upset when left by/separated from their caregiver.



## Language skills

Children experience challenges with:

- Reading/writing and with numbers.
- Unable to read and write simple words
- Unable to attach sounds to letters
- Difficulty with memory, counting to 20 and recognising numbers

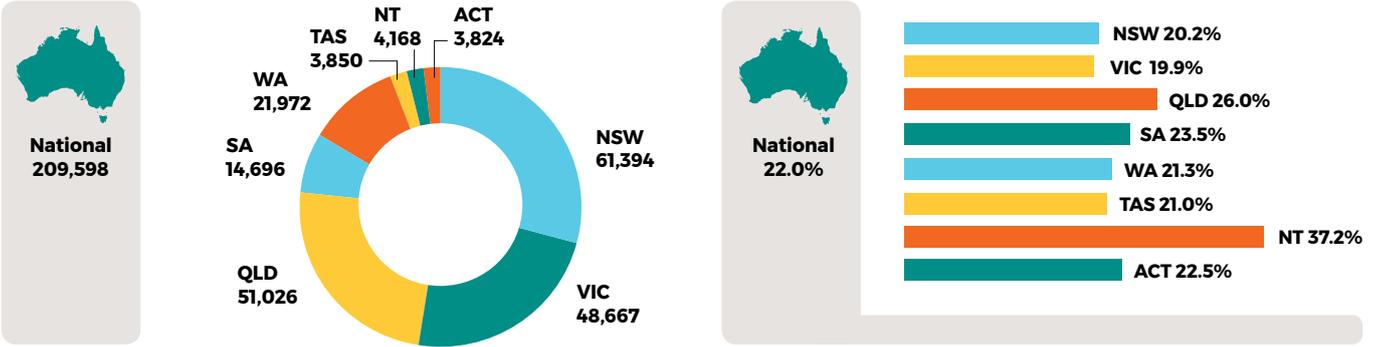


## Communication skills and general knowledge

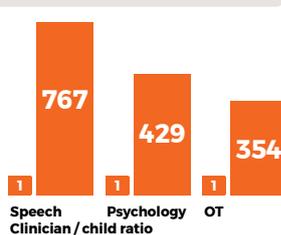
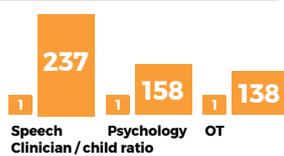
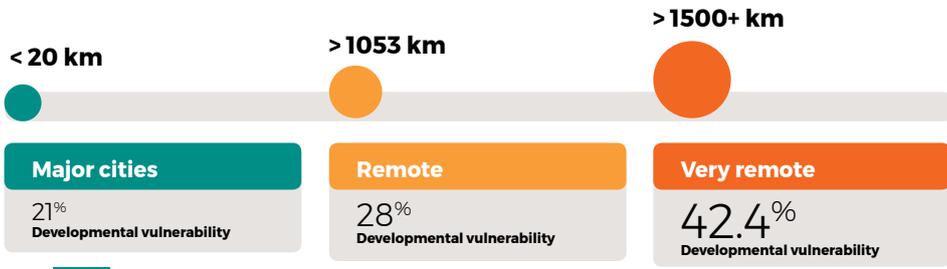
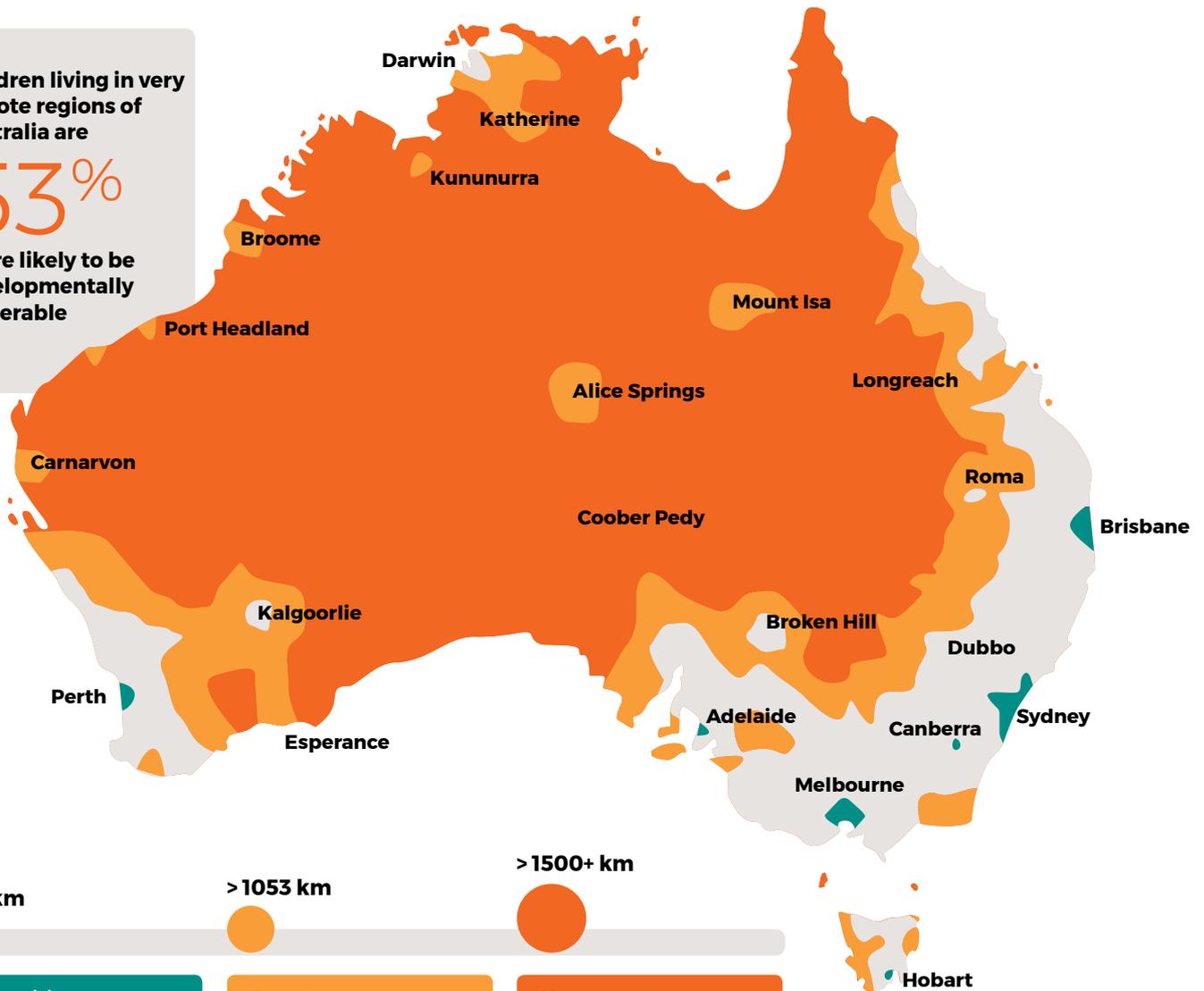
Children experience:

- Poor communication skills and articulation
- Limited command of English (or language of instruction)
- Difficulty talking to others
- Difficulty understanding and being understood
- Poor general knowledge

# Number and proportion of children who are developmentally vulnerable



Children living in very remote regions of Australia are **53%** more likely to be developmentally vulnerable



# 1. National leadership and stewardship

## Recommendation:

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.

**There are many local examples of practical approaches to unique rural and remote health issues. However, national policy change must accompany community and local health service actions for these approaches to be adopted and sustained more broadly. Without this, our country children and regional Australia's long-term health and prosperity are at risk.**

**GDP Growth**

**10%**

**60 YEARS**

**Based on analysis undertaken in Canada, the economic costs of not halving developmental vulnerability would curb Australian GDP growth by 10% over the next 60 years.**

**\$1  
SPEND**



**\$3.10  
RETURN**

**The lifetime economic return has been calculated at \$3.1 for every \$1 invested in child health.**

Families' and service providers' lived experiences clearly demonstrate the need for coordinated services for families as they seek support for children's developmental challenges. One service provider noted: "You can't silo a child", and yet this happens to families daily as they attempt to navigate the health, education, disability, and social services systems to access support for their children. Whilst research suggests the benefits of multi-component approaches to intervention, service delivery across the country remains focused on individual clinical disciplines and sectors, placing the onus on families to manage and coordinate services for their child.

Children with developmental challenges may require access to a variety of clinical services, including allied health (speech and occupational therapy in particular), paediatric specialists, and mental health practitioners. However, for rural and remote children there are many barriers to accessing these services individually, let alone as a coordinated team. Research indicates that rural and remote children may have limited access to clinicians due to:

- practice areas stretching across multiple areas which clinicians can only visit periodically (perhaps once a month);
- clinicians having a generalist remit rather than a paediatric specialty, or far fewer clinicians to service the number of clients requiring their assistance;
- chronic workforce shortages.

In 2018 Project Catalyst reviewed workforce data for allied health workers across Australia by Accessibility and Remoteness Index of Australia (ARIA). The clinician counts for occupational therapists and psychologists shown below are those registered and working as ‘hands-on’ clinicians. In each discipline there is a dramatic decrease in the number of working clinicians the further the distance from a major city.

These factors in combination result in long waiting periods for diagnosis and treatment. Families’ accounts of experiences with accessing services matched these findings. As one parent said:

*“to be able to get into a therapist out here, you really have to go privately because the ones in the public system are very few and far between. The waiting lists are around 9, 10, 11 months to get a child in to see a speech therapist or an occupational therapist. We don’t even have any psychologists here at the moment that see children. So we are constantly referring to private psychologists, private speechies, private OTs and they’re mainly located over in [towns of between an hour and an hour and a half away]”.*

**Parent**

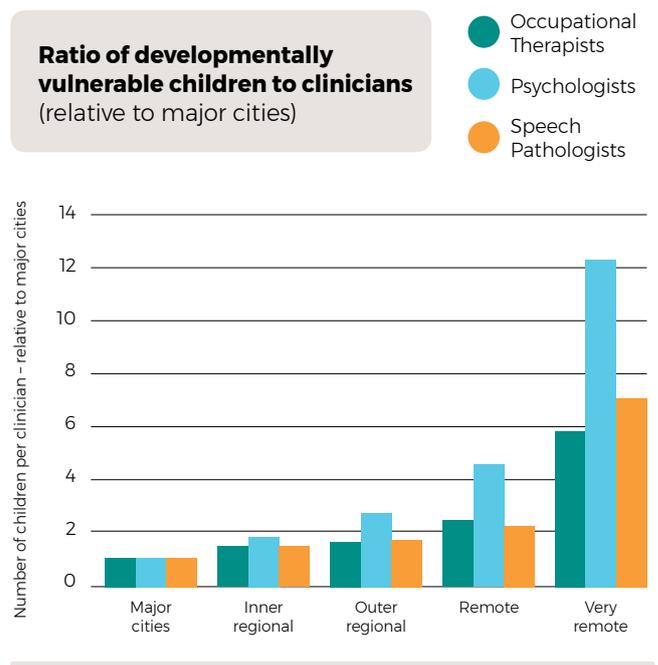
This message was common and consistent across multiple families and communities.

Many parents and providers spoke of benefits when practitioners meet for case conferences to discuss children across disciplines:

*“My passion is to get all the specialists under one roof – all the therapists together. That’s where the most effective gains are made because you have joint meetings and you’re constantly talking about this student or child and working out what’s best and you’re all working together under one roof”.*

**Health Professional**

However, in practice this is difficult to achieve consistently in rural and remote areas.



## 2. Early identification and intervention

### Recommendation:

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 services. Place the priority on small, isolated communities, and those that are most socially disadvantaged.

***“The highest rate of return in early childhood development comes from investing as early as possible, in disadvantaged families. The best investment is in quality early childhood development for disadvantaged children and their families.”***

James J. Heckman December 7, 2012

Services don't just need to be present, they need to be delivered consistently by the right team, at the right time, supported by parents, preschools and schools, and other community players.

*“Looking at paediatricians around here at the time I think there was a six month waitlist, and because [child] had to go to school I said ‘well that’s not good enough’. I need this sorted before we go to school because I need her to go to school as a child with a learning difficulty as opposed to ‘she’s a naughty child I don’t know what to do with her’.”*

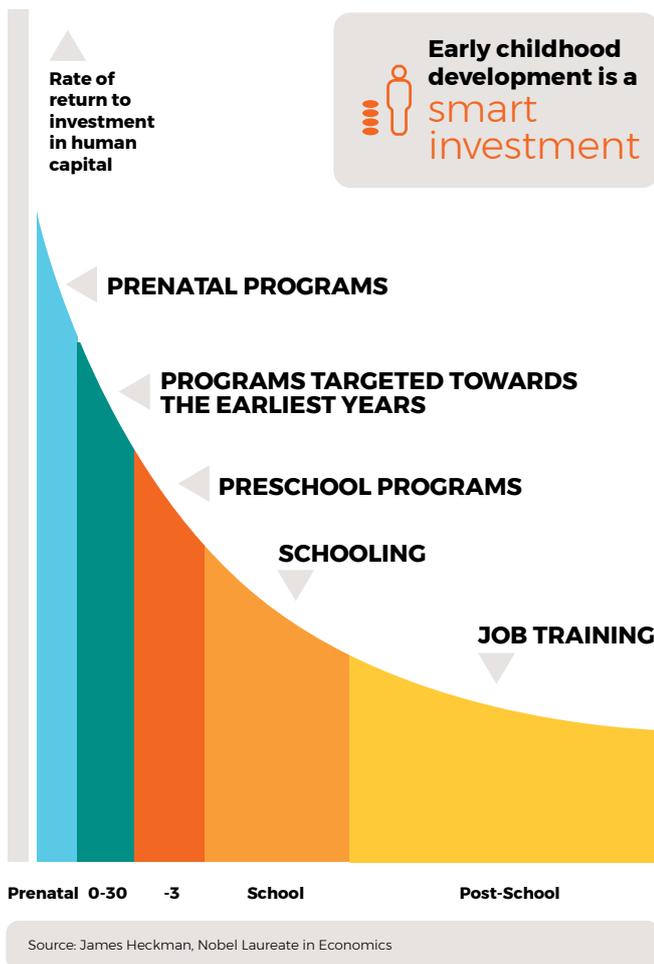
#### Parent

Participants suggested that simple but proven universal screening options such as the children's personal health record, recording infant development into early childhood, be extended to middle and later years. They also proposed reinstating screening programs previously delivered by community nurses in early childhood education settings or schools.

One parent noted that the NSW Health 'Blue Book', a guide and record about early childhood health and development, might be a useful source for families, however as she noted:

*“once you’ve passed that stage of going for the baby checks and the vaccinations – once that stops, you forget about it”.*

#### Parent



Where screening is available it is clear the prevalence of developmental vulnerability is high. Since 2014 the Royal Far West Healthy Kids Bus Stop screening program has screened more than 2500 children in over 40 rural communities across NSW. RFW data suggests that in some communities up to 80% of the children screened, who were found to have challenges, had not yet been identified.

*“If speech was addressed in those early years, then their language would be so much better, and they’d get to high school and their essay writing would actually make sense – you definitely see that with the ones who have been able to access some support and ones that haven’t. They just struggle and are likely to want to leave school early and things like that. So, it definitely makes a big impact on the rest of their lives.”*

**Teacher**

Community members expressed concerns that, even if there was funding for early identification and intervention, the workforce is often intermittent:

*“I think there is also a stigma though for therapists coming out to the country. I just think well hang on what incentives have they got to stay here? What are you giving them as part of their career development? You can’t expect someone in the prime of their life to come out here and go ‘this is fab!’ especially if they are not used to it. So I think definitely there has to be some encouragement to come out here whether it’s monetary or something else, but it has to be for a minimum term too”.*

**Community Member**

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





### 3. Fund and scale innovative service models

#### Recommendation:

Prioritise funding for innovative approaches that provide rural and remote communities with ready access to coordinated 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.

Once rural and remote families have obtained assessments and/or diagnoses, the next hurdle is consistently accessing the appropriate services for their child. Participants in multiple studies noted the following major barriers to accessing services:

#### 1. Travel to access services

*“where we lived previously [child’s name] would have to go 360km one way to see the paediatric specialist, and then we’d have to go another way, 100km...to see the orthodontist and then you’d have to go 200km one way to go to the paediatrician... so we were looking at a 700km round trip once or twice a week, which was physically impossible, so that was one of the big issues for us... [family moved towns to access services]”*

#### Parent

*“[My daughter] has ADHD – I put her in the car – I need to get her to [the nearest town with therapy available] – that two hour trip puts her in a foul mood. So when I get there to do this therapy that’s costing me \$175 she is not going to participate or she might participate in some, and then I have to strap her back in the car and drive home. The whole process of going – it’s just so daunting – okay right we’ve got to go two hours for a one hour session. It’s going to cost me this much – is it really worth it?”*

#### Parent

## 2. Lack of holistic or co-ordinated planning for the child

*“I mean this coordination thing is a major problem as well, because you think about it – the amount of money to travel to get a paediatrician – now that Paediatrician never talks to the OT. You can never get appointments on the same day, ever – or you can’t get to see the hearing specialist on the same day either or the ENT... And they don’t talk to each other... There’s just no integrated approach for kids who have multidisciplinary issues.”*

Parent/Carer

## 3. Perception of lack of service access for children in the middle years (8+) and early adolescence

*“It’s very, very hard to get any support for [allied health service] in particular, for an older child especially. You might get some for children that are just early starters at school, such as the preschool and the kindies but if you have a child with an [allied health service specific] issue as they’re older, it is really, really difficult... They [service providers] said ‘oh no, if [child] hasn’t got a really, really major problem, and [child]’s this age...it’s going to not happen.’ I was blocked at every place...”*

School Principal/Teacher

## 4. Perception of lack of service access for children with mild to moderate issues

*“There’s nothing, like I said, for the middle of the road where you know if you can put some good support, or good wrap-around services, or some good interventions right now, it’ll set that person up for a much more successful outcome in the end... There’s just no services. There’s no one here. There’s just no services.”*

School Principal/Teacher

## 5. The impact on parent/carer health and mental health trying to access the services their child needs

*“I’ve had to go and access mental health [services] for myself in order to cope with it all... Because I was really struggling mentally, with my mental health...I just felt there was something not quite right at home. And being always dismissed was not sitting right with me. The doctors are telling me I’m fine, but really I wasn’t coping with all the stresses I had to deal with...”*

Parent/Carer

## Cost

The lived experiences of seeking support for children with developmental challenges highlight the multiple difficulties for families living in rural and remote areas. Accessing services is difficult and lengthy. This is compounded by a lack of services in their community, the cost of privately-provided services, and the costs of travelling to access these services – both financial and emotional.

In addition, family income may be affected if parents cannot access flexible work arrangements or annual leave, must take unpaid leave days to take their children to therapy, pay for care for siblings, or need to leave work altogether to manage their child’s needs. Rural and remote families’ wages are likely to be below the Australian average, yet they are faced with higher costs of accessing services (including fees and travel costs), lost work or leave time, and lost education time for their children.

*“... Just like my husband would say that’s 500 bucks. I really don’t have \$500 for a session of OT...yet that’s what it is... Before you know it, the \$500, you multiply that by at least four or five. So...I’d love to tap into OT...but I just can’t ...I feel like the gap sometimes of where – what the kid should be getting and what they’re are getting just grows.”*

Parent

## Medicare

Many participants expressed frustration about the lack of access to Medicare rebates for ongoing therapy sessions. Some parents had received incorrect information about the number of allied health sessions they could claim, the gap payable, and the treatment plans available from their GP. There was also confusion as to how and when a clinician could be accessed for assessment, treatment, and plan management, and the differences between “going public” or “private”.

Financial barriers are present and real, with many practitioners charging a gap fee that makes accessing services prohibitive.

## 4. Integrate health and disability services for children

### Recommendation:

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

The mainstream approach to the NDIS is not working for children in rural and remote Australia.

The feedback from families and providers suggests that, although integrated and co-ordinated service delivery would make families' efforts to access support for children much easier, there are perceptions that the NDIS does not provide funding to support a coordinated approach. There are also significant barriers to access services, due to an inability to navigate the system as well as a lack of services locally. Parents reported receiving NDIS funding for services that were simply not available in their community:

*"They gave us funding for social supports, to build social skills. So a part of his package was to be able to do group sessions with other children. Yeah, that's really good. Where's the group? That has to be looked at by the government as a whole really because you only get NDIS funding for a specific thing".*

**Parent**

*"And because there's no services for the kids at [home town name] we have to travel so far, and because the speech therapy was such a huge wait at [nearby regional town] – waiting time 3-4 years for [private service] and I had so many problems... because there is no services for these kids – what are we meant to do...the service isn't there...you know, it's all great for the NDIS to say 'yes we've rolled out all across Australia but... – major cities are the places where the services are.' Well, you know, put a little bit more money into getting the clinicians into rural areas – via Telecare, or via one day a fortnight or two days a fortnight, to let these kids get access."*

**Parent/Carer**

Similarly, for parents whose children need assistance, but do not have a clear diagnosis, difficulty navigating the system means they are often forced to wait until the situation worsens before they can access support – a critical issue when early intervention is so important:

*"...at the moment I'm still waiting for [child's] NDIS approval...we first put in the paper work [almost one year] ago ....so [child's local disability support organisation] worker is really good...informally she's been trying her hardest to push it along for us, and support us the best way she can... and we called the other day – and it's in the assessment folder. And [local disability support worker] asked them how to hurry it up and [NDIS] the only way to hurry it up is if [child]'s at risk of harm. So then [local support worker] had to try and find out if 'risk of harm' could be covered under the bullying – or if it literally means at risk of harm from [child's] parents...'cause when she said 'if he's at risk of harm they can hurry it up,' I said 'don't do that! I don't need DOCS on my back!'...and she's like, that's why I've got to see what their definition of 'risk of harm' is..."*

**Parent/Carer**

Some parents can't access the NDIS for their children without coordination and support:

*"The parents aren't able to, it's too complex, and they try and get people to come out and so they said the people who do come out often can't answer their questions because they're still trying to work it out... They need to send out advocates that can - or train advocates and come to our community. You know I'd be happy to pay...we would actually pay for a community member that they've trained to go around and work with our community to fill out the paper work."*

**School Teacher/Principal**

Some schools are even seeing a reduction in services available locally with the advent of the NDIS:

*"We have two main feeders of support into our school at the moment. We were accessing more, but we've had to drop off with the NDIS because things have changed and diminished too - it hasn't gotten better."*

**School Teacher/Principal**



## Provider perspectives

**If families are forced to wait for NDIS approval, the opportunity for early intervention is lost:**

*"There are very few therapists available through the public health system and my concern is if a child's concerns are not big enough to be able to access the NDIS at this age - and they may be bigger next year - they won't be able to find appropriate help. I understand what NDIS is trying to do but it's just missing so many more."*

**Provider**

**Service providers themselves (though not under the NDIS) were also experiencing complications as a result of the introduction of the NDIS:**

*"we're getting a lot through the door, and technically, we're not meant to be doing anything with NDIS, but who is going to help them fill out the paper work, and who's going to follow-up for them, you know, out in a rural or remote area? No-one else is going to do it, the NDIS person only comes through once a month, for a day and a half, maybe. So, to fill out paper work - it's too hard. A lot of ours are illiterate. If you're near a service provider that can do that case coordination and follow-through it's probably better, but I think for self-funded packages, that's where it's getting lost a little bit."*

**Provider**

**Even providers who are well-connected with their community and had updated their knowledge about the NDIS were finding systems difficult to access and navigate:**

*"it can be very, very confusing as to how families can access therapists because of the NDIS...the waiting list up here for the NDIS is enormous and there are lots of confusions with it. Families that applied last year have either dropped off the waiting list and had to apply again or are only just getting funds through now [August]."*

**Provider**



## 5. Adopt a broader approach to children's mental health

### Recommendation:

Build a 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.

Mental health cannot be separated from physical and developmental health. Powerful evidence of the link between developmental vulnerability and mental health outcomes continues to grow in Australia and globally. Over the past 12 months, both Federal and State Governments have invested in delivering more services, better research, and greater reach to Australians with mental health concerns – including a focus on young people and telehealth. However, these interventions often commence in high school, and there is a clear gap in mental health services for younger children where the opportunity exists to intervene early. There is still too much focus on the pointy end, when issues are already escalating. Particularly in rural and remote areas, a big part of the issue is lack of access to services.

One participant suggested that delays or absence of early intervention can have very serious consequences:

*“I think the biggest issue is that it’s all a little bit too little too late. You’re trying to do everything and it always takes so long ...if someone is waiting six months to get into a behavioural therapist as the child gets older...you are opening the gap for more to go wrong.”*

**Parent**

Several schools shared their perception that the prevalence of developmental and mental health needs they see coming into the schools is increasing:

*“Within our area we’ve seen children come through with, I guess, a deficit, particularly in the area of speech. It seems to be a great number of children that are coming through the early learning framework unable to maintain conversations, whether it be through speech formations not being established correctly... We understand a lot of that is developmental, but there seems to be a gap that’s widening between developmental progress and speech. Even to the point where the physical cross-brain stuff doesn’t seem to be happening as freely and as easily for little people as what it once was.... Even in our more high functioning families, I don’t think they understand the importance of talking with, to, about and beyond with their children. I think the conversations in the home are definitely changing. Little things like... whenever the children get into the car they put the DVD player on. Children aren’t talking to each other in the backseat anymore.”*

**School Principal/Teacher**

*“A lot of these little people, speech is one of their issues. In the largest majority of cases, speech is just one component of their learning problem, but the confidence that comes with being able to articulate and participate, the value added to any educational experience is enhanced greatly.”*

**School Principal/Teacher**

Speech therapy, occupational therapy and psychology via telehealth have been proven to improve health, education, social and economic outcomes for rural children, families and communities. With the increased focus on addressing mental health at a national level, there is an opportunity for a paradigm shift, where policy recognises that speech, movement, social development and family are all connected, and all impact on a child’s mental health.

## **Schools at the Frontline in Mental health**

**There is a growing need for psychology interventions in children, with more than one in six children living in rural areas having mental health concerns. The National Mental Health Commission identified a critical gap in prevention and early intervention resources, supports and services for children. Demand for psychiatry services at has doubled over the past 12 months alone and the RFW psychology team has expanded by over 50%. This is driven by the increasing prevalence of mental health, and a lack of services regionally.**

**For those who seek support, both the education and health systems provide a major resource. Schools are often the first line of action. For those 14-17 year olds who seek mental health support, 40% do so at school, and only 3% receive support from specialised mental health services. There is a fundamental link between language and other social, emotional and learning outcomes, with substantial evidence base that early language development is a primary indicator of child wellbeing. These links include greater risk of conduct disorders, greater risk of mental health difficulties, offending, and entering the criminal justice system. A recent study by University of NSW found that childhood risk for mental illness may be detectable at school entry, and may be useful to guide targeted administration of intervention programs at school.**

(Green, M. 2018)

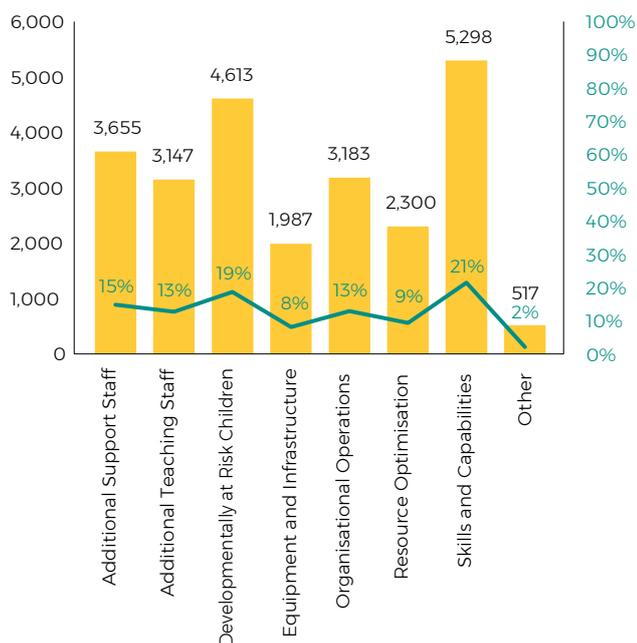
## 6. Teacher capacity building and support

### Recommendation:

Improve 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.

Educators are keenly aware of the important role that early childhood education and school can play in identifying and supporting children with developmental challenges. Project Catalyst conducted a Services Innovation Study, a survey involving thousands of principals, childcare directors and educators in 2018. The survey found that their top two priorities day-to-day are ‘Skills and Capabilities’ and ‘Developmentally at Risk Children’ accounting for 40% of all tested priorities.

#### Organisational Priorities



Principals and teachers from rural and remote schools spoke about their perception of a growing prevalence of developmental, behavioural and mental health issues for children:

*“We’ve got more and more kids presenting with developmental disorders...We’ve got definitely a growing area with fine motor because kids aren’t coming to school with finger dexterity like they used to. ...I’ve been in the game for over [number of decades] years...and I just see students presenting now that aren’t developmentally ready...”*

**School Principal/Teacher**

Schools also spoke about the need to build their capacity to support their students, particularly around mental health:

*“We’re attempting to educate, but I think there’s... many more kids presenting with anxiety than ever before. I don’t think we really know what to do with anxiety. I don’t really think we know what we’re doing with mental health with little people yet.”*

**School Principal/Teacher**

Parents frequently mentioned the role played by early childhood educators or teachers in identifying a concern with a child’s development:

*“As time progressed some of his carers – he was in day-care – said: ‘No we compared to the other children, he’s not meeting the milestones’”.*

**Parent**

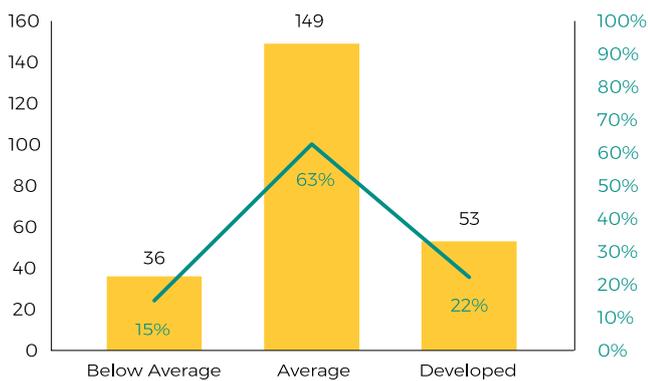
However, as the locus for services shifts to schools, one of the educator participants noted:

*“[many services] don’t seem to go on after early childhood – that’s the problem. I think the idea is schools are meant to kind of pick it up after that, but we’re just not trained therapists in those areas...we’re happy to run programs at school, but we can’t develop them because we’re not specialists in the field”.*

**Teacher**

It is clear from both lived experiences and the Services Innovation Study that there is a need for funding for appropriate supports for schools to manage the growing prevalence and complexity of developmental vulnerability. The study showed a concerning lack of capability and capacity of schools and early childhood education settings to manage developmental vulnerability in their student population, with 78% of educators self-reporting below average to average competence.

#### Developmental Vulnerability Management - Capacity and Capability





## 7. Increase the use of telehealth

### Recommendation:

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.

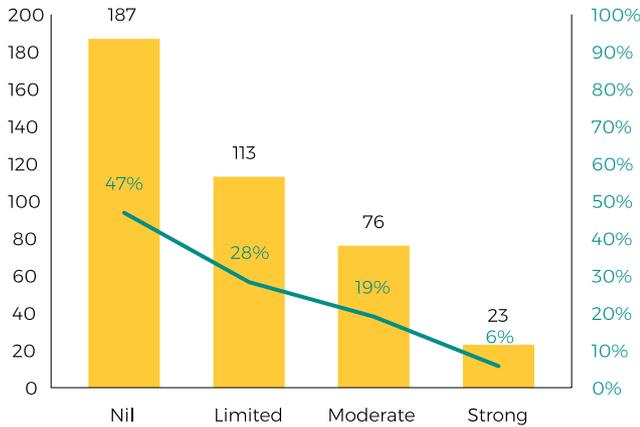
Over 100,000 children in rural, regional and remote Australia can't access the developmental health services they need. Recent media coverage highlights this inequity, with "remote people only accessing mental health services at 20% the rate of those who access services in the city". This "systems failure" is not highly visible but is critically important and persists despite policy and programs attempts to fund and supply on-the-ground services.

While it would seem to be an intractable problem, evidence shows that telehealth:

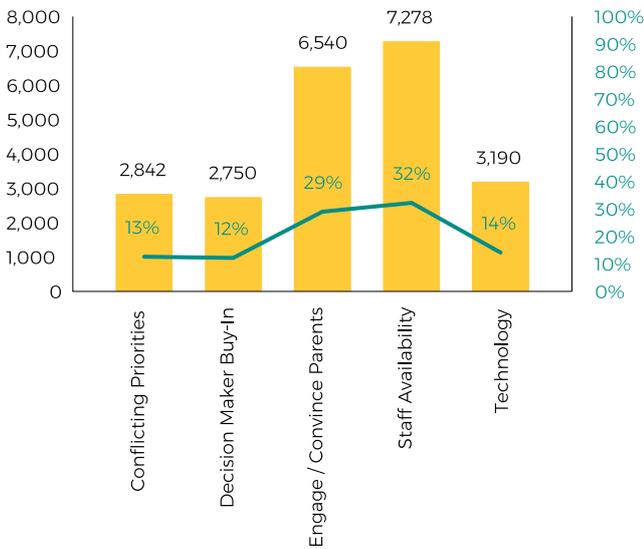
- is just as effective as face-to-face therapy,
- can counter workforce shortages,
- improves continuity of care,
- can be more cost-effective than "fly in/fly out" service models,
- increases reach,
- shortens wait times, and
- provides specialised multidisciplinary support in remote areas.

There are evidence-based models for addressing mental health - especially for younger children - which involve primarily working with the parent, and with an allied health team broader than just a psychologist. The current Medicare Benefits Scheme item for telehealth psychology doesn't cover these models for children.

### Telehealth Experience



### Telehealth Barriers



There is limited information and guidance for parents and educators wishing to engage a telehealth service. RFW’s Services Innovation Study discovered that only 6% of the respondents have strong telehealth experience and 47% have none. In addition, there are considerable barriers for telehealth adoption. 40% of teachers reported difficulty in convincing a parent or a principal, and 1/3 barriers to uptake of telehealth related to staff availability, again a greater problem for regional and remote areas.

Schools that had participated in telehealth supported programs and other allied health services spoke about the positive change in school culture resulting from capacity development:

*“Everyone’s on-board here. All the teachers, they know there’s a need. They know that’s so important. The language skills are so important for that child to move ahead academically. OT-wise, it’s sensory. I have a huge, huge amount of children that we’re still trying to get that together. We’d love to have a sensory room where instead of these children just getting worse and worse and worse during the day, take them out before they hit level two and start fighting and taking them out and do some sensory with them. We did it the other day so they saw how well that worked. A little [child] was in a big fight out there, a little year [# year at school]. Five teachers were trying to drag [student] off this child. They brought [student] in here and [student] was off [their] face. I just did a few massages with [them] and rolled the ball over [them] and used my brush to brush out..[Child] went to sleep. [laughs] We were able to take [child] back up to class and [he/she] was relaxed...That’s my next goal, to try and do a bit more sensory with some of our children before they get to that level...It’s really good that everyone’s on-board. The whole staff is on-board...I don’t know. It wasn’t like that in the beginning.”*

**School Principal/Teacher/Education Support Staff**

## 8. Prioritise models for providing culturally appropriate services for Indigenous children

### Recommendation:

Establish a national program to codesign culturally appropriate service models for children and families in rural and remote Indigenous communities.



**42% of Indigenous Australian children have developmental challenges - nearly double that of their non-Indigenous peers.**

**The AEDC reports that 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.**

Not only do Indigenous families in rural and remote areas face the same lack of access to services as non-Indigenous families, but this is further exacerbated by a lack of culturally safe and appropriate services, and for many families the deep and continuing impacts of intergenerational trauma.

Many barriers can be overcome by services being culturally competent and equipped with an understanding of the diversity of Indigenous people's experiences, history, values and trans-generational legacies. However, RFW's experience in working with Aboriginal children and their families points to the issue being as much about how services are delivered, as what those services are.

Telehealth, for example, offers a practical solution to overcoming issues of distance, transport and chronic workforce shortages but there can be questions about whether telehealth is culturally sensitive and appropriate. Royal Far West's experience working in the Fitzroy Valley in the West Kimberley region of Western Australia suggests telehealth itself is not the issue. Rather, like other service types, effective telehealth models are designed and delivered with local Aboriginal communities and are built on strong relationships on the ground with trusted community members.

Overall, there is a need for a much greater focus on the co-design of service models that focus on the developmental health of Indigenous children and their families, on further research and development of culturally-appropriate measures of developmental screening, as well as means of providing effective interventions and supports for children and families.

**Since early 2018, Royal Far West and Marninwarntikura Women's Resource Centre have been partnering with the Yiyili Aboriginal Community School to pilot a telehealth service for students and educators. Yiyili is a very remote Aboriginal community in the West Kimberley region of Western Australia with extremely limited access to services. The pilot is aimed at supporting children's developmental needs and improving outcomes through sustained speech and OT assessment and therapy, together this professional support for teachers and Aboriginal educators.**

**While the pilot is still running and there have been a number of learnings, it is clear that telehealth can be used successfully to support Indigenous children in remote communities if the model is built on strong relationships and cultural safety.**

**This work suggests there is enormous potential for tackling the tyranny of distance by using telehealth to improve the developmental health and educational outcomes for children in some of Australia's most under-served and isolated Indigenous communities, helping to address a range of speech and language, behaviour, mental health and learning issues.**

## 9. Increase the 'health literacy' of parents and carers

### Recommendation:

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.

Poor health literacy and lack of understanding of children's development is not unique to rural and remote communities. However, in these settings, socio-economic and geographic factors specific to rural and remote communities can further impede families' and communities' health literacy.

Rural and remote service providers are often aware of children in their community whom they believe require health checks and assessments. But commencing the process of health and developmental assessments can be difficult due to issues such as lack of transport, low income, lack of literacy, mistrust of service providers in general and lack of knowledge about the benefits of early intervention. Similarly, attracting appropriate clinicians to these communities, and enticing them to stay, is very difficult.



*"It's about educating the parents as well about the benefit of these kind of things. Because you could say: 'I've noticed this about your child, I'd really encourage you to get something done', but they're going: 'well, you know what, I've got to put food on the table next week and that's my priority. It's not to get speech therapy'. They don't see what the benefits of [it will be] later on in life."*

**Service Provider**

*"I sort of knew there were some processing issues happening in the background. So, if you tell them two things they go stand outside the door and they come back in, 'what'd you tell me?' So I went 'that's not quite right'. I suppose just from my older kids ... I'd never had that before."*

**Parent**

*"When we were in kindergarten a fellow class mate's mum mentioned that she had been going to occupational therapy for her daughter, and she had just noticed some similar behaviours in my daughter. She was like: 'you might just want to go and get her assessed', so that's where we got started."*

**Parent**



## Practical Considerations

### Supporting Families

As a society we need to recognise the difficult emotional work of accepting that a child has a developmental challenge. This is not just an immediate acceptance of the need for treatment, but potentially that the child's life course and opportunities may be changed from what a family might have hoped for.

The lived experience of seeking support for children with developmental challenges is often very difficult, and many parents noted the importance of empathetic providers and having strong peer-support networks. One parent explained her experience:

*“It’s very isolating to have children [with disabilities], even for me, my children aren’t severe, but even for me, as a parent, it’s isolating, because people don’t understand. You know, people don’t get why you don’t take them out like you did your first child, or you get embarrassed because their behaviours are just over the top, and everyone goes, ‘oh, you can’t control your children’”.*

**Parent**

In addition to the structural and social challenges of seeking help for a child with a developmental challenge, families can feel guilt and self-blame about their child:

*“What did I do wrong? How do I turn that around? Is this my fault? Is there something I should have done differently? Even though you know in yourself that there’s nothing you could have done differently to have the outcome that you wanted for your children”.*

**Parent**

From a family's perspective, noticing that there might be something different about their child is a scary prospect, that might prevent them from seeking assessment and treatment:

*“There is a fear of ‘oh there is a difference’ so now what do I do? Do I just ignore it or do I just pretend my child is naughty?”*

**Parent**

A service provider noted that:

*“I’ve had parents that are very, very well educated and are just so overwhelmed by the process. So, I just think the families that probably aren’t as educated, they’re not even going to bother attempting it”.*

**Provider**

Another provider said:

*“I often say to parents, it’s not a bad thing for you to just seek an appointment yourself. Just go and just have a big chat about it. And just to get some strategies to build them up because it is such an exhausting job being a parent 24/7 of kids with disabilities. And these parents just need so much more support. So – I mean, I’m at – yeah – we – I try to do what I can do. It – yeah, we need more. We need more support out here for them. Because once – they can’t afford to crumble, they have to stay strong for their kids.”*

**Provider**





## 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 improving country children's developmental health, allowing them to thrive. Our goal is to work in partnership with healthcare providers, Aboriginal Medical Services, schools, local government and community groups. We deliver multidisciplinary services, build capacity and advocate to achieve sustainable outcomes for children most at risk.

Through our team of over 80 paediatric specialists and our innovative use of technology, we support thousands of isolated and vulnerable country children annually, 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.

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**RoyalFarWest**



## About Charles Sturt University

Charles Sturt University (CSU) is committed to advancing higher education and research opportunities for the people of regional Australia. With campuses across New South Wales at Albury Wodonga, Bathurst, Canberra, Dubbo, Port Macquarie and Wagga Wagga, with specialist campuses in Parramatta, Goulburn and Wangaratta, and Study Centres in Sydney, Brisbane and Melbourne we bring strength and learning back to our regions. Together, we're improving economic and social wellbeing and creating sustainable ecosystems for future generations.

CSU champions research that helps communities flourish and shapes the world we want to live in. We engage in strategic, applied research focusing on significant matters in society. We work with industry partners, professions, and our regional communities. Our research activities cover three key areas: Resilient People, Flourishing Communities and Sustainable Environments.

As Australia's leading regional university, CSU also promotes social justice and human rights for Indigenous Australians. We do this both within our regions and across Australia. The Wiradjuri phrase *yindyamarra winhanganha* means the wisdom of respectfully knowing how to live well in a world worth living in. This phrase comes from traditional Indigenous Australian knowledge but it also speaks to the mission of our university - to develop and spread wisdom to make the world a better place.

Full report references can be found at  
[www.royalfarwest.org.au/research-advocacy](http://www.royalfarwest.org.au/research-advocacy)