



WHITE PAPER

Lived experiences of seeking support for rural and remote children with developmental challenges

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Executive summary

Introduction

Current estimates from Australian Early Development Census (AEDC) data suggest that approximately 22% of children in Australia are developmentally challenged on one or more developmental domains as they begin school.¹ Children in rural and remote areas are more likely than their city-based peers to experience mental health problems, and to be unable to access the health services they need. These difficulties are likely to be compounded by the poorer social determinants of health – such as education, employment and income – frequently experienced by those living in rural and remote communities.²

Known difficulties of seeking support for rural and remote children with developmental challenges include: long waiting times for assessment, diagnosis and treatment; a lack of appropriate services in their community; the costs of privately provided services; and of travelling to access those services.³ While numbers such as these have been in the public domain for some years, far less visible are the stories of children and their families who make up the numbers.

The purpose of this White Paper is to share the lived experiences of families and service providers involved in seeking support for rural and remote children with developmental challenges. The stories provided through these accounts are matched with recommendations for changes to policy and practice that respond to the needs raised.

The stories were sought through a research project conducted by Charles Sturt University in partnership with Royal Far West. Ethical approval for the research was granted by Charles Sturt University, and prior to consenting to take part, all participants were provided with clear information on the purpose of the project, the voluntary nature of participation and ways in which the information would be used. Seven in-depth interviews were conducted with participants, and additional material was gathered through Royal Far West's series of public town hall meetings, held in regional towns in New South Wales during 2017 and 2018. Participants included non-Indigenous and Indigenous family members, and service providers such as allied health practitioners, family support and mental health workers and educators from the early childhood and school sectors. To maintain participants' privacy, no identifying names or locations are given alongside the accounts shared in this paper.

There are four sections to this paper:

- **Section 1** addresses experiences of identifying children's developmental challenges
- **Section 2** addresses experiences of assessment and diagnosis
- **Section 3** addresses difficulties relating to ongoing access to the right services
- **Section 4** addresses systemic gaps and problems, and their impact for those seeking support for children with developmental challenges.

There is a brief summary of main findings at the end of each section.

¹ AEDC, 2018

² Barclay, Phillips and Lyle, 2018

³ Arefadib and Moore, 2017

The Australian health system

Australian health services are delivered by public and private providers, and are funded by federal, state/territory, and local governments. The Australian Government is responsible for Medicare and the funding of community-controlled Aboriginal and Torres Strait Islander primary health care. State and territory governments are responsible for public community-based and primary health services (such as mental and dental health), and preventative screening services. Local governments play an important role in delivering some community and support services, as well as some public health and health promotion activities. All levels of government are involved in funding public health programs and services, and Aboriginal and Torres Strait Islander health services.⁴

For families seeking services for children with developmental challenges, rebates are available for some services through the Medicare system. When the number of treatment sessions required exceeds the number Medicare covers, and/or where the provider's charge is greater than the Medicare rebate, families must fund the difference – known as the 'gap' – out-of-pocket themselves. Private health insurance schemes may also provide some rebates, however there is usually a 'gap' between the rebate and the full cost of a service.

In 2013 the Australian Government introduced the National Disability Insurance Scheme (NDIS). The Scheme provides personalised packages of funding to people under 65 years with disabilities, as well as to their families and carers. Funding can be used for everyday assistance services, to help build independence and skills, or to access

necessary equipment or technologies. Packages for support can be managed by families or individuals, a plan manager, or service providers.

Key findings

Long delays in accessing appropriate assessment, diagnosis and therapy have negative impacts on potential improvements in children's developmental challenges.

Lack of holistic planning and service coordination increases the difficulty for families (and service providers), of seeking support and therapy for children's developmental challenges.

The timing of early intervention can make a great difference to improving children's developmental challenges. There is a gap between services for birth–seven years – considered 'early intervention' – and those who require assessment after seven years.

Services need to be provided in rural and remote areas that are affordable, accessed within reasonable timeframes, and that are suitable for children's developmental challenges.

When families and children have to travel long distances to access support:

- travel and treatment costs compound the difficulty and stress for families
- children miss valuable learning time at school and opportunities for social engagement
- family members may sacrifice paid work or annual leave time
- the travel itself can be very stressful for children and potentially interfere with the efficacy of the treatment.

⁴ Australian Institute of Health and Welfare, 2018

More support is needed for the families of children with developmental challenges throughout their journey of seeking support. Families need:

- more information about typical and atypical child development
- opportunities to meet with others whose children have challenges
- ongoing help to implement home treatment plans
- support for their own mental well-being.

Communities play an especially important role in supporting children with developmental challenges in rural and remote areas. They can coordinate service directories, provide events and peer support opportunities, and facilitate fundraising.

Early childhood and school-age teachers are valuable allies in identifying potential developmental challenges. Greater information is needed for the education sector to support teachers to identify and refer children appropriately.

There is a need for accessible information about children's developmental challenges that community members can make use of.

Implications of the turnover of allied health practitioners in rural and remote areas include:

- children missing out on the timely provision of services
- re-assessment costs for families needing to re-join waiting lists
- interrupted treatment time while new practitioners establish relationships with children and families.

Gaps between Medicare rebates and the full cost of allied health support services were problematic for many families. The number of treatment sessions also frequently outlasted the number covered by Medicare.

Families' problems concerning NDIS funding included:

- receiving funding for services that were not available in rural and remote communities
- not being qualified for support for developmental challenges that would improve with treatment
- overcharging by providers when a child was registered for NDIS funding
- lengthy waiting periods for services to be covered by NDIS funding.

Author's note

So many of the stories shared in this White Paper are compelling and poignant. In combination they present a powerful picture of the complexity and difficulty of seeking support for children with developmental challenges in rural and remote communities.

The stories also show the incredible resilience and strengths of families who travelled by multiple means and multiple times over an extended period to get support for children. Also clear was the strength of local communities who considered it their collective responsibility to champion the needs of all children in their community.

The process of sharing these stories demonstrated to me the determination of families and service providers to get the help children need to thrive. Sharing stories was often an emotional experience for participants, and I have great respect for those who shared their stories – whether through interviews, or via the Royal Far West public town hall events, thank you.

1. Families' experiences of identifying children's developmental challenges

One of the first challenges families face is in recognising that their child may have developmental challenges. For parents with more than one child, concerns about developmental issues might be raised by observing differences in their subsequent children: *"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 and say, '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*

Other parents have also played a role in identifying potential challenges: *"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*

Participants also 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*

Social challenges

Families with children who have development challenges can experience very complex feelings in addition to experiencing difficulties gaining the help they and their children need. 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'".*

As well as immediate concerns, parents: *"...have all the concerns of what are they going to grow up to be? Because all you want them to do is succeed, but in what capacity are they going to be able to? So, that rides you, as a parent, the whole time, and it's debilitating at times".*

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'.

These worries can be heightened by others' ignorance or insensitivity: *"Before [my son] went to school I was talking with someone and they said that children like my child shouldn't be allowed into public schools because it makes it harder for their children to learn. And that got me quite upset, and I had that in the back of my head going to school. [But] we've been really lucky that they've all made sure [my son is included]. We'll be*

walking down the street and the kids will come out of their way to say hello to him and stuff like that. And I suppose that's when you see too that inclusion in a mainstream school can be so important, not only for the child but for the larger community of kids with similar disabilities". **Parent**

Inclusion in a mainstream school can be so important, not only for the child but for the larger community of kids with similar disabilities.

Self-blame

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: "There's all that guilt: '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**

And: "...he was throwing tantrums that were epic and all the rest of it, and obviously we went through the process of thinking it's our parenting". **Parent**

Avoiding the problem

From a families' perspective, noticing that there might be something different about their child is a scary prospect, and one 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**

It is unsurprising that some parents cannot make or sustain their efforts in the face of these difficulties: "I try and help those around me – lots of people come to me now for help. A friend of a friend will say, 'Oh, have you been down there [to Royal Far West] and what do you do here and what can I do there?' And I'll certainly try and help them where I can and point them in the right direction. But it doesn't give the answer to the problems often, especially if I can't say, 'well how are you going to fund that?' 'Well, I don't know'. It still doesn't answer that question ... it's still that commitment that parents financially have to make, and they just can't do it, not with the travel as well – not out here". **Parent**

Another parent shared: "When I had to get my son's hearing tested someone told me to ring the audiologist here – they said 'no we don't do children, ring this person'. So I rang that person – 'no sorry we don't do that either, but you can try this person', and in the end I found someone who could do a basic test but that still took me three phone calls to have a list of what's available ... I think that's where parents go 'nah too hard' or 'oh they don't have it – I am not going to Wagga for that'". **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".

Lack of access to transport is another issue for families living outside towns, and without their own car or public transport. These problems can be compounded for those who do not have strong English language literacy. For Indigenous families who have intergenerational trauma, an understandable "...hesitancy to work with anything government-based" can sometimes also be a reason for not seeking support.

In another community, a different provider shared that: *“We are constantly referring to private psychologists, private speechies, private OTs [occupational therapists] and they’re mainly located over in Orange or Dubbo. So, parents are then having to drive. So, it’s a day off work and the travel expense and working out what to do with other children if they’ve got little kids at home – it’s a whole day out sort of thing. So, it becomes too challenging for them and they try as much as they can and it has to fall by the wayside because they just cannot sustain doing that kind of thing. So, the kids are constantly missing out which is very frustrating”.*

Supporting families

Many participants identified the need for support for the families themselves, as well as the children with developmental challenges. One service provider noted: *“There’s been such a stigma around going to a psychologist, but they are so good at giving strategies of getting through tough times. 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. We need more support out here for them. Because they can’t afford to crumble, they have to stay strong for their kids”.*

For a family support service operating in one community, holistic family support was making a clear difference: *“...we look at parenting, we look at daily living activities, it’s a strength-based service focused on the child. So, what do we need to put around that child for them to be able to succeed? Our focus is making the child successful, to the best of their ability. Once you take the pressure off*

and you put programs in place to support mum and dad, you find the outcomes are much easier to achieve. Especially with children with a lot of difficulties, everything else seems to fall in place, and even the other kids start to fall in place as well.”

We need more support out here for them. Because they can’t afford to crumble, they have to stay strong for their kids.

In some places, families or service providers who had successfully navigated the complex health sector were offering advice to others beginning the process. For example, in one community, a regular meeting was facilitated for families with children with disabilities: *“We find our meetings are more just a coffee chat. We do plan things but it’s about building relationships with other families that are going through what you’ve been going through. Or touching base with them and having that sounding board, having that person to confide in, having that person to just get advice on things”.* **Service provider**

It’s about building relationships with other families that are going through what you’ve been going through. Or touching base with them and having that sounding board, having that person to confide in, having that person to just get advice on things.

A parent who often provided advice to others noted the impact of peer support: *“[saying] ‘I know what you’re going through’. I don’t think a professional could get up there and do it, I*

think it needs to be someone who has walked the walk and has gone through the process, because then they can relate, and the people can relate to them. I don't think you can do it without having someone who has gone through the process of it all".

SUMMARY

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

It is very valuable for families to have opportunities to be with others to hear about what sustains them in the face of difficulties, as well as where to go for assessment and treatment. Multi-disciplinary support is very effective for a whole family, not only the child with challenges.

2. Experiences of assessment and diagnosis services

Children with developmental challenges require access to a variety of clinical services, including allied health (in particular, speech and occupational therapy), paediatric specialists and mental health practitioners. However, for rural and remote children there are many barriers to accessing these services.

Prior research indicates that rural and remote children have limited access to clinicians due

to issues such as: practice areas stretching across multiple regions 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.⁵ These factors in combination most frequently result in long waiting periods for assessment, diagnosis and treatment.⁶

[As you] travel through the early days of assessment it's a never-ending battle. That's what I feel like anyway – every time you turn a corner, there's someone saying no.

Families' accounts of experiences with accessing services matched these prior findings. For example, demand for allied health providers meant that one family was: "on the waiting list just to get an [OT] assessment for 12 months, and that was at a private provider". Similarly, in another community, a service provider noted: "There is an occupational therapist supplied by the Department of Health who can do assessments one day a week for children who live in the [wider local] community. I was talking to a family on Friday and they started the conversations in October [last year] and I think her appointment is today [August]".

Another parent lamented that: "[As you] travel through the early days of assessment it's a never-ending battle. That's what I feel like anyway – every time you turn a corner, there's someone saying no".

When rural and remote parents want to investigate concerns about their child's

⁵ O'Callaghan, McAllister and Wilson, 2005

⁶ Arefadib and Moore, 2017

development, these long waiting periods can have significant implications: *“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**

Managing assessment, diagnosis and treatment

The need for more integrated service delivery has long been advocated by researchers in the fields of disability support and early intervention.⁷

Integrated service delivery can refer to the co-location of services concerned with a particular client group (for example, an early childhood education centre that also has an occupational therapist [OT], child health nurse or family support onsite), or, it can refer to coordinated services for families. When services are integrated to provide a multi-component intervention, they are more likely to be successful than those providing only a single intervention.⁸ In Australia, collaboration across sectors to provide integrated service delivery to families is made difficult by the different levels of government, scope and client eligibility requirements involved in their funding and implementation.⁹

Many parents lamented the lack of holistic planning as they began to seek support, as in this case: *“No one tells you where to go and what to do after you’ve got the diagnosis”*. Two other parents commented: *“when we were in the early days, we were just, ‘what are*

we doing - we don’t know...”, and *“how do I ask the right questions as to the information I need?”*

Similarly, the current systems in which families access support for children’s developmental challenges place the onus on families to gather and communicate their child’s care. One parent noted: *“I had to take three days off work to get all the assessments and everything that we needed to do, because they all want a mountain of stuff beforehand ... It’s very challenging for parents to navigate all of that”*.

There was a six-month waitlist, and because [child] had to go to school I said ‘I need this sorted. 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’.

Many shared experiences of multiple steps required to discover what to do: *“It took us nearly two years to get to the point of going to Royal Far West. We saw Community Health, we saw education providers, both in early childhood and school age. We saw doctors, we saw speech therapists, we saw paediatricians – we were going this full circle for about two years before we finally got in the door at Royal Far West and we saw everybody again, all under one roof, which was great”*. **Parent**

The excerpt above, and that which follows, highlight the benefits experienced by parents and providers when practitioners can meet for case conferences to discuss children across

⁷ Ah Chee, Boffa and Tilton, 2016

⁸ Flannery, Watson and Tully, 2008

⁹ Hilferty, Redmond and Katz, 2010

disciplines: “[When you] 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 the one roof”. **Service provider**

SUMMARY

In the early days of seeking support, little assistance seemed to be available to help families know where to start, or who to talk to. Trial and error, or random advice from other parents, were often the means of finding out where to go. Even when families did find the right services, long waiting times to access assessment and diagnosis frequently meant that children were not receiving the timely treatment that could improve their outcomes. The process of managing multiple treatment options was made more complex by the lack of an integrated approach across disciplines and jurisdictions.

Needing to be a strong advocate for a child’s needs was matched with determination and persistence to find the support services needed. Families needed help to implement home treatment plans to enable sustainable change for their children.

3. Ongoing access to the right services

Once rural and remote families have obtained assessments and/or diagnoses, the next hurdle is consistently accessing the services their child requires. One parent reported that: “I rang up occasionally at the hospital to see if there was [an OT], but the waitlist’s always prohibitive. And they’ve said, ‘Oh, well there is

one, but there’s probably a six-month wait to see her and when you do get to see her, she’ll be able to do an assessment, but she won’t be able to do any therapy’. I said, ‘well, we had all the assessments done at Royal Far West, I need the therapy’, ‘no, well we can’t provide that’”.

Even when services were available, they were not always suitable for the age, or the particular developmental challenges, of the child. One parent shared that: “We started seeing a psychologist here ... she had finished her studies ... and I just found her a little bit inexperienced, especially dealing with that age group [child was four years old]. She was a young girl, nothing against her personally, and of course you all have to start somewhere, but I just thought ‘this is not enough for this situation’. [The psychologist] was on kind of the right track but not really. Obviously trying to sit through a therapy session with a child of four, it just wasn’t going to work”.

When you’ve got no one else, anything is better than nothing.

In another instance, a systemic issue proved to be a barrier to a family accessing services: “One of my clients got their appointments cancelled because no one was able to contact them. And I said, ‘well what numbers [were you using to contact the family]?’ ‘Oh, we’ve got mobile numbers’. ‘Well, mobile numbers don’t work out on the mission’. ‘Well, we haven’t been able to get in contact’. So, they cancelled the appointment”. **Service provider**

For many participants, accepting whatever help was available was the norm: “I got really frustrated with my own kids being told by Community Health that, ‘oh, sorry, your kids are too high needs’. I get the fact that her reasoning was that she deals from zero to 80

[years], and when they're too high needs, then she doesn't feel that she had the capacity to be able to put what they need in, which is nice for her to say. But when you've got no one else, anything is better than nothing." **Parent**

Going private

In many of the communities and for multiple families, it was the case that: "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 occupational therapists and they're mainly located over in [towns of between an hour and an hour and a half away]". **Service provider**

In contrast to families who had to take what services were available regardless of their quality or age-appropriateness, families who could pay a private provider to access specialised services saw great benefits. Speaking about her experiences with a specialised children's OT who was a private provider, a parent said: "Their philosophy is really child centred and I can only assume their training as well – just the way they approach things – they really know what they are doing and any of the resources they give us – I just trust that it's very researched based – they know exactly what they are talking about".

Nonetheless, the costs associated with accessing private service providers were high: "I went through many different phone calls to different providers, and unless I was willing to travel to Orange or Dubbo, I wasn't getting any speech whatsoever. At the end of last

year, I bit the bullet, knowing [the children were] coming up to [starting school]. I spent six months travelling my kids back and forward to Dubbo, once a week, which is an hour-and-a-half trip, \$120 per child, and it nearly broke us doing it, but you had to do something to get them ready to go to school". **Parent**

And "...I'm paying \$270 a week for speech therapy for three children, which seems very expensive. I don't know how most people would do that". **Parent**

I spent six months travelling my kids back and forward to Dubbo, once a week, which is an hour-and-a-half trip, \$120 per child, and it nearly broke us doing it, but you had to do something to get them ready to go to school.

Compounding costs

As the stories above highlight, costs of paying for therapy services are often compounded with those of travel – with one parent sharing that early on in her son's treatment: "We had to go to Dubbo for three days [at a time], so we actually stayed in a motel in Dubbo".

Another parent outlined other compounding costs of needing to travel to access the services their child needed: "It's a two-hour trip, so if you're going over there to try and access a couple of services in a day you end up staying overnight. So you're missing school, we take time off work to do it we'd have to arrange care for our other son so he can continue to go to school".

The intergenerational commitment of families was illustrated by the following story: "Our client [who now goes to Royal Far West with

her two grandchildren], when she first started, she didn't want to go, she was very hesitant. [But once she had been, she said] 'it's so good to go up there ... the teachers didn't quite understand what we were talking about [at home] ... the benefits outweigh anything to taking them up there'. And it's not easy for them to get there. So, this client will catch a bus [for two hours], catch the train to Sydney [seven hours], and then the ferry across to Manly [one hour] – it's not a simple process. But she's committed – her grandchildren have needs, and she's very committed and very good with that. She's raised four of her own kids, eight of her grandkids, and she's now on her last two grandkids now". **Service provider**

Other parents reported one solution was to pay for therapists to travel to their town: "...we're now looking to go to Wagga for an OT. We will go over and see him but then we will also have to pay for him to travel over and spend the day to come to the school. So it becomes quite an expensive exercise". **Parent**

Other parents wondered whether the long travel to attend therapy was worthwhile, especially for children whose developmental challenges made long distance car travel difficult: "[My daughter] has ADHD – I put her in the car ... and 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?'"

For rural and remote families with children with developmental challenges, finding a balance between accessing therapy in a way that does not detract from their learning and social engagement is also very difficult: "We found ourselves for a time going to a lot of

doctors and therapists and it can become quite stressful for the child just because that's what they're always doing. My other son he's doing his sport in the afternoon, where for [son with Autism, going to therapy has] become his extracurricular activity. So to be travelling to get there [for two hours] ... it's not a fun time for him". **Parent**

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?'

Another implication of families having to travel to access services was that children had to miss school time: "I've got three children that need therapies of one sort or another, logistically organising that is quite difficult. So, if it's a speechie appointment that's not at the school, if I've got appointments booked for 9:00am, 9:30am, 10:00am – I've got to pull three children out of school at 9:00am or not take them to school. We have one in there doing the appointment, I've got the other two outside, then we do tag. I'm there for an hour and a half – the boys are all out of school that hour and 40 minutes there and back". **Parent**

One parent spoke of the contrast between travelling to access therapy then being able to access therapy while her children were at school: "...it means that that child's only missing out on that little session of school, rather than the big session of school, which I think has been really good as well. Because we know that [the morning] is a key learning time – if it doesn't happen between 9 and 12, well it's probably not going to happen today".

Another family was going to enormous lengths and costs to secure specialised

support for their child within his own school environment: “[Child] qualifies for a fulltime aide and they’re two gorgeous girls who look after him. But they’re not specialised aides, they’re not trained in any way towards special needs and in particular Autism ... we are trying to get [the teachers’ aides] to do some more training and we’re offering the school to pay for travel and training for these girls. But then they have to take time off, they have to get in replacement aides. So what we’re doing at the moment is if they go away we actually take [child] out of school and I stop work and I just mind him so that they can go, and to make it easier if they can’t find replacements”.

That child’s only missing out on that little session of school, which I think has been really good. Because [the morning] is a key learning time – if it doesn’t happen between 9 and 12, well it’s probably not going to happen today.

In this instance, the alternative to having their son in mainstream schooling in his own community was for the mother and son to move to Wagga Wagga (two hours away) during the week for him to attend a specialised Autism school. The family had chosen to take the approaches above to give him the best learning and social support possible, and to keep their family together. This case demonstrates the complex and stressful situations in which families endeavour to do their very best for their children, and when sufficient appropriate services and supports are not available close to home.

¹⁰ National Rural Health Alliance, 2017a

SUMMARY

Allied health services may be available to rural and remote children within their community, but these may not be appropriate for children, or, for a child’s particular needs. Many families reported accepting whatever help was available as this was the only option. Despite being 25% less likely to have health insurance than city families,¹⁰ rural and remote families were paying the costs of private providers just to access appropriate services.

Treatment costs were compounded by the costs of repeatedly travelling long distances to access the treatment. Lost school time, lost income from work absence, using annual leave up, and stress for the children associated with the travel, all add to the direct financial costs to families of seeking treatment. Children’s needs for social engagement – as well as school time – were also often compromised by travelling to access support.

4. Systemic gaps and problems

Discontinuity of early intervention

Early intervention programs aim to assist children’s development, well-being and daily participation.¹¹ Research suggests that interventions for challenges in early childhood (especially for children from low-income families) are most effective when existing programs continue into primary school, or, when challenges identified as a child begins

¹¹ ECIA, 2018

school are acted upon quickly.¹² However, as one early childhood educator noted: “We do have an early intervention centre about 25 minutes away so then the families have access to some therapists. But, once students hit that seven years age bracket, you don’t access that anymore. So, that’s been another stumbling block because it doesn’t automatically become better when they turn seven”.

The biggest issue is that it’s all a little bit too little too late.

Delays in receiving, or absence of access to 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 – I am not going to say they’re all going to commit suicide – I am just saying you are opening the gap for more to go wrong.”

Parent

By contrast, the following stories detail the sort of difference that timely intervention can make to children’s immediate experiences, as well as their longer term trajectories: “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”. **School teacher**

“[Our early intervention service] did nearly two years’ worth of intensive work with [child]. When we first got involved with her,

she couldn’t even go into the shopping centre or anything in our little town, so the staff would take her and would tell her appropriate behaviours when you go into a shopping centre. She had no social possibilities, so it was teaching her to say thank you, and speak to somebody, and so the capacity had to be built. We had to delay her going to kindergarten by 12 months, because she had no ability to go.” **Service provider**

“One family, who were homeless, had five kids, and one of them was about to be handed over to the Disability Forensic Assessment and Treatment Service because he had behaviour issues, [was] developmentally delayed, a whole range of issues, and they just couldn’t deal with it. At one point he couldn’t even be at school because of his behaviours, and he was just striking out, and he had to be in class for three hours a day with a teacher’s aide with him. [Our early intervention service] worked with the family and Royal Far West to get him the help he needed and now he goes to school five days a week”. **Service provider**

Disconnects between early childhood and school-age education

As indicated in the stories already shared, children’s transitions to or within the school system are often critical times at which parents become aware of developmental challenges, and take action. One school teacher spoke of the benefit of identifying challenges before a child transitions to school: “If they’ve been able to gain previous education before hitting school, it’s made a huge difference. And often those [early childhood] centres are very good at picking up

¹² Hilferty, Redmond and Katz, 2010

little things that just don't seem right and try and refer".

The importance of early identification and diagnosis was highlighted by another teacher: *"I think that's where the danger is with kids slipping in through the cracks [prior to school age]. Unless someone really says, 'hey, this is not right, what else can we do here?' they seem to get into school and go along their merry way."*

If children have not had challenges identified prior to school, there can also be difficulties with identifying and intervening once they begin school. One school teacher 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 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".*

I think that's where the danger is with kids slipping in through the cracks [prior to school age]. Unless someone really says, 'hey, this is not right, what else can we do here?' they seem to get into school and go along their merry way.

These difficulties can be compounded by the limited numbers of clinicians providing publicly funded services for children outside the early intervention age bracket: *"We've got one speech therapist up at the hospital, then Community Health, and she's got a huge waiting list and she's not even seeing anybody over the age of seven. She just can't – she can't even look at kids at that age". Parent*

SUMMARY

Accessing appropriate intervention before starting school makes a big difference to children's short and long-term outcomes. However, there is a lack of appropriate services for children of school age – both those who have already been receiving early intervention, and those who are only identified as needing support once they begin school.

Educators in both early childhood and school-age education need additional support in identifying, appropriately referring and working with children's developmental challenges.

Getting the message out

Socio-economic and geographic factors specific to rural and remote communities can impede families' and communities' health literacy.¹³ At one town hall event, a panel member noted that the general community is: *"not very well informed about the norms of early childhood. Unless you work in that field you are not likely to know about brain development or usual development. So there are few people with enough knowledge about what they should be expecting".*

Rural and remote service providers are often aware of children in their community whom they believe require health checks and assessments. Despite their best efforts to convince families to begin the process of health and developmental assessment, issues such as lack of transport, low income, lack of English language literacy, mistrust of service providers in general and lack of knowledge about the benefits of early intervention, can mean children do not get the help they need.

¹³ National Rural Health Alliance, n.d.

As one provider noted: *“Sometimes we’re battling with the parents to actually acknowledge that their child has some difficulties”,* while another said: *“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 [speech therapy will be] later on in life”.*

Another provider spoke of an ethical dilemma, requiring her to balance respect for families’ choices with her role as: *“...the advocate for that child. You’re the one going, ‘look, you need to follow this through, and we’ll walk with you, and we’ll do the paperwork, we’ll help you out, and we’ll give you the capacity to learn and to go forward, but you have to make sure that it’s met”.*

Unless you work in that field you are not likely to know about brain development or usual development. So there are few people with enough knowledge about what they should be expecting.

As these stories indicate, therapy that will make a difference to children’s developmental challenges is not a ‘quick fix’, however: *“the families sometimes see, say, speech therapy, as putting a car in for a service. Where they take them there and bring them home and they’re not fixed – ‘what’s the problem?’ And this can go across the spectrum – professional working families and non-working families. So sometimes part of the message is getting across to them what speech therapy is all about and how important*

it is to make a program everywhere the child goes. And it’s the consistency – the ability – once you actually have a therapist who you can see, being able to consistently get to appointments and back it up at home”.

Support for developmental challenges often requires an intensity of appointments that is difficult for families to maintain. One service provider spoke of the need for support for families to implement their home programs: *“I want a better referral system back to our service, so we can then follow up with the client, so they don’t collapse when everything pulls back from them. So giving them some backup – whatever therapy the specialist suggests and then being able to step away. [That would also help with] people who are not very confident in themselves, or who will ‘get around to it”.*

One way of addressing families’ health literacy was to take a very personalised approach: *“the most success I’ve had with getting families to think about speech therapy is a book I put together talking to them about children being able to speak properly, means they’ll be able to make sounds properly, means they’ll be able to attach them to letters properly, means they’ll be able to read properly – went through this whole thing – whole flow chart – and in the end I said, ‘this child can’t speak, they’ll probably get bullied at school’. 100% take up. But I had to show the consequences for their child. If I’d said, ‘speech is really important for reading’, then I might’ve got some but not many”. **Educator***

We just want to see that these kids get a chance when they grow up ... it’s creating a real face for these kids and a real platform for them to be recognised for what they can do.

In another community, service providers and families worked together to educate their community: *"...directing people to different therapists, specialists, if we hear of somebody that's really good, or bringing specialist or speakers to educate the community. We set up community events and fundraisers. We get a really good crowd and it then gives you an opportunity to educate the community about [disability]. We just want to see that these kids get a chance when they grow up. [So when] they leave school and the community already knows them and they're able to go 'oh, I remember Jackson – we know him, we'll give him a chance in our business' or that sort of thing. So, it's creating a real face for these kids and a real platform for them to be recognised for what they can do".* **Service provider**

One parent noted that the 'Blue Book' – a guide and record about early childhood health and development – might be a useful source of information for families, however as another parent noted: *"Once you've passed that stage of going for the baby checks and the vaccinations – once that stops, you forget about it".*

SUMMARY

There is a need for accessible information about children's developmental challenges that families and community members can make use of.

Information is also needed to communicate to families the benefits of therapies and need for ongoing attention to completing recommended activities at home.

Local solutions

While the bulk of this White Paper has shared the difficulties of seeking and gaining help for rural and remote children with developmental

challenges, for many families and providers their location was a source of great support and strength. As one parent reflected: *"It's one good thing about country towns I suppose. What you rely on here are people with a lot of heart and who are willing to give the time".*

One diagnosis and assessment approach that had worked well across two New South Wales communities was the Royal Far West Healthy Kids Bus Stop program. The Bus Stop program operates health screening for 3–5-year-olds living in rural and remote areas. Funding to have the program visit is provided by a partnership with Local Health Districts, Aboriginal Medical Services, Primary Health Networks, pre-schools and schools. Local communities and partners can identify a need for the service. Since 2014 the service has screened over 1,800 children in over 40 communities.

Royal Far West data suggests that up to 80% of the children screened had not yet been identified as possibly having developmental challenges. Service providers in the communities that received the visits said: *"We picked up so many kids with needs when that bus came through that we had been frustrated about. It was such a successful thing for us as a service".* Another service provider volunteered: *"The Royal Far West bus stop was an absolute godsend in that we were able to get families to the one spot at the one time with their children. Because another problem here is there's no public transport".*

Participants from a number of communities also mentioned the perceived benefit of schemes that had operated in past years. In two communities a Community Health nurse (or similar) would conduct routine and universal screening for all children as they began school.

If we sit back and wait for money to come, it isn't the answer. We have to be willing to do something.

In another community, a local group had been set up by volunteers to address concerns about children's developmental challenges in their local government area. One group member noted: *"If we sit back and wait for money to come, it isn't the answer. We have to be willing to do something"*. Their activities included operating a Facebook social media page for parents to find out what to do if they have concerns, or have received an assessment or diagnosis for their child.

SUMMARY

Local communities and services are an important source of collective information and influence in rural and remote areas.¹⁴

Improved health literacy for family and community members in rural and remote areas could be addressed through both universal screening and localised support.

Workforce recruitment and retention problems

Problems attracting and retaining adequate numbers of appropriately qualified allied health staff for rural and remote settings have been ongoing for decades.¹⁵ Data from participants confirmed this trend.

One family, who were reliant on publicly provided services for a child with very complex needs noted that: *"Funding for behaviour support started in 2017. I found out*

that funding had been allocated much earlier – possibly as far back as 2015 – but ADHC/FACS never had anyone to do the job".

Allied health practitioners, especially younger practitioners, seemed especially difficult to recruit and retain: *"[Speech pathologist graduates] come out here, they get a year or so worth of experience under their belt and then they go"*. **Parent**

"I could give you the list of all the specialists we've had and it's not because we've left any of them. We've had seven OTs in five years. You just get this churn factor – it's because of – 'I'm sorry, I'm leaving, I'm going to do this [or] I'm getting married' – and I get that people have lives, but it just seems to be a parking point for temporary specialists out here. I don't understand that exactly. At the moment we've got no OT, again, because of that same factor". **Parent**

Other reasons cited for high rates of turnover among practitioners included professional isolation, unmanageable caseload and choosing to go into private practice.

It's not just a matter of starting a program with somebody, this person's got to get to know your child before they can do a program, and they've obviously got to do an assessment, and that means there's going to be new reports required. So, okay – there's another \$1,000 for their initial assessments.

¹⁴ Bourke, Humphreys, Wakerman and Taylor, 2012

¹⁵ Denham and Shaddock, 2004

As one participant noted, however: *“I think there is also a stigma for therapists coming out to the country. I 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”*. **Parent**

There are also consequences for families of the high rates of turnover among allied health clinicians: *“I’ve got to start the process now with another one. So, that means I’ve got to pay for another round of new assessments. So, it’s not just a matter of starting a program with somebody, this person’s got to get to know your child before they can do a program, and they’ve obviously got to do an assessment, and that means there’s going to be new reports required. So, okay – there’s another \$1,000 for their initial assessments”*. **Parent**

SUMMARY

Families and service providers were frustrated by the persistent systemic issue of workforce turnover in rural and remote areas. For families, this meant missing out on services, or losing their place on a waitlist. If they needed to start a new working relationship with a new therapist there were often repeated costs, and it took time for the therapist to develop familiarity – and potentially effectiveness – with their child.

Medicare

Participants raised a number of issues concerning the lack of coverage of Medicare

for ongoing therapy services: *“The Enhanced Primary Care plan that you can get from a GP [is] only five sessions at half price, and you get \$52 back. That runs out very quickly when you’ve got a child with a speech delay or something like that, that needs probably 20 sessions”*. **Parent**

On the same issue another parent noted: *“You get ten Medicare referrals a year for combined Medicare health referrals. If you happen to need both a speechie and an OT that gives you five. So, that’s one every three months or so – what’s that going to do? And I’ve still got to cover the gap of \$90”*. **Parent**

That runs out very quickly when you’ve got a child with a speech delay or something like that, that needs probably 20 sessions.

Another parent had concerns about how the five sessions were used by OT services: *“There’s a real gap in what the government’s doing with OT. For your first assessment it can take two sessions, and one of the [five] sessions has to then pay for the report, so you’ve only got two sessions in the middle of it. Your assessment and report should be fully covered – they shouldn’t be part of your five sessions”*. **Parent**

SUMMARY

Families frequently found that the number of sessions covered or subsidised under Medicare was inadequate for meeting their child’s needs. There also seemed to be some differences in approaches to which services provided by allied health practitioners could be charged to Medicare.

National Disability Insurance Scheme

One of the most-discussed issues for families, children and service providers was the National Disability Insurance Scheme (NDIS).

No services available

Parents reported receiving funding for services as part of a package that were simply not available in their vicinity: *“They gave us funding 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

“I literally have to dress my seven year old every morning because she refuses to do it. She refuses to get dressed and get ready and she has no kind of life skills. [The NDIS officer] said ‘well that’s something that’s best looked at through the normal services – all your needs will be met’, and that’s the problem – they keep saying ‘all your needs will be met through the services’ but they’re forgetting we don’t live in the city so there are no services”.

Parent

Not qualified for support

Others reported difficulties when their child’s developmental problems were not considered permanent, and did not qualify them for NDIS support: *“She had sensory processing disorder and ADHD, and although her condition is permanent, because there is research to suggest that with therapy she will get better she doesn’t qualify for NDIS. And I said to them ‘firstly, I need to pay for the therapy for her to get better, and if I can’t do that she isn’t going to get better’. Then [the NDIS officer] actually*

said to me ‘the medication fixes it’ and I said ‘right okay the 9am–3pm relief we get means she can learn at school but also causes an onset of suicidal behaviour – so which bit is it fixing?’ So their definition of what a disability was or how an impairment affected people was just so clinical”. **Parent**

Similarly, for children who need assistance, but do not have a clear-cut diagnosis: *“There are very few therapists available through the public health system. 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”*. **Service provider**

One parent raised concerns about the way services charged families whose child was receiving NDIS funding: *“[One of my children] has NDIS funding but the others don’t. But, we have the same therapists seeing all the children, providing the same service. I noticed that the bill for this child is X amount, and because we mentioned that this one is funded, the bill for this child is now a different amount. It’s not right that the fee for the same service for that child should be remarkably different because it says NDIS next to his name”*. **Parent**

Provider perspectives

Participants who were service providers themselves (though not under the NDIS) were also experiencing complications as a result of the introduction of the NDIS: *“Technically, we’re not meant to be doing anything with NDIS, but who is going to help people fill out the paperwork, and who’s going to follow up for them 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 paperwork – it’s too*

hard. A lot of our clients 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".

Service provider

Even providers who were 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. We used to have a general pathway straight to our early intervention and they're now hooked up with the NDIS. Since signing up with the NDIS and becoming a provider [the early intervention service] has access to multiple speech therapists and occupational therapists. But, children are not able to access them unless they pay a lot of money or access the NDIS". **Service provider**

This in turn was generating new problems for the service provider: "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 [8 months later]".

SUMMARY

The introduction of the NDIS does not appear to have made a positive difference for these families and service providers. Major problems included a lack of appropriate services, difficulties with developmental challenges not being eligible under the NDIS, and difficulties understanding and managing support packages.

Conclusion and recommendations

The lived experiences of families and service providers seeking support for children with developmental challenges in rural and remote areas are complex, and highlight many issues. Some of the stories shared here echo existing research findings, and some present new perspectives and issues.

Some of the known difficulties of seeking support for rural and remote children with developmental challenges are: long waiting times for assessment, diagnosis and treatment; a lack of appropriate services in their community; the costs of privately provided services; and of travelling to access those services.¹⁶ The lived experiences shared in this White Paper shed light on the compound nature of these difficulties, and add evidence of the negative effects for families and children.

The costs to families seeking support for children's developmental challenges are high on all counts – rural and remote families' wages are likely to be below the Australian average,¹⁷ and they are 25% less likely than city-based families to have private health insurance.¹⁸ Yet the lived experience of many families was that they had little option but to pay for services out-of-pocket themselves to get timely access to the services their children needed. They were also faced with higher costs for accessing services (including fees and travel costs), along with the costs of lost work or leave time. These experiences reiterate the pressing need to address unequal access and lack of appropriate services between publicly

¹⁶ Arefadib and Moore, 2017

¹⁷ National Rural Health Alliance, 2017b

¹⁸ National Rural Health Alliance, 2017a

and privately provided resources for rural and remote families.

There is clear evidence that timely intervention for children’s developmental challenges can make a great difference to their life trajectory. Similarly – as stories in this White Paper show – there are also immediate and medium-term disadvantages that accrue when children cannot access the help they need. Universal developmental screening may assist in identifying challenges early. However, standard developmental screening tools may not accurately identify children who are at risk of, or who already have, developmental challenges.¹⁹ Existing tools may also fail to appreciate the ways in which Aboriginal children have developed that are culturally valued and useful.²⁰

There is a need, therefore, for further research concerning culturally appropriate measures of developmental screening, as well as a means of providing appropriate interventions to Indigenous Australian children.

There are also costs to children’s social inclusion and education when they must travel to access therapy, and as they face ongoing stigma and social isolation. Regardless of their location, families should not have to feel ‘lucky’ that their child is included and accepted in their school and community. The lived experiences of seeking support for a child with developmental challenges raises questions about children’s rights. Article 23 of the *United Nations Convention on the Rights of the Child* states that: “A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled

children and their families”. The same logic must be applied to children with developmental challenges.

You can’t silo a child.

Families’ and service providers’ lived experiences also clearly demonstrate the need for coordinated services for families throughout the process of seeking and receiving assistance for children’s developmental challenges. As one service provider noted: “*You can’t silo a child*”. Although research suggests the benefits of integrated approaches to intervention, service delivery remains focused on individual disciplines, and existing systems place the onus on families to manage and coordinate services for a child. While integrated service delivery would make families’ efforts to access support for children much easier, it also appears that the NDIS does not provide funding to support a coordinated approach.

Families’ and service providers’ stories of difficulties with the NDIS are echoed in an evaluation of the implementation of the NDIS in the early childhood intervention sector.²¹ Both sources highlight the need for recognition of the additional difficulties of implementing the NDIS in non-metropolitan communities, for more accessible and culturally appropriate information about the NDIS, and for involvement in addressing the shortage of appropriate therapists outside metropolitan areas.

According to the World Health Organization, health literacy is defined as having the capacity to acquire and understand basic health information and services needed to make suitable health decisions. Stories in this White Paper demonstrate the need for improved health literacy in the general

¹⁹ D’Aprano, Carapetis and Andrews, 2010

²⁰ Byers, Kulitja, Lowell and Kruske, 2012

²¹ Purcal, Hill, Meltzer, Boden and Fisher, 2018

community, as well as among service providers and families. With a system siloed by discipline or sector, high rates of turnover and potentially fewer cases of developmental challenge than in larger centres, rural and remote service providers may find it difficult to know when and where to refer a family.

Health literacy also increases families' capacity to better support their children. Previous research examining the effects of a rural parent information program showed that with appropriate information, parents felt less isolated and had greater confidence, empathy and skills to use with their children with Autism.²² Understanding the importance of timely intervention and the difference it can make for children's life trajectories may be one way communities and governments can better support families as they identify and seek support for children's developmental challenges.

As noted in previous reports and research, the persistent and widespread problems concerning recruitment and retention of allied health professionals needs to be addressed. Some of the issues raised by participants in this project echoed previous research, suggesting key reasons for allied health professionals to leave rural positions were: their partner was moving elsewhere, they had insufficient resources to do their job, or they had insufficient support from management.²³ One way of managing these problems could be the development of paraprofessionals who can implement therapy programs in ways that suit children's and families' needs (for example, during school hours, or on school property).

Together, the lived experiences shared in this paper reinforce the need for much greater action by governments concerning the needs

of children with developmental challenges in rural and remote areas. The World Health Organization states that a good health system is one that "delivers quality services to all people, when and where they need them".²⁴ In Australia, reform of the Medicare rebate system, or more public provision of services, seems necessary if governments are also going to take serious action on addressing the disproportionately high levels of children's development challenges in rural and remote areas.

However, with distance a variable that cannot be changed, there is a need for solutions that can coordinate and deliver multiple services that do not rely on people being in the same place at the same time. One cost-effective option could be to enhance integrated service delivery within existing investments – for example, through greater coordination and planning services for families between Australian federal, state and local government-funded services. Telehealth services – including assessment and diagnosis, allied health treatment and case coordination – offers another complementary solution to difficulties of distance and lack of coordination. More research is needed to establish the scope of its efficacy and cultural appropriateness, and what local resources are needed to best support successful and sustained implementation.

In 2011, the National Strategic Framework for Rural and Remote Health was released. However, there have been no reviews or reports of progress against Framework goals, and Australian government resources allocated to rural health have been drastically downgraded.²⁵ Further, between 2000–2014, only 1.1% of projects funded by the National Health and Medical Research Council were for

²² Farmer and Reupert, 2013

²³ Denham and Shaddock, 2004

²⁴ World Health Organization, 2018

²⁵ National Rural Health Alliance, 2017a

Australian rural health research, receiving just 2.4% of the total allocated funds in 2014.²⁶

The release of the Australian Government's Stronger Rural Health Strategy provides some hope that change may occur. This Strategy addresses some of the issues raised in the lived experiences discussed in this paper, notably via the Workforce Incentive Program and Aboriginal and Torres Strait Islander Health Professional Organisations Program. The Workforce Incentive Program will provide financial incentives to support eligible general practices in regional, rural and remote areas to employ nurses, Aboriginal health workers and practitioners, and allied health professionals. The Aboriginal and Torres Strait Islander Health Professional Organisations Program will support and develop an appropriately trained workforce to work with Indigenous Australians.

While the implementation of these programs may increase the numbers of practitioners, they may not necessarily guarantee their continuity of tenure. Benefits of continuity include coming to understand the community context as well as those people requiring therapy, and the development of longer-lasting professional networks.²⁷ Additionally, neither program mentioned above specifically addresses the needs of children. Therefore, while there may be more practitioners available, they may still not provide the specialised knowledge and support that has the best chance of making a difference to children's developmental challenges.

The Stronger Rural Health Strategy might also provide an opportunity for amplification of advocacy and action. One means of furthering action could be to advocate for the establishment of a national target to reduce children's developmental challenges in rural

and remote Australia from 22% to 10% by 2025. Royal Far West has begun advocacy on this agenda, however cross-sector support seems most likely to create the momentum needed to effect policy change. Further, as lived experiences also suggested, local approaches are often very effective. Whether in relation to community health literacy, allied health workforce retention or other issues related to children with developmental challenges and their families, using place-based or collective impact approaches²⁸ is likely to be a very useful complement to policy-driven approaches.

²⁶ Barclay, Phillips and Lyle, 2018

²⁷ Flannery, Watson and Tully, 2008

²⁸ As recommended by Arefadib and Moore, 2017, and the National Rural Health Alliance, 2018

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