

Hilary	<p>Welcome to season three episode three of the ASID “Research to Practice” podcast.</p> <p>This podcast was recorded on the unceded lands of the aboriginal peoples of Australia. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.</p> <p>This episode explores current research projects about the experiences of NDIS participants and service providers in rural and remote areas of Australia. First, we chat to Dr Stuart Wark about his research on rural and remote issues and the NDIS. Later in the episode, we will hear from Dr Angela Dew about her research looking at workforce recruitment and retention in rural and remote areas. We also hear about her current research looking at NDIS planning in remote areas.</p> <p>Dr Stuart Wark is the Year 3 Clinical Academic Coordinator in the School of Rural Medicine at the University of New England. He has a two-decade working history in the community and public health sector and retains strong relationships with both rural and metropolitan Non-Government Organisations (NGOs). His research interests relate to supporting people with intellectual disability across their lifespan, with a particular focus of issues associated with rurality.</p> <p>We met with Dr Wark to talk about his research on rural and remote issues including the inconsistency of access to services and health inequalities.</p> <p>When the NDIS was originally envisaged in its early kind of pilots and design phases, the idea was that it would operate in much</p>
---------------	--

	<p>the same way across Australia. A central feature of the design was that it would be nationally consistent.</p>
Dr Wark	<p>I think the original concept of the NDIS arose to some extent out of the Productivity Commission in 2011. But part of the premise was to look at getting consistency. And back then you had significant fragmentation. Each state would do things slightly differently. An individual didn't have funding allocated to them that could then be transferred to different locations and across state boundaries.</p> <p>So, the NDIS conceptually is very good from that perspective and the idea of consistency and a national rollout makes sense to everyone. Unfortunately, what we're seeing is that in rural and remote areas, there are a number of barriers that mean even though the idea of having one model works, there's all these impediments that mean it isn't actually happening. In small areas, you don't have significant choice in service provider. You might have service providers that are there but don't provide the support that you want.</p> <p>So, the concept of choice, which is inherent to the NDIS to facilitate decision-making and give people autonomy to make decisions about their life, is just not actually feasible when there are no services out there. And so that inconsistency that's coming out is that people in rural areas are being disadvantaged simply due to a lack of service options, amongst many other things.</p>
Hilary	<p>After talking to NDIS participants about their experiences, access to and types of services and the impact of NDIS on their quality of life, Dr Wark has identified some key issues.</p>

Dr Wark

One of the problems we always face is the whole issue of silos. Government loves having silos and putting people into neat boxes. And in the real world, people don't fit into neat boxes.

There've been some practical examples whereby people are saying they haven't been denied service. They are saying you are eligible for it but they get prioritized so lowly on the list that in practice it will never get round to them actually receiving that service. This is particularly problematic for therapy. In rural and remote areas, a lot of therapy services used to be provided by the government, that's no longer the case anymore. They've been outsourced in a number of states to NGOs and private providers. It is not financially viable in many areas for services to be provided.

And so, the market dictates unfortunately where these services are provided, and this means that in some rural areas it's not financially viable to do so. Therefore, the service simply doesn't exist. So, the flow on from that is that NDIS carers in particular talking to me about the fact that they are looking to move from where they live to a bigger area not always a metro area, but certainly to a regional centre because they can't access the support that they need in their community. Where this is perhaps a little bit tragic in some ways, is that in, you know, previous decades, we used to have a variety of smaller services in those communities, and they were sustainable.

With previous government ideology around getting greater diversity of services, it meant that you unfortunately ended up with a lot of services only having three or four people in a town, for example, and they are now no longer economically viable. So, they've now left and you end up with only one service option again. And rather than having the old specialist services where they would all assist and one group would look after or provide very good, tailored support for people with autism and someone else who provide good support for people who are older for children, you've ended up with a larger group of very generic

	<p>providers who try and do everything for everyone to the best of their ability. There was no criticism implied of their services, but a lot of the specialist service in rural areas have disappeared. And so, when people have particular needs, there simply isn't the option available for them to get that service they would require.</p>
<p>Hilary</p>	<p>Many NDIS participants rely on their Local Area Coordinator (or LAC) to shepherd them through the NDIS process of accessing services and assisting with identifying goals and planning.</p> <p>Dr Wark has been conducting research looking at the function of local area coordinators and their effectiveness in rural and remote areas. He has found varied feedback from carers. One of key determinants of LAC effectiveness has been their level or prior knowledge of the disability sector.</p>
<p>Dr Wark</p>	<p>There have been reports of some local area coordinators who are not up to speed either with the area or the disability sector. That means there's a time delay while people bring themselves up to speed.</p> <p>Some areas have been very proactive in identifying the gaps. The response to that identification, perhaps hasn't been forthcoming. But I do recognize they have actually recognized the gaps and identified them as requiring remediation, but nothing's really changed. Whereas in other areas they've actually been stymied, I think, by some local area coordinators not having sufficient knowledge and over time that obviously develops. But as we're still in the fairly early stages of NDIS roll out across Australia, a lot of that stuff is still, I think, falling under the radar a little bit while everyone brings themselves up to speed.</p>
<p>Hilary</p>	<p>During the COVID-19 pandemic, there was an increase in the provision of telehealth sessions to maintain access to services.</p>

	<p>We hear from Dr Wark about how telehealth services could be used to support access to services in rural and remote areas.</p>
Dr Wark	<p>In some areas of medicine, telehealth is quite effective.</p> <p>Rural and remote doesn't always have the infrastructure to do that support. Where it's been innovative is that quite often GPs will be proactive and hospitals GP clinics will often have reasonable internet access. And so, when someone comes in to see the doctor or goes to the hospital, they will then coordinate those visits with specialists so that they can tie that in at the same time, use the reasonable internet access that they've got at that point to then contact the psychiatrist, the GP, and the individual can then have a session.</p> <p>And equally that way the GP is kept up to speed with what's going on, Allied health therapists, in particular in Western New South Wales, have been very innovative in looking at and the same applies with Queensland in looking at how they can support an individual between their visits.</p> <p>And so, they will look at training up an implementer where they find either a family member, a carer, paid carer, or unpaid carer who they will train to implement the therapy programs in between their visits. And so, the therapist might only come four times a year, and that might be all the funding that's available, but they can actually give a very clear plan for someone else to follow, but then use telehealth to check that it's being implemented correctly.</p> <p>Where we're seeing good improvement is that the therapist can sit in Brisbane and look at someone somewhere in Queensland. And look at the physical therapy being provided and actually say, "Oh, I think you're doing that slightly wrong. You need to move this way. You need to do something slightly different."</p> <p>So, it's not three to six months until I go back again, to realize that the program isn't working, they can actually monitor it on the run</p>

	<p>on a weekly basis and just check and say what's happening, see if there are improvements going on there's pool a lot of training going on by therapists who are working with the local people to try and implement those sorts of models.</p>
Hilary	<p>Dr Wark has also been looking at the impact of health inequalities on people with disabilities living in the community.</p>
Dr Wark	<p>Some of the health inequalities that we're seeing again are particularly evident in rural areas. The only place you can get 24-hour nursing care is residential aged care. And so you have this problem where lots of people in rural areas end up in residential aged care very prematurely simply because that's the only place where they can get the nursing care they need. And a number of the people I've spoken to who are under 30 and living in a nursing home, and it looks unlikely that they will move in the near future, even though everyone wants them to simply because they cannot get the nursing care they need.</p> <p>In fairness they can't move into the community without that because they do need that care and they would die without it. So, you have this very interesting inequality. And I think it is worth noting not all of this is rural. Some of the work we've been doing is a comparison between urban and rural. And some of those issues are just as evident in rural, in urban areas as well.</p> <p>One of the things around health inequalities that we noticed, in particular around health service access, was that if you live in inner city areas, you generally have very good access might take you a little while, but it's generally available. Outer metro areas, and in a regional, so sort of looking at outer suburbs of a city versus large inland cities like Toowoomba or Cairns, Wollongong places like that, not particularly different.</p> <p>However, once you move beyond those large regional centres, it really falls apart. Access becomes very spasmodic, and some</p>

	<p>areas are well serviced, and they just happened to be lucky that they have got a GP, for example, who was very interested in disability and actually then promotes it and actively goes out to support that they provide examples where GPs will provide training online to all their colleagues through the division of general practice. Other areas if there's no one doing that, the health inequalities just grow because no one is conscious of looking for the issues. And again, the sort of things that are fundamental, screening, just don't happen for people with disabilities because no one thinks they're relevant to do unless someone's promoting it. So, you end up particularly in rural areas with this inequity actually increasing, and we're seeing more health comorbidities and particularly as the cohort ages.</p>
<p>Hilary</p>	<p>Dr Wark shares how some mainstream settings are taking a proactive approach to minimise health inequalities.</p>
<p>Dr Wark</p>	<p>There's a variety of annual health check type screening tools and they are being promoted quite heavily in some rural areas. And so, there's a recognition that if we work proactively to identify the problems you then don't have the chronic problems emerging down the track.</p> <p>It is dependent on area, unfortunately, that some are pushing it quite hard, some are not, within the hospital system, differing hospitals will have different approaches.</p>
<p>Hilary</p>	<p>Dr Wark talks about future areas of research.</p>
<p>Dr Wark</p>	<p>I think one of the things that in Australia, in terms of the NDIS that we haven't done well is learned from overseas experience. If you look at the UK, they've had a lot of the same issues that we're having, but they had them 15 to 20 years ago and we didn't say learn from any of that.</p>

And so, in terms of research, again, part of it is looking at what the experience is overseas. And rather than making the same mistakes over and over again, try and see if we can learn from them and pre-empt them. It is a matter of looking at that research that's already existing from overseas locations, how much of that actually relates to Australia. Some of the people on the islands in Scotland, their issues about remoteness are very similar to Australia, in fact, even worse in some cases. The Scottish data is stuff that I've looked at quite closely because it is quite relevant. The geographic distances in Canada are quite similar to Australia, they face similar sorts of problems.

The other one that I think is very important within this, and this is something every research has failed to do is include the voice of people with severe and profound intellectual disability. In rural areas, we have not been successful in including them in research to a meaningful extent. Part of that is to do with the cost factor. We recently did a comparative study, where we looked at people aging in the mainstream community and people aging with intellectual disability. And so, people aging in the mainstream community all got sent a survey and they completed it online and sent it back to us. For the people with disability, we did it face-to-face. That is incredibly expensive. And to try and include rural and remote magnifies that problem.

Now with Zoom and the COVID change that we've all seen, there may be opportunities to now look at how do we include people with more severe disability into some of this research. Can we use some of the online technologies to actually expand that? In the past we've relied on proxy respondents, we know that they're not particularly reliable. They don't necessarily have the same information that the individual does. So much of our research that we see just reports on, "we interviewed X number of people with intellectual disability", or "we did a survey of people with intellectual disability", or "we interviewed carers", they don't even think of the geographic factor to it.

	<p>And so, the big part is thinking through: am I likely to see a difference in experience for someone who lives 500 kilometres away from their nearest capital city? If you're looking at health service access they're going to be fundamentally different.</p> <p>And all research for people with intellectual disabilities needs to think through: do we need to include that rural sample? Because at the moment evidence-based medicine determines our policy structure. If our policies aren't actually informed by the people on the ground, our policies might not reflect the practices that we need. And so, if you don't include people in rural areas into that evidence base, we will continue missing that section of the community.</p>
Hilary	<p>We will put in a link to Dr Warks IDA article on rural and remote issues in the show notes. ASID members can also access the webinar that Stuart Wark and Laura Hogan presented on the ASID website.</p> <p>Associate professor Angela Dew is a sociologist with 40 years' experience in the Australian disability sector. Her research and teaching relate to understanding the intersections that impact on the lives of people with disability due to a range of complex support needs. Her work includes people with disability living in rural and remote locations, people from Aboriginal and Torres Strait Islander backgrounds, and those from refugee and asylum seeker backgrounds.</p> <p>We caught up with Dr Dew to hear about her research on rural and remote issues including workplace retention as well as her current work as part of an ARC, indigenous discovery grant.</p> <p>The NDIS scheme was intended to provide a consistent and equitable experience to NDIS participants. Dr Dew shares her</p>

	<p>insights on the experience of the NDIS model for Aboriginal and Torres Strait Islander people.</p>
Dr Dew	<p>We've always known that it's not possible to roll out any scheme in Australia that's going to be nationally the same. Australia is such a big country with such differences in terms of geography and in terms of the way that states and territories manage things. And in terms of the different population groups for people who are living in very remote communities and for Aboriginal and Torres Strait Islander people the idea of a market that's going to respond to what people need in those areas is just not realistic at all.</p> <p>Often their numbers are very small, which means that you can't think that there's going to be a service established somewhere because it's just not going to be viable in terms of maintaining that service. In terms of geography, just getting service to people where they need them. That's got many problems associated with it.</p> <p>And the other thing I'd say in terms of Aboriginal and Torres Strait Islander people is that the schemes are being developed as an individual model. For Aboriginal and Torres Strait Islander people very often that individual model is at odds with the way that they live their lives and interact with family and broader community which is much more around a collective model. And so, trying to separate that out and apply it individually is really problematic for people.</p>
Hilary	<p>Dr Dew's work has looked at some of the root causes of these inequities, in particular the workforce issues in rural and remote areas. We hear about some of the reasons it can be difficult to recruit allied health professionals to rural and remote areas, and the strategies overcome them.</p>

Dr Dew

The work that we've done over many years and is based a lot on the work that was done for the medical workforce. So that's where most of the research around workforce for rural and remote has occurred within the medical workforce. And very little had been done that was disability specific. And in particular, looking at people who are outside that kind of perhaps allied health roles. So, people in support worker roles, for example.

So, the key issues I guess can be divided up into things around recruitment. So, what makes it difficult to recruit people into positions in rural and remote areas? And then retention. So what factors are in play to keep people in those areas? A large bulk of the work that I've done in this area was from a project that was funded by the National Health and Medical Research Council. It was a grant that Sydney University got to look at allied health services in particular, in Western New South Wales. So regional, rural, and remote areas of Western New South Wales.

And workforce was one of the main areas that we focused on, although we did also look at things from the perspective of people with disability and their families. We identified that though the sort of inflexible workforce practices that were really run out of the regional centres were a major problem for people. And that was around really applying policy that had been developed centrally. So, it had been developed in this case, in Sydney.

There were also things around, cross sector competition, particularly for allied health workers. Health services for example offered much better pay and conditions for those workers in those areas than the disability services sector did. There were also things around people's tenuous employment. People were often employed on sort of casual short-term contracts. In a small community, the relationships that you form with people are so important, in the way that you're able to do your work.

And a lack of incentives. So, in terms of relocation expenses, or bonuses because you are working in a remote area. But also,

	<p>they're not just strictly financial, they're also sort of things that impact on your lifestyle. So, things like can your partner get work here? Can your kids get education in this area? Or are you going to need them to go to boarding school?</p> <p>So, all of that together makes those positions really problematic in terms of retention. So, some of the things that we've found that worked for people in terms of retention strategies were things like being able to give people some degree of choice about where they were located. So, if I used Western New South Wales for an example, the central office of the organization we were working with was in Dubbo, but they covered the whole of Western New South Wales, which is a huge area. And so, they were looking at practices like people being able to be based in some of the smaller towns. And then working out of those smaller towns.</p> <p>And it gave their partners more flexibility in terms of where their work was based as well. Another really important consideration was around professional support and access to professional development. And I think those two areas are particularly problematic.</p>
Hilary	<p>As we heard from Dr Wark, a lot of NDIS participants in rural and remote areas have limited access and limited choice of service providers. Researchers have been examining the factors affecting workforce retention. We hear about some of these factors from Dr Dew's research.</p>
Dr Dew	<p>As part of that work, we did a survey of the disability workforce in Western New South Wales. We used what was called a discrete choice experiment where we got people to trade off certain attributes for their work against other attributes.</p>

<p>Hilary</p>	<p>A discrete choice experiment is a quantitative method used to obtain a participant’s preferences without directly asking them to state their preferred options.</p>
<p>Dr Dew</p>	<p>And the thing that came through as the most important thing that people valued was autonomy. Was being able to have some say over the way that they worked, and where they worked, and how they worked.</p> <p>And then the second most important thing was the number of workdays that people were away from home. So, needing to travel to very remote areas. And people were prepared to have about three days a month away from home. But over that, it was problematic for people. And then the third most important thing was having access to professional development.</p> <p>Some of the other things are probably things that you would more expect. Which were things like people's concern around sort of the burden of administration, the paperwork that they needed to do. The travel burden of course, which, you know, out in some of these areas is a big one- the inflexible and inequitable work arrangements. So, they were things that were barriers for people in terms of retention.</p>
<p>Hilary</p>	<p>Dr Dew also reported that one of the unexpected barriers to retention was the ethical difficulties that allied health professionals experience in rural and remote regions. She found that the staffs’ ability to provide best practice services to people with disabilities were impacted by an increased waiting time, slower processes and a lack of options in rural and remote areas.</p> <p>In 2016, the Centre for Applied Disability Research at National Disability Services asked Dr Dew and her colleagues to complete a rapid review of the literature, looking at the barriers around a rural and remote workforce for disability as well as examples of good practice.</p>

	<p>Recently Dr Dew has been working within an Australian Research Council indigenous discovery grant, looking at NDIS planning in remote areas. The project is being led by Associate Professor John Gilroy from the University of Sydney, in collaboration with researchers from Deakin University, the University of Canberra and Flinders University.</p>
Dr Dew	<p>The work really came from the work that we'd done earlier at Sydney University. But also, some work that John and others of us had been involved with the NPY Lands in Central Australia with the Anangu people there.</p> <p>Where we'd been looking at what makes a good life for people with disability in really very remote communities. One of the things that was raised in that work was the idea of that individual planning, and how that was going to work for people in these really very remote situations, and what knowledge the planners would bring into that process that would be helpful for people. We were concerned about that and the partner organization on that work was the NPY Women's Council, who do fantastic work in those remote communities, and were very concerned about this as well.</p> <p>So, we applied for a further grant to really tease out some of those issues specifically around planning. We decided that we would look at not just at what was happening for Aboriginal people in remote, rural and remote areas, but also non-Aboriginal people so that we could talk about this more broadly. And so that we're looking at both of those experiences. We're talking to people themselves, people with disability and family members. But we're also focusing on talking to the local area coordinators, and the planners involved. So that we can really know what those issues are, and our aim is to really try and put forward some recommendations about how to better prepare that workforce for working in those areas.</p>

	<p>The work is only just getting started with COVID, we've struck some problems with getting out into the field to do those interviews. And we're really kind of rethinking the way that that might happen at the moment, because we're not sure exactly when that might happen. We're working in both Western New South Wales in the area that we worked in previously. But also, again, back in central Australia, there's some major challenges around that. The focus is really on what would a well-prepared and well-trained workforce around local area coordination and planning look like for people.</p>
Hilary	<p>At the time of the interview, Dr Dew and her colleagues have also been looking at international best practice and the literature on rural and remote areas in North America and parts of Europe.</p> <p>Dr Dew talks with us about what needs to be looked at within a national research agenda around workforce issues for the NDIS and rural and remote areas.</p>
Dr Dew	<p>I think what's really important is to look at how the market had actually responded. So, one of the things that we were told with the advent of the NDIS was that the market would respond. And that there would, it would in fact open up lots more opportunities for people to be much more flexible about the types of services they used. I'm not convinced that that's happened. I think we really need to understand that to really know what's occurred in these smaller communities, these more remote communities about that response.</p> <p>There was quite a lot of talk about whether family members would be able to sue people's funding to provide assistance to people how much that's worked and how well that's worked, I don't know. So, I think they're the sorts of things we probably really need to have a good look at. I think also, in line with that whether individualized funding has actually meant more flexible</p>

	<p>work practices. With the Sydney University work again, we started to have a look at private practice in the early days of the NDIS and found that private practitioners were quite keen to look at how they could work using that model but had lots and lots of concerns about how viable it was going to be, in terms of their business model. Because obviously in private practice you've got to think about whether you're actually making money and able to survive. So, I think we need to have a much better look at that whole workforce in particular around private practice.</p> <p>Another thing that's come up recently with COVID is our much greater use of technology. And there was some really good work done earlier on around telehealth methods and some of the work that we did at Sydney Uni showed that people with disability and their families were actually much more open to receiving service that way than the practitioners were in providing it that way.</p> <p>I really wonder whether COVID's pushed us into that shift more quickly and that could have some real positive benefits. But it would also be interesting to know where the problems were with it and how they might be addressed. And the final thing I'd say there is I think we do need to have a much better focus in our research outside of those sort of allied health roles in disability. So, you know, we do need to be looking at some of the new roles that have emerged with the NDIS and thinking about how they are working in the models that are working well there.</p>
Hilary	Dr Dew explains some of the barriers to accessing and collecting data.
Dr Dew	Much of the data that we can get access to is provided at quite a high level. So, what I'm saying is that it's difficult to often get the intersections that we would be interested in. So, knowing how this variable and this variable interact with each other.

	<p>Often what we can get access to is just information about one variable or another. And we have to then draw some conclusions around what that might mean in terms of those intersections and that's always problematic because it's a bit of a guessing game. It's based on the data. But it's extrapolating that in ways that perhaps it's not always intended to be compared. And very often the data we collect in the field is quite small scale.</p> <p>We try to get as many people involved as we can. But often there are lots of reasons why people don't want to be engaged in research as well. So, you're often seeing quite small samples, particularly with the qualitative research that we often do. And so, you can then be criticized for whether that's generalisable and applies more broadly.</p>
Hilary	<p>You can read more about this research in Dr Dew's article in IDA. See the link in the show notes. Look out for the upcoming rural and remote special issue of journal <i>RAPIDD</i> which Dr Angela is guest editor for. This is expected to be published in mid 2021.</p> <p>Thanks to Dr Stuart Wark and Dr Angela Dew for talking to us about their research.</p> <p>Thank you so much for joining us for episode 3 of season 3.</p> <p>You can subscribe to the ASID Research to Practice Podcast via iTunes, Stitcher or anywhere you find good podcasts. Keep up to date with all things ASID on twitter via the handle @ASID_ltd, on Facebook @ ASID.asn.au or via the website ASID.asn.au. Or better yet become a member and enjoy access to a number of publications and benefits. Just go to our website asid.asn.au</p> <p>This episode was produced by Emily Churchill, Gordon Duff, Sophia Tipping, Buffy Gorilla, & Hilary Johnson.</p>