**Podcast transcript**

**Special Series: Living with COVID**

**Interview with Chair of Disability & Health, University of Melbourne, Professor Anne Kavanagh**

**George Taleporos:** Hi and welcome to Reasonable & Necessary, Australia’s premier series on the National Disability Insurance Scheme, brought to you by the Summer Foundation. I'm your host, Dr. George Taleporos, and this episode is part of our special series on COVID-19. In this series, we have been tackling the important questions about how we can, as people with disabilities, stay safe from COVID-19 as Australia opens up. My first guest is the Chair of Disability and Health at Melbourne University, Prof. Anne Kavanagh, and we'll talk about what's needed to get the Australian vaccination program back on track for people with disabilities and how we need to do better to vaccinate people who have high and complex needs. We'll also discuss the role of rapid antigen testing in the disability sector.

**GT:** Hi Anne. Thanks for joining us.

**Anne Kavanagh:** Thanks, George. Great to join you.

**GT:** You were on our show last year when COVID just started really, and a lot's happened since then, hasn't it?

**AK:** Yeah, it sure has. It feels like a very long, well, over 18 months now, nearly 2 years of working on COVID and trying to improve responses for people with disabilities.

**GT:** It's been a very big year for us, especially yourself and I know that you do a lot of work in this area. Just so people get a sense of what you do, can you just tell us about what you've been working on?

**AK:** Yes, I guess I've had a few roles, but in terms of my research, I've done a lot of research in this area, over the pandemic, as well as being involved in advising government and also working with advocacy organisations and also other public health experts. So, the research really is concentrated on, has been mainly focused on the disability support workforce, looking at their risks of infection, infection control procedures, use of PPE and then access to vaccines. But we've done other little bits of work looking at also vaccine uptake among people in phase 1B of the vaccine rollout, also critiquing the government's response to COVID-19, but really through our Centre for Research Excellence in Disability and Health, we're public health researchers, so when COVID came along, we saw that we had a real role to play in helping shape, appropriate responses to what is a real public health emergency.

**GT:** Yes. That's what we all want to do. I'd love to start with the basics and for people who might not be aware, why are people with disabilities more at risk of illness and I guess hospitalisation as a result of COVID-19.

**AK:** In terms of individual factors, many people with disabilities do have medical conditions that put them at risk if they got COVID, ‘cause they might have compromised immune systems or respiratory systems, that put them at risk if you get COVID. And then also some people with disabilities require support, which requires more contact with other people.

And so they have a lot of people who are paid or unpaid that might provide support. The paid support workers might go between a number of other people with disabilities so the risk of transmission of infection is higher, just simply because of the contact people are having and the types of contact, which might be quite close, in a close proximity. And as we know, COVID is predominantly airborne. And then I guess the other issue which has been there for a long time is just the systemic problems with the health system and with people with disabilities navigating the health system. We know for a long time there's been discrimination and prejudice within the health system, difficulties in getting appropriate access to care and so forth. And all those cracks have emerged in the COVID-19 scenario.

And I think that those factors together and I think the other thing that's been problematic when we look back at the pandemic is we have the disability system, service system, not really able to respond to a public health emergency and the health system, which we have known for a long time, which has not been providing and as the world commission has shown in particular that the health system isn't responsive to the needs of people with disabilities. And the intersections between them mean that people with disabilities tend to fall through the gaps.

**GT:** Now vaccination has been a real problem. It’s been relatively slow when we were promised that disabled people would be prioritised. And the sad thing that I felt was that we were promised prioritisation and we didn't quite get that in the end did we?

**AK:** No. And I share the immense disappointment with that. I think we were very excited that we actually had got prioritisation and thought that for once we'd overcome some of the policy barriers, but it completely fell down in the implementation or the rolling out of the vaccine strategy. And I think that has been an enormous failure of government in the pandemic, in getting vaccinations to people with disabilities, who would be prioritised because they knew were at risk in COVID and international evidence shows us that again and again and again, that even though we haven't had the deaths in Australia that we have overseas sure as hell, if we do have a bigger pandemic here, it will be disabled people who will be disproportionately affected. And that's why we wanted to prevent that by getting the vaccines out.

**GT:** And we need to do a lot better with the vaccinations, especially for people who have complex needs. I remember you telling me about your son who has a disability and when I heard the story, I thought I want to talk to Anne about this in my podcast because people don't actually see how complex it can be for some people.

**AK:** Yeah. I think this is very true. So, should I tell you the story of …

**GT:** Yeah, just tell me a bit about your son and how it was solved.

**AK:** Yeah. So my son has an intellectual disability and autism, and he's been... he's very... as many people with autism and intellectual disabilities, he's very very frightened of any medical procedure and hasn't really had any medical procedures other than a general anesthetic maybe 4 years ago now and so we were really worried about how to get him a COVID vaccine and our first attempt was when we saw his pediatrician for the last time, because he's now 18, when we went to the children's hospital and we attempted to go through the immunisation clinic there and we had a little bit of sedation, but it was not as well planned as we had thought through and he was too scared in the busy environment of the children's hospital, despite having a little bit of valium to take the edge off his anxiety, so that didn't work. And we went away thinking that the only way we were ever going to be able to get him

a vaccine was actually to have much heavier sedation, more equivalent to a general anesthetic. Now that's a really big decision to make for someone to get a vaccination, to have to actually give them a much heavier level of sedation than a benzodiazepine, valium or some people call it diazepam. So we thought, we made those bookings anyway, because we thought we should, we had to get him vaccinated because he was at risk and likely to be exposed to a lot of people. But it was with some reluctance. And so we then decided we'd ring the disability liaison officers at DHHS. My partner rang them and they were absolutely terrific because we talked about his requirements.

I should go back and say that if he had have gone through the system, through the children's hospital of having more akin to a general anesthetic, he wouldn't have had his first dose ‘til tomorrow, that was the earliest we could've got in. So he wouldn't be vaccinated whereas now he's fully vaccinated. We rang the disability liaison officer and said, these are what's happening: You know he's very anxious, he never goes into a doctor's surgery, he's very scared about needles, you won't actually be able to examine him. It's really difficult. These are the issues, but what sort of environment can you provide that might work? They talked us through various options and one of them was coming to the home and we actually decided not to do that because we thought that would be not such a great place for him because he'd start to become fearful of visitors coming to the home. So we didn't want to, you know, create a sense that home wasn't a safe place.

So the disability liaison officer said, well, okay, there's this particular clinic, it's very small it only has 6 cubicles and we'll book out 2 immunisation spots and we'll make sure he's the only person there so there's not too much going on and he can be supported. So then we visited the vaccination centre and talked to them about Declan, about my son going, and then Evan and I decided we'd actually get him supported by 3 support workers. So he had 3 support workers come with him to the clinic after having had valium. We didn't go because we thought we'd actually make him more anxious. So we rang the clinic, they had him all ready for him to come right the way in. He was brought in, supported by the workers, he was scared and frightened, but he did it with the health of a bit of valium and a lollipop afterwards.

I think what it showed is, and so he is, he's now had his second, he went back to that same place. He was prepared to go back to it again, so I think what it showed was it was difficult, but with a lot of planning and a lot of people from the vaccination nurse, briefing her to the centre, allowing us to go in and have a look at what it looked like and planning where he would walk and where he would go and how the workers would support him and making sure he had the pediatrician giving him the valium. Everybody was involved in coming up with a plan that enabled him to be supported, to be vaccinated and now he's vaccinated. So it was a lot of work.

**GT:** What I love about that story is your son got vaccinated, most importantly. And the other thing I love about it was that it showed that there are health professionals who are really willing to do what it takes.

**AK:** Yes.

**GT:** …And make adjustments and book out the rooms and whatever's needed right. And this is a thing that I often find people don't understand is that, we do often need things done quite differently. It's not always about fitting us into the system. The system needs to adjust to what we need for things to work.

**AK:** Yeah, I love that comment. I think that's absolutely right. And I think it was a combination of the expertise of the disability liaison officer who knew all the vaccination centres and knew lots of things about them, from where they’re set up to the kind of people who were in them to get that flexibility. And then the vaccination centre itself who were really willing to go the extra mile and, were prepared for us when we got there. It really was best practice if you like we should be seeing that in all kinds of healthcare and it can happen but it doesn't unfortunately, and I dread to think how many other people haven't been able to get over the hurdle we got over for him to be vaccinated. I feel there's a lot out there who aren't vaccinated because they haven't had that option yet.

**GT:** Well, hopefully there are some people listening who will think that, yeah it is possible, no matter how complex things might feel, you just need the right person at the other end of the phone sometimes.

**AK:** I think the DLOs in Victoria are a really good service, and I don't think they've got them in other states. I think it's kind of almost like a system navigator for someone with a disability, you don't go cold into a health system, that's not designed for us, you know?

**GT:** Yeah Victoria has definitely done some good work in that space. I'd like to turn now back to your professor hat on, if that's okay. Have any of you recently worked with a group of experts who have put together some guidelines on what we need to do to keep people with disabilities safe from COVID. And I'd really like to focus on some of those suggestions and recommendations if you are happy to share some of those with us.

**AK:** Sure. Thanks, George. And of course you were part of the group that put those guidelines together and we've worked a lot during the pandemic.

**GT:** We have spent a lot of time together.

**AK:** Yes we have. So this group is a group of experts from a range of different sectors and disciplines, so there are economists and political scientists, infectious disease control specialists. And there's a small group of them involved in putting this working paper together, it's called OzSAGE.

**GT:** Why is it called OzSAGE? I don't know if that means anything.

**AK:** OzSAGE which I have to say, I've forgotten what that acronym means. There's a SAGE that comes out of around COVID, that's come out of England, and this is the Australian version of it.

**GT:** Perfect.

**AK:** So that's why it's called OzSAGE. But what we've done is tried to link in these guidelines some of the other guidelines that OzSAGE have also put out and are continuing to put out around COVID-19, and Australia's response in COVID-19. So OSAGE is trying to be as independent of government, trying to provide advice to government and other organisations about how best to do this.

The other issue within this pandemic, and more generally in sort of knowing what's happening is the fact we have very poor quality data in Australia. And most of our evidence about what's happened to people with disabilities has come from overseas in part, because we haven't had the same experience, but, there is a lack of transparency in reporting of the data.

What data is reported relates to NDIS participants only, and sometimes only to a proportion of those participants. So I think we know that the NDIS only includes about 10% of people with disabilities and so we're missing a whole bunch of data, but even having said that the NDIS data is not reported very frequently and we know that the cases are under counted in that data. So unless we know really what's happening, we can't hold government to account and we can't design new solutions. And I guess the other major issue here is we need to aspire to very high vaccination targets for people with disability. It's really fantastic to see how much Australia is taking on vaccination and how high our vaccinations are in eligible populations, but we really should be aiming for 100 per cent of people with disability and their support workers and the people around them, allied health professionals and their families. We need a 100%, we need a 100% for all of them, and we need to work until we get the whole 100%. And some of the people who aren't vaccinated at the moment are the people that probably are at the highest risk, the solutions haven't been come up with. As you and I know, a lot of people who need vaccinators to go into the home haven't had them, and that's really problematic.

So we need to think about how we're going to do that much better, and literally, very individualised solutions to vaccination. We haven't had good education and communication about the vaccine to people with disabilities, and I think the role of the DPOs or the disabled people's organisations and advocacy groups in reaching out to people with disabilities, that really must be enhanced, and to get to every single person with a disability. And then how…

**GT:** Can I just step in there? How do we get, that's a very ambitious number, 100%, I’d be happy with 99%, but how we get to 100%? We have mandatory vaccination for support workers, we... What else do we need to do to get to 100%?

**AK:** Well, obviously mandatory vaccination for support workers means we do get support workers vaccinated. I think we should aspire to 100 per cent. And that means that every single person has every opportunity to get the vaccine. So we gave the example of my son, and that's the amount of effort or more that will have to go into getting a lot of people vaccinated who are not vaccinated.

So it's not as simple as we ask that person or we ask that service to offer this person a vaccine and they go and get it, it means following up and making sure someone can reach out to that person, or as we've talked about before, reach out to the family members who might be the blocks to that person being vaccinated.

It really has to be a very concerted effort to make sure we know why a person hasn't been vaccinated and that they've given every opportunity to reach out to get that done. Like you, I suspect we won’t get to 100, we'll never get to 100, but I'm aspiring to 100, I think it's what we should be getting to.

**GT:** What do you do with these parents who might be vaccine-hesitant or, I won't use the anti-vaxxer term because that's polarisng, but parents who have, I guess this isn't making power over their son or daughter, how do we deal with that? Because that really concerns me, that there are parents out there that are putting their sons or daughters at risk.

**AK:** Yeah, I completely agree, and it absolutely terrifies me if that is the case. We shouldn't take simple nos from parents as a lack of consent, we just can't accept that. I think we need to... There are a range of strategies. There's soft strategies, I guess, like getting other parents or other people with similar disabilities to their child, for instance, or their son or daughter, and talking to them about why it's important and what are the risks if they're not.

But I think at some point, if they keep saying, no, we really need to think about whether they're acting in that person's best interests and what are the legal channels that we need to pursue to ensure that someone has the access to what is a very basic preventative care measure, because, really, these people are at significant risk, and I know you share those concerns, it's a real worry.

And hopefully there are only a few of those people, we can bring people around, but we don't have much time left, do we, particularly in New South Wales and Victoria? So we really might need to make some hard decisions about what we do with the people who aren't getting consent from their substitute decision makers.

**GT:** What do you think the roles of support coordinators are in this area? Do you think they need to be doing more?

**AK:** Well, I think it would be fantastic. This is the problem with the whole response to COVID. I think we've still thought there's been this disability and there's been this health response, but they're completely integrated, aren't they? It’s not that a person with a disability doesn't have health needs, and if the support coordinator is a trusted person in that person's life, they're a very helpful person to help perhaps talk to the person with the disability or their family members about the importance of vaccination. And this is a role that the NDIS could play for support coordinators or even local area coordination units, but it hasn't really been something that's been done in the pandemic, drawing on those kind of resources. I think we've seen our response as either health or disability, but not how we interact across those 2 systems. So yeah, that's right.

But in terms of the other things that we could do, I'm just thinking about the OzSAGE recommendations that we were talking about before. I just wanted to emphasise for the listeners some of the other strategies that we need to be thinking about just besides vaccination. And in OzSAGE, we talk about vaccine plus, so those things include not just vaccination, which is obviously the ultimate thing we want to do, but it's to reduce risk of transmission. And that requires thinking about things like indoor air and the safety of indoor air.

So, particularly for people who live in maybe group homes or boarding houses or work in supported employment, but anywhere where someone with a disability is going, it's really important to make sure that those spaces are really well ventilated. So there needs to be some information going out to providers and to people with disabilities about how they make the space safe, whether they should be using HEPA filtration units or whether they can create some sort of additional ventilation - in toilets and corridors are places where there's not good ventilation. So we really need to think about that and what's the role, potentially, of the NDIS services, the Quality and Safeguard Commission in terms of what do we do there?

**GT:** Are there some tips? I've read opening a window can be a really important factor. Getting one of those air purifiers, are they a good thing or is that just media hype?

**AK:** No, there are roles for those things, but I think I would recommend that people actually look at the recommendations for safety, indoor air ventilation from OzSAGE, because there's a hierarchy of things you can do. Obviously opening the door and opening the window are the best things, and then there are places where it's not easy to ventilate that way. Of course one thing you can do is invest in these CO2 monitors to see where there's likely to be poor ventilation, and when there's high levels of CO2, you might need to think through how you're going to ventilate that space.

The other thing is compulsory mask use for workers. I think it was interesting to listen to the Victorian press conference yesterday, because I noticed that recommendation that masks could stop being used indoors, November 24 or something, but they could be used in other settings. Until we're into a much different situation, I think it's really important that workers continue to wear masks. And they need to be trained in using them properly. I don't know about you, George, but there's a lot of people who don't seem to think masks should go over their nose.

**GT:** There are people who wear them like they’re chin nappies.

**AK:** You need a well-fitting mask, it needs to be tucked under the chin, it needs to be over the nose and so forth. And also, we have a lot of advice on that on the OzSAGE website, but I really think it's important that the workers really understand the importance of mask use and putting it on properly. And the other thing I think is the use of rapid antigen testing in workers, because…

**GT:** Yes. Let's talk about that, Anne. I'm really interested to hear your views on how we can use this technology which is going to be available from 1 November in people's homes even, is that right?

**AK:** Yeah. The thing about the rapid antigen testing is that... In England, it's provided free to everyone, which is quite different than what we are planning to do in Australia. The latest I hear is that it's going to cost $15 a test, so who's going to buy them?But if we did have rapid antigen testing and we were able to implement it in the workforce, you could do that with disability support workers several times a week or before they come on shift and make sure that's negative before they work. Where needed, you could also do that with people with disabilities themselves. But it must have a role in reducing the transmission, because if you're testing people regularly, you're going to pick up the COVID infection eventually. Not as sensitive, obviously, as the other tests, but far better to be testing people frequently with these rapid antigen tests than not to be testing them at all.

And I think we're all worried that testing will fall off a bit now as we seem to be moving to a different era where we're worrying about hospitalisations and deaths and less about the number of infections. And people won’t get tested, they must continue to get tested and people in the disability sector need to continue to make sure that people... People with disabilities need to make sure that people are continuing to test themselves. So I think rapid antigen testing has an important role. I think we need to come up with some strategies and policies about how it can be used in the sector to give people with disabilities and services the guidance needed about how it could be used. Because it may be that the settings for people working in group homes mean that they need to be tested more regularly than people working in other settings, but we need to work out what those particular policies should be.

But I think it's got a very important role going forward. And I think also the real importance of making it free to everyone is really critical because otherwise, people aren't going to buy 15 bucks a test. They're not going to pay for that for their rapid antigen test. So those are my comments around that.

I think the quality of the tests are going to improve over time. Well, I suspect we'll find that they'll get more and more sensitive. And so, they'll actually be an even better way of controlling the pandemic and identifying people who are COVID positive early. So I think there's a lot, rapid antigen testing's got a really important role going forward. Exactly what that looks like needs to be planned out. But I want government and infectious disease folk and that to work on this ASAP because it's too late already. We should have these policies in place as we're starting to open up.

**GT:** You made some really good suggestions, but as I was thinking, listening, I was thinking there's so many things that we can do now, right? So double vaccination and then get your booster when you’re due, wear a mask, open a window, have rapid antigen testing. Part of me feels like do we need to find a balance between doing all of those things and working out what our tolerance of risk is, I guess?

**AK:** Yeah, that's true. I mean, it's ultimately up to the person with disability themselves how much risk you're willing to tolerate…

**GT:** Because I wouldn't mind seeing a human face. I haven't seen one apart from on a screen in 2 years and will I ever get to a point where I'll be able to see a support worker’s face?

**AK:** Yeah.

**GT:** Just seeing someone laugh and smile, I miss that.

**AK:** Oh, I do too. I agree. And I think we do... It's that sort of, we talk about the individual risk all the time in this space, don't we? I agree completely, we need to have that conversation. But I think there are things that are not that disruptive to ordinary life, which can be done easily. I mean, obviously, if you decide you want to see the mask come off, that's a decision, but it's possibly better to do outside rather than inside. You know what I mean? To reduce the risk.

**GT:** Yeah, yeah, yeah.

**AK:** It's about the balance of making those decisions.

**GT:** And before we go, it's been really interesting, but I'd want to just ask, is there any final words that you want to share with people listening around how they can adjust to living in a COVID world, where everything's opening up, we know that there's a lot of options out there to stay safe. But do you have any other words of advice you'd like to end on?

**AK:** Well, I think obviously, the strongest thing you can do for yourself and from everyone else in the community is to get vaccinated. So if you're not vaccinated, get vaccinated and if you are vaccinated, I think it's really important to talk to those around you and encourage them to get vaccinated. There's the information on how to have those conversations. But I think everyone needs to understand that part of getting vaccinated is about not just about yourself, but it's about protecting everyone in the community by reducing the chance that you'll give someone else COVID

And I would be I think getting the third vaccine shot, I'm hoping that that will actually provide people with disabilities with a lot better protection and potentially make us a lot less nervous about going into the world. So words of wisdom, I think the top of the list is vaccination, vaccination and vaccination, and also avoiding indoor air environments where there's poor circulation of air and no mask use, I think is really critical.

**GT:** Great advice, Anne. Thanks for joining today.

**AK:** No worries.

**GT:** That's all we have time for on today's episode of Reasonable and Necessary, brought to you by the Summer Foundation. To be notified of future episodes, don't forget to hit the subscribe button and the notification bell. Thanks for watching and until next time, stay well and reasonable.