**Special Series: Living with COVID**

**Interview with Disability Discrimination Commissioner, Ben Gauntlett**

**George:** Hi and welcome to Reasonable & Necessary. Australia’s premier podcast series, on everything you ever wanted to know about the National Disability Insurance Scheme. Brought to you by the Summer Foundation. I’m your host Dr George Taleporos and in this episode in our special series on COVID-19, we talk to Australia’s Disability Rights Commissioner, Dr Ben Gauntlett, about the human rights impact of the pandemic. Check it out.

**George:** Commissioner Gauntlett. Welcome to the show.

**Ben:** Thanks for having me, George.

**George:** It’s great to have you on. I’m going to start by asking you about the vaccination rollout. We know there are Australians who have a disability are behind the general population when it comes to the rates of vaccination. Why do you think that is?

**Ben:** I think when we look at the COVID-19 vaccination rollout with the benefit of hindsight, what we realise is that for the vaccination to have proceeded at pace or as originally intended, required there to be careful consideration of the reasonable adjustments that were required or the reasonable accommodations, tailored communication and also, tailored information for people with disability, and unfortunately, what occurred - or for that to occur, we needed a lot of levels of government to interrelate seamlessly across Australia but also we needed service providers, etc to be able to assist in that setting and what did occur is that there has been some challenges getting those different levels of government and different service areas to interrelate.

That’s not uncommon in the disability area. We know that whenever the disability service system interrelates with the healthcare system, particularly since the National Disability Insurance Scheme has started, we’ve had challenges but what occurred in this case was that we didn’t have the appropriate mechanisms in place to enable the vaccination rate to occur in a way that was intended and that’s meant there’s been hiccups along the journey.

**George:** Can I ask though, we know that there was a Royal Commission hearing into this and we heard the Commission say that there was a de-prioritisation of people with disability who were in residential care. Did that concern you as our human rights commissioner that we were de-prioritised?

**Ben:** The entire vaccine rollout has been of concern to me and that doesn’t mean that there hasn’t been aspects of the vaccine rollout which have on occasion, worked well but the entire vaccine rollout is something where there can be really serious human rights issues for everyone. When you hear the Royal Commission produce statements or release a series of recommendations and findings like they did, it is deeply concerning but within that deep concern, I think we also have to be very pragmatic and constructive and move forward but in moving forward, I think what we really want to do is also say, “We do not want this to ever happen again in the way that it did and to do that, how do we constructively build a system which prevents people with disability being put into a situation where they have very grave fears as to their health and safety?”

That requires an interrelationship between state and federal government and also service providers to be improved. It requires improved communication and information, a better knowledge of reasonable adjustments and accommodations but also the collection of data and linking of datasets to ensure that we can see in real time or in a timely manner, whether people with disability are being included in policy systems.

**George:** Yeah, I really think that we can look back at this and say, “Mistakes were made. What can we learn from those mistakes?” and I’m hearing you’re saying you’re being constructive and saying, “What can we do better moving forward?” One thing that concerns me greatly is that there are a lot of people with intellectual disabilities who have substitute decision-makers and often, these are parents that – in most cases, parents do the best thing for their son or daughter, but I’ve heard of instances where their parents have said no to vaccination because of their views, and some of them are against vaccination. What can we do in this situation to make some of the basic human rights of receiving healthcare – is not prevented by someone’s parents who might have quite strange views on what it takes to stay healthy?

**Ben:** I think when we look at how we protect human rights in any circumstances where there’s an emergency or a near emergency of the provision of health assistance to people in what was a global health pandemic which was deeply challenging for each and every health system across the world, when you say, “How do we protect human rights?” I think you have to get your processes and procedures to be really pretty much bulletproof in terms of ensuring that you have things set up to ensure that people are provided with accurate information, that that accurate information is provided in a timely manner, that they are able to ask questions in relation to that information, that you make sure that you don’t have a situation where an egregious view held by a substitute decision-maker can prevent a person accessing a system and you can in a sense, challenge that view.

But to do so, what you need to do is to put time and resources into the issue to have very specific solutions for different individuals and to tailor the response for where you know the challenge will arise. So, for people with an intellectual and cognitive disability who may have substitute decision-makers, we need to deal initially with the vaccine hesitancy issue with good information. Now, the data does suggest that the level of vaccine hesitancy in Australia is actually quite low, so what we need to do is to try and provide further information to individuals as to how to prevent vaccine hesitancy but within that, we also need to be really cognisant of always understanding that we’re looking at the person with disability and what is in their interests and to make that front and centre of any decision-making process.

The best way to do that is clear, transparent processes that are verifiable where information is given and people are given time to come to the decision which they want and it can’t be hurried. You actually have to take the time to do it right.

**George:** Yeah. What happens when the parent says no and they do it because they think that they’ll be personally harmed by the vaccine? I almost feel like there comes a point where government needs to step in and look at what we can do to keep that person safe and do what’s in their best interest. Do you think that there’s a role for government to step in? We do in other areas where a person is neglected. Why not when it comes to vaccination?

**Ben:** I think we want to - this is often on a continuum, this issue of vaccine hesitancy etc, and I really think that when we look at this issue, to have to obtain say, court orders to enable a person to obtain a certain form of medical treatment should be the last resort. What we need to do is try and take the time to educate individuals about the issue and then hopefully deal with the issue to the extent that we need to use powers to ensure that people receive appropriate health assistance.

The legal system does have the access to do that often, in life-threatening circumstances where a person would seriously be harmed, but that is very much the last resort often in this instance, and I think it is very, very important that what we try and go down is the information, educational route, and we look at also educating substitute decision-makers such as public guardians and to give them the appropriate information, and then hopefully, what will occur is that the issue is not as pronounced as is perceived and those egregious situations can be dealt with on an individualised basis.

**George:** Yeah, that’s right. So, we need to educate, inform, make sure that all the information is available and then we do need to look at the last resort options if it comes down to that I think. I’m really interested to talk a bit about the advice that you’ve been providing to the disability and the health sector around how to protect human rights. I was in a meeting with you where you were very, very strong and very loud about the importance of human rights in the context of this pandemic and you even developed some guidelines and you published some of these last year. Can you maybe talk us through some of those key points that you want the health and the disability sector to understand?

**Ben:** Sure. I’d like to think at the meeting, I was trying to be as helpful and constructive as possible, George.

**George:** Always, as I am as well but it doesn’t mean that we don’t sometimes need to be a bit assertive as well.

**Ben:** But what I suspect I was hoping to articulate was that particularly last year, some of the evidence that was arising from overseas countries as to the treatment of people with disability was very much pointing towards practices that were not consistent with human rights principles and they in particular, dealt with the provision of medical treatment but in particular, the provision of intensive care beds and life or death decisions relating to people with disability in overseas jurisdictions and what was arising from those countries was a clear narrative about people with disability not being considered the equal of people who do not have a disability.

So, when we chose to write the guidelines, what we did was we consulted widely with not only people with disability and their representative organisations but also the medical professionals and health professionals and allied health professionals and what we sought to do was to try and bring to the foreground what were some of the key concerns for people with disability but to write the guidelines in a manner that informed the health professionals and allied health professionals as to what they could do in the circumstances.

I guess a couple of the clear points are the need for reasonable adjustment or reasonable accommodation when assisting people with disability, the need to understand the importance of accessible communication and the need to understand the importance of supported decision-making for people with disability and above all, what we wanted to convey, that each and every person who is entered into the healthcare system or is admitted with COVID-19 has an absolute right to be treated with dignity and respect and decisions made in relation to their health and welfare, including whether they’d be for example, ventilated or not, are decisions where there is clear checks and balances to ensure that they are treated in a manner that’s both ethical but their human rights are considered in a way that’s reflective of modern conceptions of people with disability and the Convention on the Rights of Persons with Disabilities.

**George:** I’m really glad that you’ve been speaking out about this because as you know, it’s an area that concerns a lot of people with disability, especially those of us that have underlying medical conditions and that issue around, “What if I need a ventilator?” I happen to have my own ventilator so that wasn’t a big concern for me. Just a bit of humour there. I’m really pleased that we didn’t get to that point so much in this country but I know that it has happened around the world and we need to be very, very loud and clear that our lives are as valuable and important as everyone else’s.

**Ben:** Absolutely and what we want to do is we want to create systems and processes where the treating doctor or the hospital understands what its responsibilities are to do its job well and sometimes, we assume that a doctor or an allied health professional or a person working in disability services is aware of all the issues and they’re not going to have unconscious biases, etc. but what we actually know when we look at how unconscious bias works both in relation to people with disability but also in other settings, that you need to educate and have systems and processes and training to ensure that people make good decisions even when they’re under pressure to ensure that people’s human rights are respected.

**George:** Yeah, absolutely. We really need to educate and also, I wish that there were a lot more initiatives to train doctors and nurses in disability awareness. I just feel like sometimes when I go into hospital, I feel like I’m in another world, I’ve been immersed into the medical world right, you’re suddenly the illness, the disease, the disability and you’re not the person and I think that we need to do a lot more to educate medical professionals. Are you doing some of that work, Ben?

**Ben:** We produced the guidelines. For example, we’ve had some really productive discussions with New South Wales Health about distributing those guidelines and when we first produced the guidelines, they were sent out by a number of Commonwealth agencies to different health organisations and different health departments across Australia.

One of the roles of the National Disability Strategy or the Australian Disability Strategy which is forthcoming this year is to look at that educative side of disability rights and it’s a clear, important human rights issue that we educate people about disability and how disability interacts with barriers in society and in particular when you think 80% of disability is invisible in nature, we need to be very, very careful to ensure that we properly educate not just health professionals but teachers, all manner of other professionals that work with people with disability or may work with people with disability.

So, what I’m hopeful for is that when the Australian Disability Strategy starts to be put into practice, that Commonwealth, state and territory governments will understand the absolute importance of making sure education about people with disability is not just in tertiary teaching curriculums but is also taught in primary schools and high schools and the awareness issues is a holistic approach to ensuring that there is an understanding of people with disability built into the community going forward.

**George:** Absolutely, it has to start very early like you said, at primary school level, absolutely. I just want to wrap up by getting your personal perspective on living with COVID-19 given you’re based in Sydney and things are opening up there and down here in Victoria as well. How’s the experience been for you, Ben?

**Ben:** Thanks for asking, George. It’s actually been a little bit unique. I’m actually from Western Australia and I moved to Sydney to take on the role of disability discrimination commissioner, so I have an apartment in the city. What I perhaps didn’t envisage was having to be in extended lockdown and how that would interact with obtaining support, etc. I’m a quadriplegic from a spinal cord injury playing rugby when I was at school, and I need a reasonable amount of assistance just to get through the day and get to work, etc. And what I have noticed, it has been a challenging time to access and acquire appropriate assistance during the lockdown.

It’s been challenging to ensure that people have access to appropriate PPE, that they’re vaccinated, etc, to have an availability of workers when we have issues with immigration and temporary visa holders and it does make you continuously aware of the importance of seeing the disability policy space as an integrated system and within that integrated system, we have to be really aware of the effect that certain policies may have in time or even relatively immediately regarding things such as the availability of workers.

So, we consider the National Disability Insurance Scheme and how it operates. It really does operate on a market model, a market where it is assumed that there are people who can provide service in particular locations. That’s not always the case and that’s one of the reasons why we have thin markets but what COVID-19 has perhaps demonstrated is that it’s very easy for there to be shocks in the market which make it difficult for people with disability to acquire the necessary services and we need to be really mindful of that in building a sustainable disability policy system going forward.

**George:** Yes, we absolutely do and I agree with you about the workforce issues and having a lot of the international students, often they’re nursing students that were working in disability not in the country, has been definitely an area where I’ve personally found finding staff has been more difficult. The other element is that when we’re opening up, I’m suddenly - I feel like I’ve become a bit institutionalised, Ben. I’m so not used to leaving the house, I’m a bit terrified to get out into the big, wide world.

**Ben:** Yeah, I share that challenge, George. I think I used to try and get outside for half an hour, 3 times a week during the lockdown into a close-by park where I lived and where no one would be and just to get out of the house, so you go from barely getting out of the house and living a very contained existence with very few people coming into the house and you being particularly aware of the challenges of infection and things of that nature to try and get out of the house to try and maybe recreate the interests or recreate some of the networks that you previously had and it is challenge.

It perhaps goes to show how easy it is for COVID-19 to exacerbate disadvantage in the community and it’s something where we need to be mindful of its effects, not just now but I think for a considerable time period because I think these weeks, days and months where we’ve spent alone and in isolation or where people with disability have had to spend on their own can have long-term effects in terms of breaking networks of support and we need to be really conscious of building back those networks of support so people can live the best life possible.

**George:** That’s right and it’s a journey that we’re all going to be on moving forward. So, it’s good to know that we’ve got other peers who are experiencing the same thing and I also think that the one positive thing from the pandemic is that we’ve learnt to adapt to using technology and making some people who even before the pandemic weren’t able to leave the house because of their disability are now going to have a few more opportunities to be included in a way that’s accessible to them.

**Ben:** Yeah, I think it’s - technology can really open up people’s lives but I think it’s equally important to note that technology can be deeply exclusionary as well. So, for a person with an intellectual or cognitive disability or a person who might be low vision, to have to use technology to communicate may be challenging and I think we always have to be really mindful of the importance of universal design in relation to technology so that everyone’s included but also universal design relating to processes for including people in the community. When you talk about being housebound, George, and the difficulties of being isolated, it does also have maybe an illuminating effect for the population of the importance of good housing for people with disability as well.

I don’t think anyone has liked being isolated during the pandemic but in Australia, we have a real problem with inaccessible housing and inaccessible house design. We’ve only just had a national construction code pass amendments which have been adopted only by a fraction of the states to make housing accessible going forward but accessible housing is a really important aspect to enabling a person to enter an exit that house as they are willing to. So, I think one of the educative aspects of COVID-19 has been the importance of universal design, not only in the built environment but also in the technology and service provision environments as well.

**George:** Agree with you, 100%. Commissioner Gauntlett, I’m a huge fan of your work. Thanks for joining us on Reasonable and Necessary and I hope to have you on the show again soon.

**Ben:** My pleasure, George. Thanks very much for having me.