**TRANSCRIPT**

Reasonable and Necessary with Dr George: Making Sense of the NDIS podcast

**Series 4 – Staying safe during COVID-19**

**EPISODE 5: 22 APRIL 2020**

Hi listeners and welcome to our Coronavirus series of Reasonable and Necessary.

I’m your host, Dr George Taleporos and I am from the Summer Foundation.

We all have a role to play in getting through this pandemic: wash your hands, don’t touch your face, stay at home. These are things that we all need to do. On top of that, we need to work out how to get the support that we need in a way that is safe.

We don’t have all the answers, but we are here to help you through it.

Please remember that we can’t provide medical advice, talk to your doctor for that, or call the National Coronavirus info line on 1800 020 080 or visit health.gov.au

On today’s episode, we’re going to New York City to talk to disability rights lawyer T.K. Small about life in the centre of the Coronavirus pandemic.

The statistics tell a very sad story.

In the first 5 days of April, 1,135 people were pronounced dead in their homes or on the street in New York City.

More than 8 times the deaths recorded during the same period in 2019. According to The Times as of 6 April, 1,100 of the 140,000 people with developmental disabilities who had been monitored by the state had contracted Coronavirus. Sadly, 105 have died.

This rate is far higher than the general population and this begs the question, how many of those deaths were the results of being denied adequate treatment and how many people with disabilities are dying because health services aren’t prioritising them properly?

That’s one thing that disability rights activists around the world are very concerned about.

Joining me now is T.K. Small, Director of Policy at Concepts of Independence, which is a provider of continued directive services.

TK is also a founding member of MND United, which is a peer led organisation of adults living with neuromuscular disabilities.

Q: Hey, TK, thanks for joining us, how are you?

A: Well, thank you, George, for inviting me on your show.

Q: I’m thrilled to have you on the show. Before we get in to it, how are you coping with being a New Yorker with what’s happening with the Coronavirus?

A: Well, it’s a lot to process and keep an eye on and as you might know, hospitals for people with disabilities, particularly for people with significant disabilities like muscular dystrophy, etc are really dangerous places in the first place, so the prospect of possibly needing to go to the hospital is not something that I’m looking forward to at all, so I’m trying to do my best and stay healthy and keep my team of care givers as healthy as possible. We’re living outside the exposure area, everybody’s washing their hands all the time, sometimes people wear face masks and it’s definitely something that’s changed my life over the last month or so, it’s quite a handful.

Q: The pictures on the news looked really quite terrifying, have you had to make any changes to how you are living in order to minimise your risk?

A: Absolutely, I haven’t been out of my apartment more than once in the last 10 days. I went out in the evening 3 nights ago, but the streets were basically empty and I ran from my apartment building right to my car and then we drove and went to a night-time ATM and then I went to a vegetable store to do some grocery shopping, but that’s it, I haven’t been out at all in 10 or 12 days and I’m out frequently. I take the subway, I drive in to Manhattan, my neighbourhood is a great place to just go out for a roll around the neighbourhood and as we go in to warm weather after being cooped up in my apartment for much of the winter, this time of year, I spend a lot of time outside, so it’s been a little bit tough.

Q: I can imagine, and how are you managing your support team? In Australia, we call PAs support workers, how are you managing them? Have you cut down the number of support workers that you have in your house? What have you sort of done to minimise the risk for that from that perspective?

A: I’ve juggled the schedule a little bit to limit some of the back and forth to my house, so I have one guy who does a majority of my shifts, so he’s able to do a back to back to back type of situation, so that’s going to happen, and I had one guy, who had a sore throat 3 weeks ago, so to be on the safe side, he hasn’t been back to me since then, but he only works one night a week and he feels fine, but he comes from the other side of the city up in the Bronx, so he has to take the subway to get to me and some people feel that the subways are really quite contaminated. But my guys are very careful, when they get to my house, they immediately change, they all wash their hands and I feel quite confident we’re doing the best that we can and I think if it stays the way it is right now, it will be okay.

Q: Do you have the supplies that you need in order to, I know that you’re a ventilator user that you probably have all sorts of equipment needs, are you able to access the equipment that you need?

A: Well, I have all the equipment that I need in my house and I’m pretty good at maintaining my level of supplies, so I think I have all the supplies. There are lots of things that I had to purchase out of my own pocket, extra gloves, extra cleaners, extra vitamins and other supplements to try and keep myself a little bit healthier. Fortunately, I work, so I can afford these things, but maybe what this really means is that those living on government supports that they don’t really have the extra money to purchase these extra supplies, so for a lot of people, it’s quite challenging.

Q: Yeah, it certainly is and we know that the prices have gone up of all the things that we need, so sanitiser is now 30 times the price it was, masks are also impossible or extremely expensive and then there are gloves. We definitely are facing some supply challenges in Australia, we also have no toilet paper, did you have that problem?

A: No, I think that was a craze for a little while. I had bought a gigantic pack of toilet paper, not because I was hoarding it, it was just I was really low and I have this lifelong phobia about not having enough toilet paper at my house, so I always have probably too much.

Q: You’ve got enough to get you through the winter?

A: Yeah, I think so.

Q: Excellent, have you heard of any of your friends with disability contracting the virus or have you heard of other people with disabilities who needed to go in to hospital?

A: Well, the testing of people has not been really great here in New York City, although there have been a lot of tests, they’re telling people if you don’t have really, really bad symptoms to just stay home and ride it out and I do have one friend who has been staying home and riding it out and he’s feeling a little bit better. He said that his fever has broken, but he’s terrified to go to the hospital because you know how the people helping you in the hospital, you have in your house, the people who help us as you call them, your support team, they know exactly how to take care of you, so not having that type of skill in the hospital can be sometimes as dangerous as whatever a condition makes you go to the hospital in the first place, so my friend is, he says as of this afternoon, he feels a little better, but these things can get bad real quick, so we’re just keeping our fingers crossed.

Q: I think that we’re all terrified of that scenario and we’re terrified of ending up in hospital and firstly, there is the whole issue of can your support workers stay with you in the hospital and in Australia, they can be quite difficult like that, that they will say that you can’t have support workers, but taking away someone’s support workers is a major, major hazard, it means that you can be stuck with people who don’t know what to do when you need help.

A: Absolutely, yeah, well, I was sick back in 2011 and ended up in the hospital and here in America, if you go in to a hospital, your support workers don’t get paid. So I ended up paying for my guys to stay with me in the hospital literally 24 hours a day and again I work, so I can afford to do that, but most people can’t.

Q: And it’s not fair, it’s really not fair.

A: I was in the hospital for a total of 15 days, so it was a hefty bill, but it was well worth it, because if I didn’t have the help, I wouldn’t have made it.

Q: I definitely think we need to educate health professionals about the importance that people have in their own team of workers who they are familiar with.

A: Well, it’s not the health workers per se, they’re happy to have the help in the hospital and they recognise pretty quickly that they don’t know how to take care of me, it’s really more the governmental programs that make the rules for the funding of these services that need to be educated. My doctor was a strong advocate and when I got admitted in to the hospital, the same day I got admitted, he went up to the nurses’ station and told the nurses in no uncertain terms that my team were critically important and to leave them alone and for the most part, the staff stayed out of their way and they were happy to have my team of guys taking care of me and that way they could move the aides and nurses to do other things.

Q: It sounds like you had a good doctor.

A: Yeah, he was great.

Q: And it’s really important that you have someone to speak up for you. We talked about some things that governments need to do, what other things do you think that we all need to be doing to stay safe at the moment from the Coronavirus?

A: First and foremost, wash your hands, wash your hands not every half hour, but don’t be afraid to wash your hands, if it feels like it’s overkill, it’s not and don’t just rinse your hands in the sink, really, if there’s soap there, scrub in between your fingers, under your nails because you don’t realise how dirty your hands are. Another simple thing is while people wash their hands and then they go right back and they touch their dirty phone, so I get my guys cleaning their phone with a little bit of bleach and a paper towel and they clean their phones. Don’t take public transportation unless you really need to, if you can wear a face mask when you’re in public, try to do that. Things like stay as far back, we call it here social distancing, people are doing a good job in terms of staying 6 feet away. As I mentioned when I was out there the other night. I was turning down the street and I saw a neighbour and this was the guy who we always talk about the street and we ended up having these interesting, elaborate conversations, he was very careful stepping back and staying 5 or 6 feet away from me and I really appreciated it. So I do think people are getting the message now. It wasn’t like that when it happened back in February before the whole thing really erupted and I think that would have improved the situation.

Q: Yeah, it certainly would be, and you’re a human rights lawyer, you’ve worked in disability law for most of your career, what do you think are some of the human rights challenges that we’re facing at the moment?

A: Well, there is some discussion of the rationing of things like ventilators and other care, so as doctors have to triage a difficult situation, there are some protocols that suggest that they can deny a ventilator to a severely disabled person in the benefits of helping somebody who is, on the surface, expected to live longer than us. I think that’s an immediate challenge and I think it’s all states in the United States are potentially going to be in that position. If there are not enough ventilators to help all the people who need them, somebody has to make a decision about who gets one or doesn’t and how those protocols are implemented. If it’s just first come, first served, that’s at least the luck of the dice, but if somebody says, well, this guy is 40 and not disabled and that guy over there is 54 and he’s disabled, I’ll give it to the young guy and not the old disabled guy, that’s of great concern.

Q: Yeah, it certainly is, are there any human rights defences that we can use? The human rights laws, are they adequate to protect us?

A: Well, when you say us, are you talking about-?

Q: Us disabled people.

A: Well, I don’t really know, because every jurisdiction has their own laws, there are laws that are in play, but the question is whether they will be properly implemented. As you may know, just because you have a law, it doesn’t mean that something is going to actually happen, so we do have laws. There’s the Americans with Disabilities Act, there is the Federal Rehab Act, both of which would apply to certain aspects of health care and decision making, so the question is you can have a law, but if there is not someone to go to court and file a lawsuit quickly, you don’t have a long time when you’re waiting in line to get a ventilator.

Q: Yeah, that’s definitely an issue, isn’t it, and TK, I’m just wondering if there are any other thoughts that you have to people listening in Australia. You’re in New York, you’re 3 weeks possibly ahead of us and hopefully, we won’t end up with as serious level of infections as you have, but do you have any thoughts or last words that you’d like to say to people listening in Australia?

A: Well, it’s neat that you have George putting on a show like this because getting the information out there is really important and as I say, be careful, don’t get overwhelmed with the news, the news is scary, but don’t let the news drag you in to fear panic. I find that that’s one of my best coping strategies, I turn the news on in the morning and I figure out what’s going on, what’s happened overnight and then after about an hour or so, I just turn it off and I go and do my work and concentrate on other things but not worry about the news, and just try and stay busy. I find that trying to be helpful and keeping busy is very good for my mental health.

Q: That’s very good advice, thank you, TK, look after yourself.

A: Thank you very much, George, take care.

Q: That’s all we have time for on today’s episode of Reasonable and Necessary, brought to you by the Summer Foundation.

Check out our Facebook page for previous podcasts and transcripts.

We also love hearing from you so please leave your comments and suggestions for future episodes.

Remember for the most up to date info on Coronavirus, call the Coronavirus help line on 1800 020 080 or visit health.gov.au

Stay tuned for our next episode and please stay safe and remember to wash your hands.

END OF TRANSCRIPT