# Speakers

Sharon Boyce - Self advocate and Queenslanders with Disability Network (QDN) Director

Keren Pointon - Disability advocate and carer involved with both QDN and Health Consumers Queensland

Dr Ben Gauntlett - Disability Discrimination Commissioner - Australian Human Rights Commission

Michelle Moss - Director Policy and Strategic Engagement - QDN

Jilann Farmer - Deputy Director-General of Clinical Excellence Queensland - Queensland Health

# Speaker 1 - Sharon Boyce - Self advocate and QDN Director.

While being in hospital in the middle of the COVID19 pandemic, Sharon used the experience as an opportunity to test processes that had been established in the development of [*Know your rights: Getting the hospital care you need during COVID-19*](https://qdn.org.au/knowyourrightscovid19/)*.* There are some gaps within the hospitalisation processes and using the different templates that QDN has on their website was very helpful and worthwhile. Sharon used these templates when in hospital to justify certain requirements to ensure that her needs were met. The checklist template for hospital admission can be found here: <https://qdn.org.au/knowyourrightscovid19/>

*“The advocacy that I had to do with myself, my family and my carers within that hospital environment was very much supported by that document.”*

According to Sharon, some key items that should be documented ahead of time in the event of a hospital visit:

* Record of personal equipment to take to the hospital
* What sort of information about your health needs to be documented?
* Doctors’ details and contact numbers
* The actual care that you need. For example, ‘I needed two carers, I needed to be fully hoisted.’
* How could I keep my team COVID safe? For example, limiting the number of carers to three.
* How to access PPE.
* GP and specialists contact information.

On 3 August 2020, Sharon was rushed to hospital with Sepsis. By being prepared, Sharon was able to coordinate her stay with her carers and the supports she needed. The next questions Sharon realised were relevant during her stay were:

* What are my rights?
* What if something happened?
* What would I need if I went to hospital; how could I ask for that?
* Why could people question what I was asking for and how would I ensure that I had a strong voice?

The staff turnover, as well as the general training of the hospital staff had meant that Sharon was not being treated with the specific care that she needed:

*“When it came time to get me onto the CAT Scan bed and I couldn't be turned because of my spine and the instability. They had no idea there was like eight people in the room, wardies trying to turn me and put a spinal board under. That area, I feel in my planning, needs to be written and really documented.”*

Rather than complaining or writing the experience off, Sharon realised that documenting the process and noting what worked and what didn’t could be used next time.

*“You’ve got to really brainstorm; you have to think deeply. Even if you don't think it's going to impact on you, put it down. Write it in your plan and get ready and be prepared, because you never know within this time what might actually happen.”*

# Speaker 2 - Keren Pointon - Disability advocate and carer involved with both QDN and Health Consumers Queensland

Keren is a parent and carer of a child with disability who frequents the health system and knows all too well how stressful these visits can be:

*“For our family and many others, we wish you didn't need to have to come to hospital or require health care. We want to be home and we want to be well in our community with our family and friends. But illness doesn't wait for anything and chronic health conditions like my daughter’s means this hasn't been possible.”*

Keren’s family still had to attend hospital for surgery during COVID-19 and confirmed [*Know your rights: Getting the hospital care you need during COVID-19*](https://qdn.org.au/knowyourrightscovid19/) helps people with disability access health care equitably and in an informed way. It reflects the

learnings of people with disability and accessing the health system. It is important to know your rights in this regard and in putting the document together reduces key points of stress.

*“Knowing that you turn up to hospital and your carer can attend, as they are not a visitor, they're a carer whether they're paid or unpaid and they're essential for equitable access for many people with a disability.”*

There is a checklist that can be prepared ahead of time which helped Keren and her family avoid complications and get out of hospital sooner.

*“For our family, those kinds of pre-prepared materials have made a difference between having an anxious and a distressed patient to an empowered and engaged patient. We've used our pre-surgery consultations to make sure these steps are in p place long before we came to hospital.”*

# Speaker 3 - Dr Ben Gauntlett - Disability Discrimination Commissioner - Australian Human Rights Commission

Ben outlined the background relating to the development of the [*Guidelines on the rights of people with disability in health and disability care during COVID-19 (2020)*](https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability) as the policy response to COVID-19 in Australia.

*“It is a trite proposition to suggest that COVID-19 exacerbates disadvantage. From what has occurred in Italy, Spain, England, more recently in the United States and in third world and less developed countries, we know that COVID-19 can have particularly adverse effects on certain groups within the population. One such group is people with disability. There was a time in Australia when a critical issue of concern for people with disability was whether the health system would be overrun during COVID-19.”*

The Disability Royal Commission had hearings relating to COVID-19 recently where the fears and concerns of people with disability were articulated. There was a need on occasion to treat difference differently to achieve substantive equality. There was also a need to recognise and plan explicitly for emergency or crisis situations. The Australian Government Advisory Committee for the COVID-19 Response for People with Disability was formed in April 2020 to deal with the effect of the Coronavirus pandemic on people with disability in Australia, and is a reflection of the Australian Government's commitment to the Convention on the Rights of Persons with Disabilities. The actions suggested under the plan implemented by health authorities and disability service providers need to be always informed by human rights considerations.

*“What struck me most was actually a friend of mine who is an intensive care doctor who is tremendously kind and a considerate individual who treats his role with the utmost seriousness. What he was especially aggrieved in the conversation that we had was that he would ever discriminate against any person on the basis of disability. What he did appreciate was that unconscious bias or stereotypes can affect decision making. There is a need to have clear structures and frameworks to ensure the best decisions are made in the greatest number of circumstances. The best decisions, perhaps understandably, are reflective of Australia's Human Rights Obligations under the Convention on the Rights of Persons with Disabilities. The convention is the most recent significant human rights treaty entered into by Australia. It was ratified in 2008. It has within it a number of guiding principles, recognising the concept of intersectionality, the right to health, the right to life, the right to equal recognition before the law, the right to equality and the right to accessible information. Irrespective, we think there is a clear benefit in adopting the policies and procedures set out in the guidelines, because they are good clinical practice.”*

Relevant links to the Australian Human Rights Commission and their disability-related readings: <https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability>

# Speaker 4 - Michelle Moss – Director Policy and Strategic Engagement - Queenslanders with Disability Network

When we first started the COVID-19 conversation this morning, we talked about the importance of the work that we've done together and with our consumer reference group. It came out of the question and issue and response that happened at the beginning of COVID where there were a range of different impacts happening for people as they were trying to access health services, and people experiencing challenges that weren't in-line with our Queensland legislation and Human Rights and our Australian Charter of Patient Rights. We know for many members and many people with disability, that essential (to others it may be non-essential) stuff is critical. It has longer lasting impacts for people. We wanted to put something together that gave people information about what the issues were. How do I understand and know what's changed and what can I expect if I am going to hospital during COVID?

It's been a very strong piece of advocacy work that we've been able to do to raise those really important issues that people with disability do need to have support people with them, as long as it's safe and as long as it's following the guidelines of what the hospital says needs to be in place around PPE. It's important that people can have a person with them. We know that hospitals and clinical care and are often not there to provide those additional supports that people need to both help with emotional support, as well as the practical and physical support that individuals need.

The key things about what you need to prepare and need to take is a support person, if that is important to you and your care. Having those important documents ready, your medications, your connection kit to help people see who you are and your communication and advocacy tools. Your phone is an important advocacy tool and being able to document and take notes or have someone assist you with that information is really important.

# Speaker 5 - Jilann Farmer - Deputy Director-General of Clinical Excellence Queensland - Queensland Health

Jilann is a Queenslander, returning a few months ago in the middle of the COVID-19 outbreak after spending eight years living and working in New York. Jilann was at the United Nations (UN) as their Medical Director. In that role, she provided support to the Commission responsible for the Convention on the Rights of Persons with Disabilities. Jilann’s role now, as the Deputy Director-General of Clinical Excellence Queensland - part of Queensland Health, focusses on patient safety, the quality of service including the patient experience. This section of government does a lot of the work around engaging with clinicians to design better health care.

*“One of the points that really resonates with me is that shift away from the medical model and I think that's certainly something that I got beaten around the head with in my early days working with the UN Committee. I had a learning journey to do there. It is something I've developed a much greater appreciation for. There really is a difference in terms of that holistic appreciation for a person with all of the challenges and benefits and understandings that come with whatever life has handed them in terms of disability or ability.”*

One positive change is that the organisation has embraced the use of technology, although Jilann has concerns that in the rush to embrace technology some might be left behind when technology does not present as helpful.

*“One of the things I've been very vocal about is ensuring that we don't create systems that entrench and institutionalise barriers that we should never have created in the first place. I've been very concerned to ensure that when we are moving to new models such as Telehealth, that we don't slip into the mindset of one thing will fit everybody, and this doesn't merely relate to disability. I think there is a particular risk for persons with disabilities to be overlooked or disadvantaged by the race to technology.”*