

Telling our story at the Royal Commission

by Dr Rebecca Kelly

Our son Ryan is medically complex – he was born with a cleft palate and three holes in his heart. He always had fluid in his ears and was mild to moderate deaf from birth, which is not unexpected given his cleft palate and Down syndrome. He also developed nystagmus and strabismus in both eyes before his first birthday. At 13 months old he was diagnosed with Acute Myeloid Leukaemia (AML) and had seven months of chemotherapy. The first five years of his life were very busy with multiple operations and many emergency admissions a year including open heart surgery at four years old and two cleft palate repairs. When he was little, he was a social and happy little boy who talked and signed. Soon after his sixth birthday, he seemed to gradually withdraw from the world until he no longer talked or signed and wouldn't look anyone in the eye. He also became angry and sad much of the time and his sleep disintegrated. He was diagnosed with complex trauma as a result of all his intense medical intervention and started medication for anxiety which helped a lot. Around this time, he also went very suddenly deaf developing a profound sensorineural loss in his left ear

and a severe mixed loss in his right. We struggled for many years to get good Ear Nose and Throat (ENT) care. This hearing loss was not properly diagnosed for over six months after it was first suspected, despite a ludicrous number of phone calls and emails on my part to push things along. In early 2019, I had his ENT care moved to Melbourne in the hope that we could access a cochlear implant (CI) for his left ear and more consistent quality care. During a surgical procedure to evaluate his potential to receive a CI, the ENT found the early phases of a cholesteatoma, a cyst that develops behind the ear drum and eats through everything it touches as it grows. I was told he required urgent surgery to manage the risks of this to protect his hearing in his only remaining hearing ear.

What followed was the worst year of my life, with consistent failures to provide care that culminated in a 10-page letter of complaint, two escalations of this complaint, referral to the Health Complaints Commissioner, serious bacterial infections, two emergency hospital admissions and permanent damage to the hearing bones in his ear. Late in 2019, I was contacted by lawyers from the Disability Royal Commission who asked me if I knew of any good case studies they could use as part of a public hearing they were preparing for a hearing in February dedicated to intellectual disability and medical neglect. I told them about our situation. After a phone conversation with a team of lawyers they said they were keen to help me prepare a statement to provide to the hearing and have me appear as a witness. I knew that there was every chance that speaking publicly could backfire and make Ryan's care worse, but I felt strongly that things have to change and that people who can speak up should tell their stories, so the country has to listen.

In January, two lawyers who worked for the Royal Commission flew to my home in Tasmania and spent several hours interviewing me and recording my evidence. I had also prepared 20 pages of notes of things I wanted to bring out in my evidence and some of my own recommendations for reform. They used





my notes and the recorded interviews as well as the very large pile of documentation I was able to provide. **I can't stress enough how important it is to email correspondence rather than rely on phone calls and face-to-face conversations** – it formed the backbone of my evidence. They sent back a draft statement for me to review so that it was my own words. I wanted my evidence to be powerful as I felt this would be my one and only chance to tell our story and spent a lot of time trying to get it just right. They told me there was a chance that the hospitals named in my statement would want to cross examine me at the hearing and advised that I secure a lawyer who would be there on the day to represent my interests. **Witness evidence during a Royal Commission is protected** so I would not get into any difficulty so long as I spoke what I believed to be the truth. They put me in touch with a legal service who gave me the details of an appropriate lawyer. **The Royal Commission pays for any required legal representation for witnesses**, so this was all at no cost to me. He wasn't too worried about my evidence and said that since I'd stuck to facts that I could prove easily with documentation, it was unlikely they'd want to cross examine me. This ended up being the case, though I only found this out for sure the day before I gave evidence.

The Royal Commission organised flights and accommodation for me in Sydney and organised taxi vouchers so I could get around. They scheduled me for the first day so I could go to an induction session planned for the day before the hearing started then fly home after I gave evidence, with the least disruption to our family. The hearings were really different to previous public hearings. The Council for Intellectual Disability worked closely with the Royal Commission to make the hearings accessible to people with intellectual disabilities. **They allowed us to meet the barristers who would question us and some of the Commissioners in the room that the hearings were to be held in.** The room itself was set up so as to be less intimidating – in a hotel conference room rather than a court style set up. **The adults with intellectual disabilities who gave evidence were also supported by facilitated question and answers with people they were comfortable with** and allowed to show videos of previous presentations they had given on their experiences with the health care system as part of their evidence. Their evidence was really powerful and set the scene where people with intellectual disabilities were themselves at the heart of the hearing.



I had met the barrister who questioned me during the induction session and we spoke then and in the lunch break right before I gave evidence about what I'd like to say, what questions she'd ask me and some of the anecdotes I planned on using to illustrate my evidence. When I took the stand, it felt very comfortable and I felt confident that Ryan's story was going to be a powerful contribution to the hearing. They asked me how he should be referred to (I could choose to de-identify him or both of us in my evidence). I said as far as possible I wanted his humanity front and centre in my evidence, that I wanted the people listening to see him as a delightful little eight-year-old boy who is much loved rather than 'Ryan the medically complex kid with Down syndrome'. Giving evidence felt like a well-rehearsed theatrical performance. After the year of horror we'd had, and all my anger at how Ryan had been failed time and again, it was very healing to tell our story and not only be believed, but have all these people agree that what we went through was neglectful and terrible. I spent last year feeling completely disempowered and like I'd been gaslighted by the doctors who were supposed to be providing him care.

Giving evidence at the Royal Commission felt like getting my power back.

Highlights were the chance to finally meet some of the amazing mums I've relied on for emotional support the last few years. Having them turn up to hear me give



evidence was wonderful and all the support I got from our community online made me feel like I had an army at my back.

I gave several interviews in the media and the next day I flew home. I don't think I've ever been more exhausted in my life than I was in the days that followed but I think it was the culmination of many months of stress and worry.

Ryan had surgery at the end of March and we are hoping for this year to be the positive life changing year last year should have been. The Royal Commission continues to support us. Emotional support is available to witnesses following the hearings to help them deal with all the difficult emotions reliving the trauma brings. A short piece from my evidence talking about the problems of the medical model of disability and how dangerous it is to people with intellectual disabilities circulated social media. It's something I'm very proud of. I've had many people outside our Down syndrome community tell me it changed the way they look at the world, which is more than I could have hoped for.

Dr Rebecca Kelly is the President of Down Syndrome Tasmania.

For more information about the process involved and the support available, please go to the Voice website: www.downsyndromevoice.org.au

