



TRANSCRIPT OF PROCEEDINGS

THE HON RONALD SACKVILLE AO QC, Chair
THE HON ROSLYN ATKINSON AO, Commissioner
DR RHONDA GALBALLY AC, Commissioner
MS BARBARA BENNETT PSM, Commissioner

**THE ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND
EXPLOITATION OF PEOPLE WITH DISABILITY**

SYDNEY

10.00 AM, TUESDAY, 18 FEBRUARY 2020

DAY 1

**MS K. EASTMAN SC appears with MS S. FRASER and MS G. WRIGHT as Counsel
Assisting**
MS K. MORGAN SC appears with MS A. MUNRO for the Commonwealth of Australia
MS G. FURNESS SC appears with MR I. FRASER for the State of New South Wales

COMMISSIONER SACKVILLE: Good morning, everyone. On behalf of the Royal Commission, I welcome everybody who is present today at this hearing being held in Homebush. I also welcome everybody who is or will be following the proceedings via the livestream that is available on the Commission's website.

5 The purpose of this hearing is to investigate the provision of health care and health services for people with cognitive disability. My name is Ronald Sackville. I am the Chair of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. I am joined today by my colleagues, Commissioner Roslyn Atkinson AO, Commissioner Barbara Bennett PSM and Commissioner Rhonda
10 Galbally AC.

Before proceeding further, we wish to acknowledge and pay our respects to the traditional custodians of the land on which we are meeting today, the Wann-gal people. We also pay our respects to First Nations elders, past, present and emerging, as well as to all First Nations people who are present today.

15 We further acknowledge the profound contributions First Nations people culture and traditions make to this – to the life of this city and region. In that connection, I draw attention to the judgments delivered last week by the High Court in a case known as Love v Commonwealth. The judgments of the highest court in Australia explicitly recognise and, indeed, emphasise the unique status of First Nations people in this
20 country, both in their relationship to the land and their position in Australian society. This is entirely consistent with the Commission's approach to First Nations people with disability.

It is also fitting that, as summer draws to a close, we acknowledge the dreadful loss of life and human suffering, as well as the appalling environmental damage caused
25 by the catastrophic bushfires in so many parts of this beautiful country. We know that among those who have suffered losses or experienced trauma are people with disability and we express the hope that they and everyone else who has had those experiences receives the financial, emotional and material support so desperately needed.

30 The hearing which commences today will continue throughout this week and next. We will be investigating an extremely important topic, namely, the experiences of people with cognitive disability with the health system. As we shall hear in evidence, the consequences of neglect or abuse by or within the health system for people with cognitive disability are as disturbing as they are profound. They should
35 shock the conscience of all Australians.

We are very well aware that the use of appropriate language is very important to people with disability. The Royal Commission uses the expression "cognitive disability" as an umbrella term to embrace, for example, actual or perceived differences in processing, communicating or remembering ideas or information, as
40 well as differences in learning, awareness or decision-making. The term "cognitive

disability”, therefore, includes but is not limited to, intellectual disability, learning disability, autism, acquired brain injury and diseases such as Alzheimer’s. In this hearing we shall be concentrating on barriers that exist for people with cognitive disability, particularly people with intellectual disability or autism or both, when they try to access health care.

5 I don’t intend to repeat what has been said in opening at the public hearings on Education in Townsville in November and Accommodation and Group Homes in Melbourne in December. The remarks are available on the website for anyone who is interested, as are the transcripts of the hearings themselves and the webcasts of the proceedings. I just want to address two matters. I shall then say something briefly about the subject matter of today’s hearing. And I shall leave it to Ms Kate Eastman SC, Senior Counsel Assisting the Royal Commission, who appears today with Ms Simone Fraser and Ms Georgina Wright, both of whom are also Counsel Assisting the Royal Commission.

10 The two matters I want to specifically address are these: first, in what way is this Royal Commission distinctive? This is an important question because it highlights the challenges faced by the Commission and by people with disability and others who seek to engage with us. Secondly, I want to refer briefly to the Royal Commission’s progress so far and what we shall be doing this week and next and throughout 2020.

15 How then is the Royal Commission distinctive? In recent times we have heard in this country a great deal about Royal Commissions. At a national level, both the Financial Services Royal Commission and the Royal Commission into Institutional Responses to Child Sexual Abuse have been hugely influential in changing established patterns of behaviour and in changing community attitudes towards previously trusted institutions. The Royal Commission into Aged Care Quality and Safety is currently underway. And as I’m sure you know, the Commonwealth Government has recently announced its intention to set up a Royal Commission to investigate the causes of the recent catastrophic bushfires.

20 There is nothing new about the use of Royal Commissions in Australia to investigate important policy questions. There have been hundreds of Royal Commissions established at both Commonwealth and State level since colonial times. They have addressed almost every topic you can think of, from changing the Constitution, to police corruption, national security, domestic violence and even home insulation.

25 The Commonwealth Act under which we operate, the *Royal Commissions Act 1902*, was one of the first pieces of legislation enacted by the Commonwealth Parliament. One way in which this Royal Commission is unusual – very unusual – is the extraordinary breadth of our terms of reference. Among other things, we are required to inquire into what should be done to prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation. The terms of reference, that is, the document that sets out the job that we have to do, stressed the

importance of exposing violence against, and abuse, neglect and exploitation of, people in all settings and contexts.

This means that our terms of reference overlap to some extent with what I can describe as the Aged Care Royal Commission since many older people within its terms of reference are people with disability. We have, however, arranged matters so that our two inquiries will complement rather than duplicate each other.

This Royal Commission is often compared with the Child Sexual Abuse Royal Commission. Although that Commission lasted for five years and assessed vast amounts of evidence, testimonies, and submissions and undertook original research, its scope was actually narrower than ours. Its task was to investigate institutional responses to child sexual abuse and to make recommendations about eliminating or reducing child sexual abuse in institutional contexts. By contrast, our task is to investigate abuse and neglect in all settings and contexts. This includes, for example, abuse and neglect perpetrated in private homes or by businesses, as well as abuse and neglect resulting from societal attitudes towards people with disability.

You can see the scope of our task from the subject matter of hearings that have already been held or will be held during this year, 2020, bearing in mind that there will be multiple hearings on some issues. The matters that have been addressed or will be addressed include education of students with disability; the experiences of people with cognitive disability within the health system, what we will be looking at over the next two weeks; violence, abuse, neglect and exploitation experienced by people with disability in their own accommodation, including group homes; the multiple forms of disadvantage experienced by First Nations people with disability, and this will be done under the guidance of Commissioner Mason, with our Indigenous engagement staff, who led community consultations with First Nations people in Darwin, Alice Springs and the remote community of Papunya last week. We will also be looking at the limitations on opportunities for economic participation by people with disability, and the experiences of people with disability in the criminal justice system, whether as accused persons, witnesses or victims of crime.

So you can see the magnitude of the task that faces us.

And this is not by any means an exhaustive list. Furthermore, we are acutely aware that the life experiences of people with disability cannot be neatly compartmentalised into self-contained categories. Neglect or discrimination within the education or health systems, for example, will have serious flow-on effects in other areas and on the quality of life enjoyed by people with disability. There are other issues, like discrimination, autonomy of decision-making and broader societal attitudes towards disability that transcends the boundaries of particular subjects.

I don't suggest that the scope of our task of itself makes this Royal Commission unique. There was after all once a Royal Commission into human relationships that some of us are old enough to remember fondly. But a Royal Commission of this extraordinary scope presents significant challenges. It requires us to determine

priorities carefully and to undertake investigations on complex issues in many different areas.

5 A second unusual feature of this Royal Commission is that the terms of reference require us to establish accessible and appropriate arrangements for people with disability, their families and carers, to engage with the Commission, share information and experiences, and give evidence. This requirement commits the Commission to a trauma-informed approach to all aspects of our work. By trauma informed, we mean that all work conducted by the Commission should be underpinned by an understanding of the physical, social and emotional impacts of violence and trauma.

10 We acknowledge that people with disability who have been abused or neglected have often been severely traumatised by their experiences. The Commission is, therefore, committed to ensuring that our policies and procedures and the manner in which we engage with people with disability are trauma-informed. We acknowledge that, for some people, additional supports such as counselling and legal advice may be required to recount their experiences in a manner that is physically, emotionally and culturally safe. Above all, the commissions approach must, to the greatest extent possible, minimise the risk of re-traumatising people engaging with the Commission. This is not the first Royal Commission that has been instructed to ensure that its processes are trauma-informed and that people engaging with the Commission receive sufficient support to be safe and comfortable. The Child Sexual Abuse Royal Commission, for example, was also expressly obliged to take into account that people affected by child sexual abuse have often been severely traumatised and have special support needs. Where this Commission is unusual and perhaps unique is that the focus of our attention is on people who not only had traumatic experiences during their lives but those traumatic experiences are directly associated with their disability. For example, during this hearing, there will be evidence about the formidable obstacles encountered by people with intellectual disability in obtaining accurate and timely diagnoses and treatment of serious health problems. It is vital that we hear firsthand from people who have had experience of the kinds of neglect and abuse – these kinds of neglect and abuse and that we benefit from their insights as to what can be done to make things better.

25 The Commission has already seen the value of receiving evidence from people with cognitive disability. For example, we have received many insightful submissions from people with intellectual disability and heard their experiences and opinions at workshops and community forums. You will find extracts from evidence given at the homes and living hearing, dealing with accommodation issues, by two advocates with intellectual disability, Jane Rosengrave and Colin Hiscoe. You will find extracts of their evidence in the first progress report of the Commission that was published in December 2019. It is an essential part of our work to ensure that people with cognitive disability can give their evidence in a manner that is comfortable for them, safe and trauma-informed. This is critical to fulfilling our responsibilities.

Advocates and witnesses themselves have suggested ways in which we can make this hearing safe and more inclusive and more accessible. And we are extremely grateful for the advice that we have received. The steps that have been taken to support witnesses who will give evidence at this hearing include extensive discussions with
5 senior counsel in the presence of a counsellor, legal advice for those who wish to have it, counselling support throughout the process and afterwards, modification of this hearing room to remove barriers and make the room more comfortable for witnesses. People present today can see the differences between this set-up and the usual appearance of a hearing room. It is, in fact, quite different. At a
10 familiarisation session held yesterday, people who are to give evidence were given the opportunity to be comfortable with the environment in which they will be giving evidence, and that was an extraordinarily valuable experience for the Commission. Let me now deal with the progress of the Royal Commission. The Royal
15 Commission is committed to transparency in communicating to the disability community and the Australian community at large the progress of our work. It was for that reason that we published in December the first progress report of the Commission. The report summarises the major activities of the Commission since the commencement of operations, including the public hearings, workshops, community forums, issues papers and research projects. The first progress report is
20 available on the website and in Easy Read format. And I suggest that anyone who is interested in the work of the Commission should, if possible, read one or other versions of this document.

I won't repeat the information in the report, but I do want to refer to some developments that postdate that report. The progress report recorded that by 10
25 December the Commission had received 428 submissions from people with disability and their families, experts, institutions, government agencies and other interested parties. That figure is now 590. And in addition, we have received 72 responses, some extremely detailed, to the four issues papers released so far. These issues papers concern education, health – the subject of this hearing – homes and
30 accommodation, and the criminal justice system. The last of these was released in January, after the progress report was published.

Many submissions that we have received recount the experiences of people with disability. These are frequently harrowing to read but they are essential to enhancing our understanding of the nature and extent of the violence against and abuse,
35 exploitation and neglect of people with disability, including, of course, children. These submissions not only inform us, but they can provide a platform for further investigations. For example, to gather evidence to be presented at public hearings such as this one, or to determine whether referrals should be made to other agencies. We sincerely thank all who have taken the time and effort to share your experiences
40 with us.

We have also received numerous submissions from advocacy groups, individual advocates, academic institutions, researchers and public agencies. Many of these submissions are deeply informed and supported by careful research or long

experience. They are of great value to our work and many are likely to be very influential in shaping the content of public hearings and, ultimately, the recommendations made by the Commission. We encourage people with disability, advocates and all interested parties to continue making submissions. The very best way of influencing a Royal Commission is to engage with it and communicate your experiences and point of view.

We have recognised from the outset that many people with disability, such as those in closed institutions or people who need support for communication, are unlikely to engage with the Royal Commission unless we take active steps to seek them out. To that end, among other initiatives, we shall be establishing a disability strategic engagement group to facilitate and encourage engagement with as many people with disability as possible. As the progress report recorded, we have already established a First Nations strategic advisory group under the guidance of Commissioner Mason. The progress report also referred to recent amendments to the Royal Commissions Act, which authorise us to conduct private sessions for people with disability. I am pleased to say that the first private sessions were held last week in Melbourne, with Commissioner Galbally, who is with us today, a little ahead of schedule. This is a very important development both for the Royal Commission and for people wishing to recount their experiences to a Commissioner in private on a one-to-one basis. You can, if you wish, learn more about private sessions from the website and also from one of a series of information brochures about the work of the Commission that will be available later this week.

The Commission has continued its program of community forums. We held fully subscribed forums in Logan and Ipswich in Queensland in the first week of February. And as I mentioned, last week, three Commissioners attended First Nations people community engagements in Darwin, Alice Springs and Papunya. I also should mention that the Commission has now established a new and vastly improved website which I hope will record very many visits. During 2020 we expect to hold at least 10 hearings in all six States and the Northern Territory. Our program of community forums and other engagement activities and consultations will continue. More issues papers will be released. Our interim report, on which work has already commenced, is due in October 2020. It will be a very busy year.

Let me say something about this hearing. The human rights framework for this hearing is provided by Article 25 on the Convention on the Rights of Persons with Disabilities to which Australia, of course, is a party. Article 25 is quite lengthy. But in essence, it provides that people with disability have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Among other things, Article 25 obliges States parties, such as Australia, to provide health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and to require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by raising awareness of the human rights, dignity, autonomy and needs of persons with

disability through training and insistence on ethical standards. We will hear during this hearing a good deal about the quality of health care provided to people with disability. Ms Eastman will say shortly more about the human rights approach required by the convention.

5 During this hearing, as Ms Eastman will also explain, we shall hear from people with cognitive disability and their families about their experiences. We will hear from advocates, experts, including advocate experts, medical practitioners, and representatives of government agencies. The evidence will also address the chronic failures of the health system to provide adequate care for First Nations people with

10 disability, a group that we know experiences multiple forms of disadvantage. In this connection, I want to refer to the latest report on Closing the Gap, which has just been released. That is, closing the gap between health outcomes for First Nations people and the Australian community in general. The background to this report, just released, is that in 2007, Commonwealth, State, Territory and local

15 governments made a commitment to work together to close the gap in indigenous disadvantage. It was recognised then that the gap was a national disgrace and required a national strategy developed in consultation with First Nations people themselves.

20 Unfortunately, as the report indicates, progress has not been quite as successful as had been hoped. For example, according to the latest Closing the Gap report, the life expectancy of Indigenous males is still nearly nine years less than non-Indigenous males, while the gap for Indigenous females is nearly eight years. The report acknowledges that the target to close the life expectancy gap by 2031 is not on track. The important point for the purposes of this hearing and for the work of the

25 Commission is that it is accepted by all governments, as it should be, that the present situation concerning First Nations People and their health is that the situation is completely unacceptable. The failure to close the gap has prompted all Australian governments to adopt new strategies in partnership with First Nations people in an attempt to improve First Nations life expectancy much more rapidly.

30 Now, consider the position or the experiences of people with disability in the health system. Ms Eastman will provide more details, so I shall refer only to two pieces of evidence that we expect to receive. Recent research has shown that the median age of death for people with intellectual disability in New South Wales is 27 years less than the general population, 54 years versus 81 years. That's a gap of 27 years.

35 People with intellectual disability in New South Wales aged between five and 69 years of age have three times the number of deaths that would be expected in the general population. People on the autism spectrum who reside in New South Wales, according to research, have a mortality rate over twice that of the general population. The second piece of evidence is that a high proportion of excess mortality among

40 people with intellectual disability and autistic populations is potentially avoidable. For example, deaths due to injury or poisoning. A recent New South Wales study found that 38 per cent of deaths of people with intellectual disability were from

avoidable causes. This figure is more than double the rate for the general population. It is striking that Mr Jim Simpson, from whom we shall hear, senior advocate for the New South Wales Council for Intellectual Disability, in his statement refers to this evidence. Mr Simpson says that the health inadequacies facing people with cognitive disability constitute a national disgrace, which demands a fundamental commitment to action by governments around Australia, health organisations and disability support providers. We shall have to consider very carefully Mr Simpson's views and the views of other witnesses who will give evidence at this hearing. Most of all, we have to pay special attention to the experiences of people with cognitive disability and their families. Ms Eastman.

MS K. EASTMAN SC: My name is Kate Eastman. I'm Senior Counsel assisting the Royal Commission and I appear today with Georgina Wright and Simone Fraser of Counsel. We are instructed by the Office of the Solicitor Assisting the Royal Commission, in particular, Lorna Davidson. In addition to the staff of the Royal Commission, we have also been assisted by Dr Hayley Bennett and Ms Janice Crawford of Counsel in the preparation for the hearing.

As counsel assisting the Royal Commission, we also acknowledge and pay our respects to the traditional custodians of the land on which we are meeting today, the Wann-gal people. We pay our respects to the First Nations elders past, present and emerging, as well as to all First Nations people at attending or watching this public hearing.

This is the fourth public hearing of the Royal Commission, and the first to focus on the area of health. This hearing will be conducted over nine days, this week and next week. I will make some opening remarks today that focus on the broad issues to be explored in this hearing. When the hearing commences next Monday, I will make some further opening remarks, albeit shorter than today, to focus on the evidence that will be given by the New South Wales and Commonwealth Health Departments. So where to start? Access to safe, effective and high quality health care is a core human right. As the Chair has identified, this right is provided by the Convention on the Rights of Persons with Disabilities, commonly referred to as the CRPD. The CRPD guides the work of the Royal Commission and Article 25 recognises the right of every person to the highest attainable standard of health without discrimination on the basis of disability.

But the right to health means more than simply being healthy. The right to health includes both freedoms and entitlements. Individuals have a freedom to make decisions and have choice about the health and their body. Entitlements refer to the legal obligation imposed on governments to ensure access to timely, acceptable and affordable health care of appropriate quality. Entitlements include the right to a system of health protection that gives everyone an equal opportunity to enjoy and attain adequate health.

If we are to take a human rights-based approach, it must mean that we focus on meaningful participation in health care systems and practices. Participation means ensuring that people with disability and their advocates are meaningfully involved in all phases of the health system, from assessment, analysis, planning, implementation, monitoring and evaluation.

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10 In the context of Australia, this means all aspects of our health system. Professor Stephen Leeder will give evidence on Thursday and he will provide a very high-level overview of Australia's health system. This system involves primary health care, hospitals, both public and private, public health, funding issues, and complex arrangements between the Commonwealth States and Territories.

15 But coming back to Australia's obligations under the CRPD, the United Nations Committee on the Rights of People with Disability recently examined Australia's progress and the extent to which we are meeting our obligations with respect to article 25. In October 2019, the Committee made a number of recommendations. In summary, the Committee expressed concerns about the significantly poorer health outcomes and access to information to health. The Committee highlighted particular concerns about people with disability living in institutions.

20 The Committee recommended that Australia revisit its approach to the access to information on an equal basis with others; that Australia look at affordable, accessible, quality and culturally-sensitive health services, equipment and related health activities. The Committee highlighted the importance of access to health services being non-discriminatory. And the Committee also highlighted the importance of health care practitioners to receive training on human rights models of disability to enhance their capacity to provide accessible quality health care to persons with disability. So this hearing will examine access and participation for people with cognitive disability. And that includes the issues raised by the UN Committee.

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30 As the Chair has noted in his opening remarks, the expression "cognitive disability" is used by this Royal Commission to include people with intellectual disability, autism, acquired brain injury and dementia. On all accounts, in 2018 there were over 900,000 people with cognitive disability in Australia.

35 Now, during the course of this hearing, reference will also be made to people with intellectual disability. Professor Julian Trollor, who will give evidence on Thursday, explains in a statement he provides to the Royal Commission, that intellectual disability is a form of developmental disability that may be characterised by impaired mental ability or reduced ability to manage the common demands of day-to-day life, what he refers to as adapted functioning.

40 He will say that people with intellectual disability may have difficulty with thinking skills that impact on planning, problem solving, abstract thinking and learning. He will say that in Australia approximately 1.8 per cent of the population has an intellectual disability. And of more than half a million Australians living with

intellectual disability over 60 per cent experience profound or severe impairments in core activities of daily living.

As the Chair has noted, language is important. And this Royal Commission recognises that labels such as cognitive disability and intellectual disability create a risk of generalising and allowing assumptions to be made about people with cognitive disability. The Royal Commission has heard already in previous hearings that labels are for jars, not for people. So it must be acknowledged that people with all types of cognitive disability each have their own life experience, their own personalities, their own hopes and aspirations. And we will endeavour to be cognisant of this during the course of the evidence in this hearing.

As the Royal Commission will be aware, the language is important. And some of the witnesses will tell you, for example, that they live with Down syndrome, they are not a Down syndrome person, they are not suffering Down syndrome and that Down syndrome is not a disease. And that's just one example.

Also, why is the Royal Commission starting its inquiry into violence, abuse, neglect and exploitation in the area of health with a focus on people with cognitive disability? Well, the Chair has noted the evidence that Mr Jim Simpson will give later to this hearing, describing the system as one as a national disgrace. And he highlights the work of Julian Trollor, who will also explain to us the basis upon this gulf in life expectancy for people with intellectual disability and the general population.

At the present time, life expectancy in Australia for a boy who is born in 2015 to 2017 is 80.5 years, and for a girl, 84.6 years. In research published by Professor Trollor and his team at the University of New South Wales in January last year, he identifies that people with intellectual disability have higher mortality rates compared to the general population, with death rates reported at two to four times higher and a life expectancy two decades shorter for people with intellectual disability.

These figures are consistent with work done by the Office of Public Advocate in Queensland in a report published in 2016. And the Office of Public Advocate recorded that the mean age of death for people with intellectual disability or intellectual impairment was 53 years for a man, that being 25 years less than the general population, and 49 years for women, being 36 years less than the general population. The Royal Commission will explore the disparity in life expectancy for people with cognitive disability and the general population to understand its causes and to ask whether it reveals serious neglect of the health of people with cognitive disability.

The Royal Commission is particularly concerned about people with intellectual disability who live in closed or segregated settings. For these people their ability to even engage with the health system may be one where they are totally dependent on their service providers and support workers to even enter the system.

Professor Julian Trollor will say, as a result of the research done over many years, the following: the current health care landscape in Australia is one of lack of preparedness for the needs of people with developmental disabilities. This lack of preparedness manifests on every level, primary, specialist and acute care settings, and in the services across the lifespan from childhood to later life. He will say such systemic lack of preparedness is a major contributor to the stark mental and physical health disadvantage experienced by people with developmental disabilities compared to the general population. Sadly, he will say, this is an issue that has been known for years.

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10 So the Royal Commission will inform itself by hearing from people with cognitive disability, their families, their advocates, experts and government witnesses. Over the course of this week and next, Commissioners, you will hear evidence from over 30 witnesses. And these witnesses will include people with intellectual disability and their experience in both primary health and hospital care, the parents of children with cognitive disability and the challenge in the past and even at the present time in

15 securing health and dental services for their children. You will hear from the parents speaking about the absence of access to rehabilitation. And you will hear from the parents whose children have died in circumstances where those deaths may have been preventable.

20 You will hear from advocates who will identify, quite clearly, the barriers to health care and the systemic issues. You will hear from medical experts and dental practitioners, such as Professor Trollor, Dr Jacqueline Small, Professor Nick Lennox and Dr Richard Zylan. You will also hear from experienced government officials responsible for the delivery of health services by the Commonwealth and New South

25 Wales. And you will also hear from the NDIS Quality and Safeguards Commissioner, Mr Graeme Head AO.

I just want to deal with a number of recurrent themes that will emerge from the evidence. The first is about the judgment that may be made about the value of a life with intellectual disability. Rebecca Kelly, who will give evidence later today, will

30 tell the Royal Commission this. There is a huge issue around ableism among medical professionals, where there is a clear lack of knowledge about intellectual disability, what it means for a person, as well as understanding the potential and value of a life lived with intellectual disability. She will say there is a perception that life with an intellectual disability is often seen as a life better avoided, through

35 screening and pregnancy termination, rather than a life of value, meaning and purpose.

Toni Mitchell, who will give evidence tomorrow, will tell the Royal Commission about her pre-natal screen in early 2000. She will tell you that a radiographer informed her that her baby had a heart condition and that her baby was highly

40 suspected of having Down syndrome. His response to giving her this news was to then suggest and give an appointment to arrange for a termination of the pregnancy. You will see tomorrow that that did not occur.

The stigma and attitudes are pervasive in the evidence that you will hear. Christine Regan will tell the Royal Commission that she worries that some doctors make decisions based on their perceived relative value of their patient to society.

5 Another theme that emerges is poor communication. The Royal Commission will hear from a number of parents of children with disability who have had experiences in hospitals and the health system more broadly, who will say that it's quite common for health care workers not to engage directly with their child. They will speak of occasions when the doctors and other health staff do not even greet their child, let alone explain to the child what is happening, even though the child's language is
10 good and the child is capable of understanding what is occurring.

But this experience is also shared by adults. And so adults with cognitive disability will also tell you that it's not uncommon for health staff to talk mostly to their support person or their parent, rather than to them. And, in the words of one witness who will give evidence shortly, she will tell you:

15 *I think doctors need to speak to the person with the intellectual disability and not somebody who's with them.*

And she will say:

I can make decisions of my own.

20 So the Royal Commission will examine communication. It may sound obvious, but the need for simple, open, respectful communication with a person with intellectual disability is an important part of supporting participation in the community and access to health care. Justine O'Neill and Jack Kelly will talk this morning about decision-making and capacity and the importance of communication in that respect. The next issue is understanding pain and this concept of diagnostic overshadowing.

25 Diagnostic overshadowing is the misattribution of physical symptoms to mental illness or cognitive disability. Diagnostic overshadowing occurs when health professionals wrongly assume that present physical symptoms are a consequence of a person's cognitive disability. As a result, the patient receives either inadequate diagnoses or treatment, a failure to provide appropriate treatment, or in some cases
30 resulting in a preventable death.

Again, these issues are not new. In May 2009, Michelle McIlquham, who was then 28 years old, died suddenly, due to bacterial meningitis in a hospital in Sydney. She had a mild intellectual disability. Her death was the subject of a coronial inquest conducted by the New South Wales Deputy Coroner over four days in October 2012.
35 Michelle's mother, Maureen McIlquham, brought this matter to the Royal Commission's attention. And she's also provided a submission to the Royal Commission, although she's not giving evidence at this hearing. The Coroner's findings are detailed and we will include them in the evidence before the Royal Commission. The Coroner heard evidence from the medical staff at the hospital and

examined the reasons for Michelle's misdiagnosis and death. He noted a few things. First, that the medical staff's failure to pay attention to those who knew Michelle best was wanting. And he said this:

5 *In hindsight, it is clear that the medical staff gave insufficient attention and weight to Michelle's mother's concerns, among others.*

And he said this, that:

10 *The medical staff operated on certain assumptions about patients. In particular, they appear to have operated on the assumption that Michelle's inability to communicate easily with them was due to behavioural issues associated with her disability or that she lacked general capacity to communicate.*

A more recent example will be the evidence of Kim Creevey. And she'll talk about her son Harrison. She will tell the Royal Commission about her experiences of unconscious bias. She will tell the Royal Commission about an occasion where a
15 paediatrician made some unfounded assumptions about her son's presentation to hospital with a breathing condition. The paediatrician assumed that the condition was caused by Harrison's disability. And in the course of that consultation, the paediatrician questioned the family about the end of life plan for Harrison. He was present at the time of this conversation. The paediatrician said this:

20 *How much more money are we going to waste keeping him alive?*

Ms Creevey will tell the Royal Commission that it turned out that Harrison's symptoms were just related to acid reflux and once they were treated there was general improvement.

25 So experiences like this have galvanised the parents of children with cognitive disability to be strong advocates of their children. Toni Mitchell describes herself as a fighter. And she will tell the Royal Commission that strong advocacy by parents might result in obtaining a reputation as being a problem mother. And we've heard in the evidence "being difficult" is a word that can often describe a strong advocate. The next issue is the lack of respect for parents' knowledge of their child's need and
30 pain. The Royal Commission will hear evidence that the parents and carers are often expected to manage their child's health needs and their child's behaviours in hospital settings. At the same time, when it comes to understanding the child's needs, the parents are not heard and at times ignored. And there are numerous accounts in the evidence that you will hear of parents seeking to explain how their child experiences
35 pain and only find that their attempts to help the doctors understand their child's circumstances being ignored, the result being inadequate or insufficient measures to manage pain. And this, in turn, results in longer hospital stays where children are away from their families, friends and school.

Narelle Reynolds will tell the Royal Commission next week about her two sons who live with Fragile X syndrome. They both experience great anxiety attending hospital and fear of certain medical procedures. She'll give evidence about her pleas that have been ignored to have assistance for her sons to access medical services. And she will talk about the nine failed attempts to undertake a biopsy for one of her sons. She will tell the Royal Commission that she sees that there is an urgent need for hospitals to have trained disability workers who can be able to manage the fears and anxieties of people with disability and make adjustments when they come to hospital. The next theme you will hear is about trauma. There is a trauma associated with medical procedures for some people with intellectual and cognitive disability. Rachel Browne will tell the Royal Commission about her son Finlay and the trauma of taking a blood test. She will say that, because of his repeated tests over the course of his short life as a boy living with Down syndrome, that taking the test became more challenging and difficult as he got older, because of his great fear of needles. And she will talk about the lack of response for something as simple as a blood test. One witness will give evidence about the cumulative effects of repeated visits to hospital and the trauma that that creates. But these events do not only impact the child themselves but have an impact on the whole of the family, and that must be acknowledged, that parents, grandparents and the sibling of a child with cognitive disability may also experience trauma. The next theme is the failure or unwillingness to make reasonable adjustments. A number of witnesses will tell the Royal Commission that making health accessible means actively considering and implementing reasonable adjustments. That may involve making changes to remove barriers, physical or otherwise, that make it difficult for patients to receive health care services. Witnesses will tell the Royal Commission that in many cases a reasonable adjustment is a very small thing. It's not costly. One is preparation. Finding out in advance what a patient may need to minimise trauma and familiarise themselves with places and procedures. Taking time to listen, to understand and communicate with a person with cognitive disability. And one parent will tell you that an adjustment could be as simple as giving the patient a familiar cup for taking medication. Professor Trollor will tell you about a larger approach to reasonable adjustments, and he will say the existence of reasonable adjustments is best practice internationally and that it would be his expectation that reasonable adjustment should be a mandated requirement for health practitioners and services. This will be an issue I will explore with him in some detail when he gives evidence on Thursday. So just briefly some other issues and themes. The Royal Commission will also hear evidence about the following matters: the lack of adequate education and training for those working in the health system; the often failure to include people with cognitive disability in how doctors are educated; the importance of continuity of care; the transition from paediatric care; issues around preventative health; issues around

dental care; dignity in death. Rachel Browne will tell you that something as important and as simple as not describing a person's disability on a death certificate when the cause of death is unrelated to the child's disability is a very disturbing and traumatic experience for her and her family.

5 Other issues are gaps in data collection and the need for targeted and accurate data. People will give evidence about the difficulty of raising complaints about their treatments and also the inability to find out what happens when complaints have been raised. They will talk about the difficulty of accessing medical records and medical reports. They will talk about the importance of community visitor schemes.

10 This Royal Commission will also focus on the health of First Nations people. And you will hear evidence of Dr Scott Avery next week that will address this issue in some detail.

But on the themes, can I just use the words of one witness. And she will tell the Royal Commission this. She will say:

15 *I am consumed with anger at the injustice and everything that has happened to my son, that he has not had timely access to dental and health care needs. Organisations can write glossy statements and protocols, guidelines and say they are meeting all the legislative requirements for equal access, but in practice this is not happening, especially for people with complex behavioural issues.*

20 So what can be done to address and remedy the barriers to health care and preventable deaths for people with cognitive disability? The Royal Commission wishes to explore this issue in depth. Every witness who will give evidence at this hearing will tell the Royal Commission about their views and suggestions for improving health outcomes, both in terms of systems and practices. And, as I mentioned, we will look closely at the evidence of the Commonwealth and New South Wales Governments next week.

30 So can I turn to how the Commission will approach the conduct of this hearing over the next two weeks. Our focus is on listening and understanding the experience of people with cognitive disability, their families, their advocates and their experiences in accessing health care in Australia. Some of the evidence will be very distressing. We don't shy away from that. But I must also stress that for this hearing the Royal Commission is not conducting a coronial inquest. We are not conducting professional conduct inquiries. We will not be making findings of negligence or breaches of any law, be it civil or criminal.

35 The Royal Commission is not intended to be a substitute for local complaint processes, internal investigations or the coronial inquiries that may occur. The Royal Commission is not a court and cannot provide remedies for particular individuals. In this respect, the Royal Commission in this hearing will not be making any findings

that a particular person or health service breached the law, committed an offence or breached a policy.

The Royal Commission acknowledges that there has been a very short period of time for those with leave to appear at this hearing to consider all of the evidence. And so
5 we have not expected governments and health services to provide any detailed responses to the evidence that will be given by our witnesses with direct experience. In this respect, the Royal Commission is committed to ensuring procedural fairness for everybody who participates in this hearing, and it acknowledges the importance of providing an opportunity to persons, governments and health providers to provide
10 information or make submissions to the Royal Commission in due course. And I will speak more about this at the conclusion of the hearing as to how that could be done. So the final things that I want to say, for those who follow the work of the Royal Commission over the previous three public hearings, is a little bit about the importance of protecting witnesses and our collective responsibility in relation to
15 witnesses. There are provisions in the Royal Commissions Act which have the very clear object of protecting witnesses who give evidence before the Commission. In particular, I draw everyone's attention to section 6M of the Act, which provides that:

*Any person who causes, uses, inflicts any violence, punishment, damage, loss or disadvantage to a person on the account of that person having appeared as
20 a witness, given evidence, or producing documents to the Royal Commission, will commit an indictable offence.*

That's a serious matter, the maximum penalty for which is a term of imprisonment. I also want to note, as we've done in previous hearings, the possible traumatic effect of watching and listening to the evidence in the hearing. The public hearings will
25 continue to be made available by the web stream. And the Royal Commission encourages anyone watching or attending the hearing here in person to be mindful of the topics that might be upsetting. And, if necessary, we encourage you to take the supports that you need.

The Royal Commission has an internal counselling and support team, who are made
30 up of social workers and counsellors, and they are available to provide assistance to anybody who requires such assistance. And there are counsellors present at the hearing today. The Royal Commission also has connection with the Blue Knot organisation. And there is a hotline that can be used by anybody following our proceedings. It's 1800 421 468. And further details can be found on the Royal
35 Commission's website.

Finally, the Chair has mentioned the issues paper. And the Royal Commission has received a number of submissions in response to the issues paper concerning health. This hearing is one part of our work. And we certainly encourage the community to engage with the Royal Commission. And anybody who feels that they wish to make

any submissions about issues concerning health are very welcome to make submissions in response to the issues paper.

Commissioners, we will start the hearing shortly. There are parties who have sought and been granted leave, and, if it's appropriate now, those parties could make their appearances. If the Commission pleases.

5

COMMISSIONER SACKVILLE: Thank you, Ms Eastman. I will ask any party appearing who wishes to announce appearances to please do so.

MS K. FURNESS SC: If it pleases the Commission my name is Furness. I appear with my learned junior MR FRASER for the state of New South Wales.

10

COMMISSIONER SACKVILLE: Thank you, Ms Furness.

MS K. MORGAN SC: May it please the Commission, my name is Kate Morgan. I appear with AMY MUNRO for the Commonwealth of Australia.

COMMISSIONER SACKVILLE: Thank you, Ms Morgan. Are there any other appearances?

15

MS EASTMAN: I think there's no further appearances today. And other counsel who will appear for witnesses during the course of the hearing will make their appearances at the appropriate time.

COMMISSIONER SACKVILLE: Thank you. We will now take a short break, 10 minutes or so. There will be another break before lunch, but this will be – we shall resume – it being 11 o'clock – at 11.10 am more or less.

20

MS EASTMAN: If the Commission pleases.

ADJOURNED

[10.59 am]

25

RESUMED

[11.11 am]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: We will hear the evidence of Kylie Nicole Scott.

COMMISSIONER SACKVILLE: Thank you. Thank you very much.

30

<KYLIE NICOLE SCOTT, SWORN

[11.12 am]

<EXAMINATION BY MS EASTMAN

COMMISSIONER SACKVILLE: Thank you very much. Ms Eastman will now ask you some questions.

5 MS EASTMAN: Kylie, would you like me to call you Kylie or Ms Scott?

MS SCOTT: Kylie.

MS EASTMAN: Kylie.

MS SCOTT: My first name.

MS EASTMAN: So Kylie, you've got some papers in front of you.

10 MS SCOTT: Yes.

MS EASTMAN: And I'm going to take you to particular paragraphs that you have highlighted and I will ask you some questions. Is that okay with you?

MS SCOTT: Yes.

15 MS EASTMAN: So first of all, can you tell the Royal Commission, what is your full name?

MS SCOTT: Kylie Nicole Scott.

MS EASTMAN: And Kylie, if you have a look at paragraph 5. Since 2016, you have been a disability consumer representative for the Sydney Local Health District; is that right?

20 MS SCOTT: Yes.

MS EASTMAN: Now, can I ask you to turn over the page and look at paragraph 12. In June last year, that's 2019, you presented a speech called Improving Engagement with People with Intellectual Disability at the Sydney Local Health District Patient and Family Experience Symposium. Do you remember making that

25 speech?

MS SCOTT: Yes.

MS EASTMAN: And the Commission has a copy of your speech and we would like to play part of that speech shortly. Are you agreeable to us playing part of your speech?

30 MS SCOTT: Yes.

MS EASTMAN: Before we do that, can I ask you a few questions about health.
Can I do that?

MS SCOTT: Yes.

5 MS EASTMAN: So if you turn to the next page. In the statement that you provided
to the Royal Commission, you talk about health care and health services and how
you feel about going to the doctor. So can I ask you to just read to yourself
paragraph 15 and I will ask you a question about that. So number 15. All right. So
Kylie, going to the doctor doesn't worry you at all; is that right?

MS SCOTT: That is right, yes.

10 MS EASTMAN: But sometimes you need help to organise a suitable appointment
and someone to go with you.

MS SCOTT: Yes.

15 MS EASTMAN: And then in the next paragraph, number 16, you say you need
someone to go with you for medical check-ups, to check when you are sick, when
you need to talk to the doctor and when you need to know how well you are. Is that
the case?

MS SCOTT: Yes.

20 MS EASTMAN: And then in number 17 you tell the Royal Commission about a
few things that work well for you when you go to the doctor. Do you want to read
out what you've said to the Royal Commission in your note at paragraph 17.

MS SCOTT: Yes.

MS EASTMAN: All right. Let me know if you need a hand at all or you would like
me to read part of it.

MS SCOTT: Okay.

25 MS EASTMAN: But could I ask you to read what you've written down in
paragraph 17.

MS SCOTT: Yes:

30 *A few things that work well for me when I go to the doctor are: (a) having a
medical report on my habits, my behaviour bits and pieces; (b) when doctors
check the Council for Intellectual Disability, My Health Matters folder to know
about my concerns, about my health background, check-ups, or for general
use; (c) when I am responsible for my own actions; (d) when someone comes*

with me to the doctor; and (e) writing everything down before I go to the doctor, so I can remember.

MS EASTMAN: So Kylie, turning over the page, you wanted to tell the Royal Commission about how important communication is; is that right?

5 MS SCOTT: That is right.

MS EASTMAN: And can I ask you to look at paragraph 24. And you want to tell the Royal Commission that doctors need to communicate properly to people with intellectual disability; is that right?

MS SCOTT: Yes.

10 MS EASTMAN: And for you, it helps when doctors ask you short questions in plain English, speak clearly and are patient.

MS SCOTT: Yes.

MS EASTMAN: And that helps you make decisions; is that right?

MS SCOTT: That is right.

15 MS EASTMAN: And you also say to the Royal Commission – this is paragraph 25 – that doctors should talk to families:

If someone's child has Down syndrome, they can take it on board and see what's going on.

20 So that's your advice to the Royal Commission and to doctors about talking to families; is that right?

MS SCOTT: Yes, definitely.

MS EASTMAN: Okay. Then over the page, you wanted to tell the Royal Commission about how you make decisions about your own health care. So you should have a little note there, paragraph 27 – number 27. Have you got that?

25 MS SCOTT: Got that.

MS EASTMAN: So you tell the Royal Commission sometimes you make decisions on your own, sometimes you need help, and if you need help, mum can help you; is that right?

MS SCOTT: Yes.

30 MS EASTMAN: And then the next paragraph you say for you it's about trust:

When I have to say “yes” or “no” to medical treatment it’s about whether I trust the doctor.

So trust is an important thing for you; is that right?

MS SCOTT: Yes, ma’am.

5 MS EASTMAN: Now, then you wanted to say a few things about what you think doctors and nurses should know. So you wanted to talk to – to tell the Royal Commission the things that doctors should know. So if we turn over the page, at the top of the next page you’ve told me you’ve thought very carefully about all of these points and they’re very important. You wanted to read them yourself.

10 MS SCOTT: Yes.

MS EASTMAN: So can I ask you to read – and take your time. If you want me to read part or ask a question, just let me know.

MS SCOTT: Okay.

MS EASTMAN: Let’s go.

15 MS SCOTT:

(A) people with disability need to get ear, nose and throat tests done; (b) it is important to assess mental health. People with Down syndrome are vulnerable, they need more psychologists for people with intellectual disability. There are a fair few people with intellectual disability with mental health problems. The big thing these days for doctors to know about is pre-natal testing or pre-natal screening. They need to know how serious it is now these days. I think we should continue people with Down syndrome not being aborted. Just being normal as other people are equal. (D) good record keeping is important; (e) yearly care plans are important; sleep apnoea checks are important. And last thing, doctors need to be aware of current research into epilepsy and Alzheimer’s in people with Down syndrome.

20

25

MS EASTMAN: And Kylie, that’s a very important matter for you, isn’t it, at the moment, that awareness of the research?

MS SCOTT: Mmm.

30 MS EASTMAN: So before we look at the video, I want to ask you just a few questions about your advocacy. And if you turn over the page to point 42, you tell the Royal Commission that people with intellectual disability are becoming more independent and visible; is that right?

MS SCOTT: That is right.

MS EASTMAN: And that's your experience of being more independent and visible. You live by yourself in your own apartment.

MS SCOTT: I am, yes. I live in Zetland near Green Square station. And people find the houses very hard to find. So my family discovered my path to live
5 independently for myself.

MS EASTMAN: And you tell the Royal Commission that people with intellectual disability are now learning to self-advocate and be more independent.

MS SCOTT: Yes. Sorry, a fair few of people in my case of people with intellectual
10 disability – a fair few people. They're hiding in ghettos but they don't seem to get out. So for them to – people with disabilities to find their voice and to be heard and, of course, live in the independent living as much as they can.

MS EASTMAN: And the final paragraph of your statement, paragraph 43, you wanted to read that out aloud to the Royal Commission. So can I ask you to read
15 that.

MS SCOTT: Yes, can I stand up?

MS EASTMAN: You can stand up.

MS SCOTT: Mr Commissioner, I want to speak up for people who can't speak up. We all need to be understood and supported. Here's Wonder Woman to the rescue. And this morning I found out on Mr Dr Google, jokingly – my mother discovered
20 this morning for myself – I wrote down, did you know that Aboriginal languages do not have a word for disability? And they want to be included as well. And they have no such word for disability. We want them to be included. Don't want them excluded out but included because my first name means Boomerang. So we all have – with the Aborigines, we should all be included out in the public eye.

MS EASTMAN: Thank you, Kylie. With your permission, can we show part of the
25 speech that you gave in June 2019.

MS SCOTT: You may now, yes.

MS EASTMAN: Thank you very much. We can have that on the screen. Thank
30 you.

VIDEO SHOWN

MS EASTMAN: If the Commission pleases, that's Ms Scott's evidence. If the
35 Commission could take the evidence as an exhibit and mark it exhibit 4-1. A copy of the statement is found in the tender bundle part A, behind tab 1. If it's convenient

now to have what will be the morning tea adjournment for 20 minutes. Witnesses following that break will be Jack Kelly and Justine O'Neill, if the Commission pleases.

COMMISSIONER SACKVILLE: Thank you.

5

**EXHIBIT #4-1 STATEMENT OF KYLIE SCOTT DATED 07/02/2020
(STAT.0045.0001.0001)**

10 **EXHIBIT #4-1.1 PRESENTATION BY KYLIE SCOTT, 'IMPROVING
ENGAGEMENT WITH PEOPLE WITH INTELLECTUAL DISABILITY'
(SYDNEY LOCAL HEALTH DISTRICT) (NSW.9999.0002.0001)**

15 COMMISSIONER SACKVILLE: Kylie, thank you very much for sharing your experiences and your ideas with us. They are very important to us. Thank you so much.

MS SCOTT: Thank you.

<THE WITNESS WITHDREW [11.33 am]

20 COMMISSIONER SACKVILLE: All right. We will now resume at 11.55.

ADJOURNED [11.33 am]

25 **RESUMED [11.55 am]**

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: If the Commission pleases, Ms Fraser is taking the next witness.

COMMISSIONER SACKVILLE: Thank you.

30 MS FRASER: Commissioners, we will now receive evidence from Jack Kelly and Justine O'Neill.

<JACK KELLY, SWORN [11.56 am]

35 **<JUSTINE O'NEILL, AFFIRMED [11.56 am]**

COMMISSIONER SACKVILLE: Ms Fraser will now ask you some questions.

MS FRASER: Jack, could you please state your full name for the Commission.
MR KELLY: Jack Kelly.
MS FRASER: And you're happy for me to call you Jack?
MR KELLY: Yes.
5 MS FRASER: And, Justine, your full name is Justine O'Neill.
MS O'NEILL: Yes.
MS FRASER: And you're happy for me to call you Justine?
MS O'NEILL: Yes.
MS FRASER: Justine, you have provided a statement to the Royal Commission
10 dated 11 February 2020.
MS O'NEILL: Yes.
MS FRASER: You have a copy of that statement with you now.
MS O'NEILL: Yes.
MS FRASER: And the contents of that statement are true and correct to the best of
15 your knowledge.
MS O'NEILL: Yes.
MS FRASER: And you've included in your statement a copy of your curriculum
vitae.
MS O'NEILL: Yes.
20 MS FRASER: Commissioners, the statement is at tab 1 of tender bundle B. And
Justine's curriculum vitae is at tab 2 of tender bundle B.
COMMISSIONER SACKVILLE: Thank you.
MS FRASER: Justine, you are the chief executive officer of the Council for
Intellectual Disability?
25 MS O'NEILL: Yes.
MS FRASER: And the Council for Intellectual Disability is commonly referred to
as CID.

MS O'NEILL: Yes.

MS FRASER: And you're happy for me to refer to it as such.

MS O'NEILL: Yes.

MS FRASER: What sort of work were you involved in, Justine, prior to
5 commencing with the Council for Intellectual Disability?

MS O'NEILL: I'm a social worker by training. I've worked in health settings, hospitals, sexual assault services with Victims of Crime, homelessness and so on. But for close to 15 years I worked for the Office of the New South Wales Public Guardian.

10 MS FRASER: And can you tell the Commission what sort of work CID undertakes?

MS O'NEILL: Sure. CID is a systemic advocacy organisation. We've been around for about 60 years. And thanks to the efforts of some in the room today we're an organisation led by people with intellectual disability. Over 50 per cent of our board are directors with intellectual disability.

15 MS FRASER: And, Jack, you're a colleague of Justine's at CID?

MR KELLY: Yes, I am.

MS FRASER: And what sort of work do you do there?

MR KELLY: So I am – I am a project worker and I work on facilitating focus groups on different areas of topics in relation to people with an intellectual disability.
20 And I work on Easy Read documents, and – among other things, as well.

MS FRASER: I'm going to hand over now to Justine, who's going to ask Jack some questions. And for the information of everybody present and watching on the live broadcast, these questions and answers have been developed by Justine and Jack together.

25 COMMISSIONER SACKVILLE: Please go ahead, Justine.

MS O'NEILL: Okay. So thank you for the opportunity to give our evidence in this way. We've prepared questions together and answers together based on previous work together and more recent conversations. So, Jack, how do you like to make decisions?

30 MR KELLY: I like to gather my information first and think about what the logistics of the location and the opportunity.

MS O'NEILL: And the pros and cons.

MR KELLY: Yes. And the pros and cons of that decision.

MS O'NEILL: Do you like to talk to anyone else?

MR KELLY: I do like to talk to family, friends and my support workers that I work with.

5 MS O'NEILL: Do you have to talk to other people?

MR KELLY: Not – not if I don't choose to, but mainly I do like to use them as a sounding board.

MS O'NEILL: And sometimes you will do some things alone, like go to the GP.

MR KELLY: Yep.

10 MS O'NEILL: What about time? What – can you say something about the importance of time in getting information and making decisions.

MR KELLY: I – I want to get enough notice so I can work around the logistics of my decisions and to think about the pros and cons and how it will benefit me in the long run.

15 MS O'NEILL: You gave an example when we were preparing about talking through worries. And you gave an example of when you were thinking of what type of work you might want to do and working in an office. And you were concerned about your typing skills.

20 MR KELLY: Yes. Well, I was, but now technology is such a great thing where dictation can help a lot in that way. So I can be independent and work efficiently as much as possible.

MS O'NEILL: Right. So you were able to get some information about things that could help remove that worry so it wasn't a barrier to you?

MR KELLY: Yep.

25 MS O'NEILL: Do you have to say yes when you are asked to do something?

MR KELLY: I – I've learnt over time – no, I don't, but I've learnt over time it's okay to say no and just focus on the decision why you say no to that opportunity at that time.

MS O'NEILL: Have you always been a confident decision-maker?

MR KELLY: Not really, but I think I'm really evolving as a person over time, has really helped me with the people that I've met and the decisions that I have made down the track.

MS O'NEILL: And I heard you say that you used to be extremely shy.

5 MR KELLY: Yes, I was. It's amazing to me the growth that one person can go to from school to after school and into adulthood.

MS O'NEILL: And you commented that you've learnt with age and with those experiences that you've had.

MR KELLY: Yes.

10 MS O'NEILL: What about hearing from other people and seeing the choices that other people make?

MR KELLY: I think that is also a good sounding board, because you can be like that's a – that's a good choice or that could influence or help you make a difficult decision, so it helps if someone is making the same decision as you.

15 MS O'NEILL: So the connections that you have with other people - - -

MR KELLY: Yes.

MS O'NEILL: - - - also help you make decisions. And you've commented that you've learnt to trust yourself and trust your gut.

20 MR KELLY: Yes. I always think it's really important to just trust your inner self, because you're you for you. Like, it doesn't matter what other people say or do and actions; it's just important that you make the right decisions for you no matter what, whether it might be health that we're talking about today or in another area in your life.

25 MS O'NEILL: Why is it important for people with intellectual disability to be involved in decision-making?

MR KELLY: Because I think – I think it's really important, because I feel like we all should be treated as an equal and not as a dis-equal. And it's, you know, just really important to see the person first and not the intellectual disability at the forefront.

30 MS O'NEILL: What have you seen in other people where they haven't had opportunities to be involved?

MR KELLY: I've seen a lot of people disheartened because they're not getting the choice and control that they want, or they get frustrated because another person is making that decision for them.

5 MS O'NEILL: And you've commented that sometimes support workers who've worked for a long time, might have – treat people differently?

MR KELLY: I think it depends on – like, if you've been in the industry a long time or before or if you came from the time in Australia where people with an intellectual disability wasn't heard or wasn't seen out in the communities, they institutionalised, but when you look at support workers today, they're a lot more
10 flexible and more outgoing, because they see the they try to live by the NDIS's stance of voice, choice and control.

MS O'NEILL: And you, also, just finally, had an observation about young people in this new system.

MR KELLY: Yes. I – it's interesting, because me being a person with a disability, it's interesting, because I have grown up now with the NDIS having all of these
15 choices and all these controls, versus someone that was – sorry – was in an institution where they were told to – the activity that they were going to do, what – like, what breakfast that they were going to eat that day for breakfast and just stuff like that.

20 MS O'NEILL: And so you're saying that younger people - - -

MR KELLY: Yes.

MS O'NEILL: - - - are speaking up more?

MR KELLY: They have more opportunity, but it's interesting now seeing people with a disability or an intellectual disability having those choices, because they're not
25 used to having those choices if they grew up in the 60s or 70s.

MS O'NEILL: Thanks, Jack.

MS FRASER: Thank you so much, Jack, for sharing your experience. Justine, the statement that you've provided to the Royal Commission focused on supported decision-making. For the benefit of the Royal Commission, can you please tell us
30 what is meant by the term supported decision-making.

MS O'NEILL: So various terms can be used, supported decision-making, support for decision-making, decision-making support. They are all ideas that we all have – we all have needs to be supported with various bits of information around decision-making from time to time. So we might go and talk to a professional person, we
35 might talk to family and friends. And with intellectual disability it might be that you need a little more support in more areas of your life more often.

And so supported decision-making is recognising adults' rights and people's rights to make decisions for themselves and trying to work out what kinds of supports do you build in to really stretch out the number of people who can make their own decisions or, at the very least, participate to the greatest extent possible. For those people that
5 really have very complex communication, that the ideas around how you might make a decision for people who otherwise can't express it is based on what has been picked up about indicators of their will and preferences and the choices they might want to make.

MS FRASER: And can you tell us, Justine, how supported decision-making can be
10 contrasted with substituted decision-making.

MS O'NEILL: So substitute decision-making is a useful tool at times for people who will otherwise not have access to supports or medical treatment or things that they need. But it's a way to substitute someone else in to make a decision on the person's behalf and it's usually done – in Australia we have a best interests model, so
15 someone else decides what's – what the decision should be. Supported decision-making tries to keep that as an absolute last resort, where you are again not looking at whether someone has got a legal capacity, but you look at supports and what can be built up to assist the person, and trying to put those supports in place and see how that impacts what level of involvement the person is able to have. And, again, the
20 focus is on the will and preference of the person, not simply best interests.

MS FRASER: And why is it important for us to think about ways that we can support people with intellectual disability to make decisions?

MS O'NEILL: Well, I think Jack and Kylie have kind of summed that one up this morning. When people with intellectual disability are able to lead and make
25 decisions, then we're all able to use our rights and participate. And we need to hear directly from people with intellectual disability about how to do that and what good support needs to be. I think in the context of this hearing around health, we're going to hear a lot of stories about what happens when people are not involved in their care, when the people who support them are not heard, and the really negative
30 consequences that comes from that sense of people with intellectual disability just being to the side and not participating in their own lives.

MS FRASER: And the example of the exchange between you and Jack that we've just heard now, it's a good example, isn't it, of the inclusion of people with
35 disabilities in decision-making and in structuring those questions and answers, you and Jack worked on that together and you heard and responded to his views.

MS O'NEILL: Yes. So that's one way of trying to do that work, and it's because of our relationship and who we are. Support for decision-making will look different in different settings. It can be a formal legal process. So for example, the New South
40 Wales Law Reform Commission has made recommendations for an assisted decision-making act in New South Wales to replace the Guardianship Act. That's a

formal model. And then support for decision-making really can take place in any interaction at any time.

MS FRASER: From your experience, what are some of the difficulties faced in building a person's decision-making ability?

5 MS O'NEILL: Well, I think, again, Kylie and Jack have kind of pointed to it. It's this – the most fundamental is negative assumptions and cultural ideas about people with intellectual disability and what people are capable of. And so that's – you know, at the most basic level it will always be a barrier. And from the work that I was involved in some decision-making support projects, it was also obvious that it's
10 the people around the person that will determine – and that applies to all of us – that will determine whether we become decision-makers. So if I'm not seen as someone who has the right to make decisions, if I'm not seen as someone who has the ability to make decisions by others, then there's probably very little chance that I ever will or that my decisions will be acted upon. And I think that I've already forgotten the
15 question.

MS FRASER: Moving now to some practical recommendations, what are some of the practical steps that a health care provider can take to encourage supported decision-making?

MS O'NEILL: Okay. So probably just to go back a little with some of the other
20 barriers around time, which is very significant in a health setting, and skill and experience. So support for decision-making, you know, happens in that formal space but it also happens in an informal way. And it's encouraged and fostered by resourcing communities, by developing policy with people with intellectual disability that is appropriate and that's going to promote good communication and
25 accessibility.

So all of those things are the responsibility of organisations like health institutions, hospitals and so on. So there's kind of a systemic element there that organisations need to recognise their role in creating a process or creating processes for staff that will encourage the involvement of people with intellectual disability. And then when
30 we get down to those interactions between people, some of the things that Jack mentioned, like Easy Read communication, so that people have communication coming to them that's in an accessible format, allowing the time for information to be gathered and considered and acted upon. It's really hard in a health setting. It might be that in some community settings, community health settings, there's more
35 time for that to be developed and in acute settings that might be more difficult, which is why it's really important for those processes to put the focus on will and preference and make sure that people are recording views. There are also tools for communication that tend to be fairly localised initiatives and they're really good and local stuff is really good, but there also needs to be some leadership and
40 responsibility for making sure that those communication tools and resources are available for everyone and, no, not just by people with intellectual disability and their

families but by the professionals who need to be using them. There are a number of things.

MS FRASER: You have identified at paragraph 46 of your statement a number of suggestions for change and I'm actually going to take the opportunity to read those now:

5

Supported decision-making means legislative and policy reform to help shift our lives on substitute decision-making arrangements.

That was (a):

10

(b) Supported decision-making needs to be acknowledged and supported to develop in communities. It is much more than a set of theories and possible laws. This can be fostered in policy, training and practice, and funded through program initiatives; (c) investment of time and resources should be made in developing inclusive practices and accessible communication, which play a key role in supported decision-making; (d) people with intellectual disability should be included in the development of legislation, policy, practice and training.

15

And finally:

20

(e), The NDIS pricing structure should include recognition of the time and support workers need to put into supporting decision-making, as well as the need for people to have independent support for major decisions and building decision-making skills.

Are there any of those particular suggestions that you would like to elaborate on at this point in time, Justine? And don't feel that you must.

25

MS O'NEILL: Well, happy to. I find this topic really interesting. I could be boring about it for quite a long time. But I think the most important one there is about people with intellectual disability being included. So, for example, we – I mentioned the New South Wales Assisted Decision-making Act that was suggested by the Law Reform Commission. Not seeing where people with intellectual disability are being invited to kind of lead the discussion about is this the direction we should go in. And I think without people with intellectual disability being involved in that way, it's impossible to reach an outcome of inclusion and support and so on, if there's no consultation about the best way to get to where you think you ought to be going. So – and we get a lot of feedback at Council for Intellectual Disability that for when we go and do training, that for audiences seeing – we do co-facilitated training, meaning whenever we present information, we do it together. And so a lot of audience will say just seeing that interaction and that relationship and seeing the leadership by the person with intellectual disability, it is often like the biggest part of the learning about shifting your thinking, about what's – what people are capable of

30

35

and what you can learn from people with intellectual disability, who are the people going to be most impacted by choices made in all of these other areas.

MS FRASER: And Jack, is there anything else at this time that you would like to share with the Commission?

5 MR KELLY: Not really. Not really, but I do feel like we do have a long way to get decision-making into the forefront of health professionals and service providers.

Yes, service providers.

MS FRASER: And, Jack, something we've heard about a few times already this morning and we're going to hear about more and more throughout the Commission is
10 the need for investment in time. But, of course, you would experience, wouldn't you, that if a doctor invests that time in the first place at initial consultations and each time they see you, the outcomes for you are much better, aren't they?

MR KELLY: Yes. Well, it makes going to the doctors a lot better and a lot less stressful, in a way, like you feel more comfortable with that specialist or GP.

15 MS FRASER: So the investment of time, it shouldn't be seen as a burden.

MR KELLY: No.

MS FRASER: It should actually be seen as a tool for improvement.

MR KELLY: Yes, it should be a positive tool rather than a negative tool.

MS FRASER: Justine and Jack, thank you so much for coming today to give your
20 evidence to the Commission. Formally, I would like to tender Justine's statement. That will be exhibit 4-2. And Justine's curriculum vitae will be exhibit 4-2.1. Commissioners, Justine will be giving further evidence to the Royal Commission later in the hearing and, as such, she will not be excused today but I would ask that Jack be excused.

25 COMMISSIONER SACKVILLE: Yes, Jack can be excused, by all means.

**EXHIBIT #4-2 STATEMENT OF JUSTINE O'NEILL DATED 11/02/2020
(STAT.0047.0001.0001)**

30 **EXHIBIT #4-2 CURRICULUM VITAE OF JUSTINE O'NEILL
(EXP.0019.0001.0001)**

MR KELLY: Thank you.

COMMISSIONER SACKVILLE: Thank you very much, Jack, for coming and sharing your experiences about your own decision-making and why it is so important for people with intellectual disability. And Justine, thank you for your contributions and your acting role as a counsel assisting the Royal Commission. Thank you very
5 much.

MS O'NEILL: My pleasure.

MR KELLY: Thanks.

COMMISSIONER SACKVILLE: Thanks.

10 **<THE WITNESSES WITHDREW** **[12.22 pm]**

MS EASTMAN: If the Commissioners please, the next witness is Ruth Oslington. Could I just ask the Commission to have a one minute adjournment so I can just check that Ruth is ready. And her evidence will be done partly with the playing of a
15 video. No one needs to leave the room but if we just have a very short adjournment.

COMMISSIONER SACKVILLE: All right. We will take a short break and you can let us know when you're ready to proceed. We will take the adjournment.

20 **ADJOURNED** **[12.23 pm]**

RESUMED **[12.25 pm]**

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: Thank you, Commissioners. You will see that I've changed my location. I wanted to introduce you to Ruth Oslington. Ruth is our next witness. And she confirms that the evidence that she will give will be true and correct to the best of her knowledge and belief and she formally makes an oath in relation to her evidence. Ruth's evidence is going to be by way of a video of a speech that she
25 made last year. We're going to show the video now and then Ruth and I will have a
30 conversation after the video, if the Commission pleases.

COMMISSIONER SACKVILLE: All right. Thank you. Okay, we can start the video, if that's ready.

VIDEO PLAYED

MS EASTMAN: Thank you, Ruth.

MS OSLINGTON: Yes.

5 MS EASTMAN: So Ruth has asked me to tell the Royal Commission that since she prepared the video and gave the speech last year, she's had a few health issues recently. And those health issues have had an impact on the way in which she can speak to the Royal Commission today. Is that right?

MS OSLINGTON: Yes.

MS EASTMAN: But she was very keen to come and share her experiences with the Royal Commission.

10 MS OSLINGTON: Yes.

MS EASTMAN: So I'm going to ask Ruth a few questions and we're going to take our time. We will go slowly and you let me know how you want to answer the questions.

MS OSLINGTON: Yes.

15 MS EASTMAN: So the first question I want to ask you is about labels and stigma. And you talked about that in your presentation. How have labels and stigma affected you in your day-to-day life?

MS OSLINGTON: Labels, stigma people make feel all the same, feel bunch problems, bunch problems together, not a person, not – labels, stigma and don't often help actually living, getting better, not – mental health most important thing.

20 MS EASTMAN: So - - -

MS OSLINGTON: Yes.

MS EASTMAN: So having the stigma can often be a barrier to getting the health services that you need and your feeling about yourself; is that right?

25 MS OSLINGTON: True. Yes, yes. Judge people by people not even know what meaning of label, yes, I think, yes.

MS EASTMAN: All right. So the next question we were going to talk about is what kinds of things help you talk to doctors, when you need to see doctors? So what kind of things help you?

30 MS OSLINGTON: Help – trust important, very important. Know have choice over life, know – doctor might help. Time, enough time understand complicated problems

and talk to me, talk to other doctors, talk family, talk support workers if try – yes, talk when needing to say, yes, me, yes.

MS EASTMAN: Okay.

MS OSLINGTON: Yes.

5 MS EASTMAN: So it's important for you that doctors listen to you?

MS OSLINGTON: Yes.

MS EASTMAN: And that you have the opportunity to tell the doctors about your health and what you want to happen.

MS OSLINGTON: Yes.

10 MS EASTMAN: The final question is a big question and that's you've got lots of ideas about what you think could be better.

MS OSLINGTON: Yes.

MS EASTMAN: Do you want to say anything about what you think could be better? So what things governments could do to make access to health better and

15 easier?

MS OSLINGTON: Pay programs helping people. Education important, people – work people, mental health, medical know – yes. I think involuntary treatment problem too much, ECT against will shouldn't – yes, yes. I think good place to live, right support to live out of hospital, people not go into hospital because need lots of support, not there.

20 MS EASTMAN: Anything else? Anything else? Anything else you'd like to tell the Commissioners today?

MS OSLINGTON: I think - - -

MS EASTMAN: You covered it?

25 MS OSLINGTON: Yes.

MS EASTMAN: You've covered it.

MS OSLINGTON: Yes.

MS EASTMAN: All right. And if there's anything that you want to send in to the Royal Commission after, you know, you're very welcome to do that too.

MS OSLINGTON: One thing, sorry.

MS EASTMAN: Okay.

MS OSLINGTON: The medical mental health disability service, different professionals need to talk, work together, not – yes, communicate.

5 MS EASTMAN: Communication.

MS OSLINGTON: Yes, yes, yes.

MS EASTMAN: Commissioners, we're very grateful for Ruth's attendance today and I know that she was very keen to participate. And notwithstanding her recent health issues, I hope that her evidence has comprehensively dealt with some of the experiences and challenges that she's confronted as a young woman today. So Ruth, thank you very much for your evidence. Commissioners, if you need to formally mark the exhibit, a copy of the video is found in part A, tab 3. And if that could be marked exhibit 4-3.

10

15 **EXHIBIT #4-3 PRESENTATION BY RUTH OSLINGTON DATED 11/11/2019 (IND.0017.0001.0001)**

COMMISSIONER SACKVILLE: Thank you very much.

MS OSLINGTON: Thank you.

20 COMMISSIONER SACKVILLE: Ruth, thank you very much for letting us see that video.

MS OSLINGTON: Yes.

COMMISSIONER SACKVILLE: And thank you also for coming and talking to Ms Eastman and talking to us. We really do appreciate it very much indeed.

25 MS OSLINGTON: Thank you. Yes.

COMMISSIONER SACKVILLE: Thank you.

MS EASTMAN: Commissioners, if that's a convenient time. It's a little bit earlier than the expected luncheon adjournment but that may be a convenient time.

COMMISSIONER SACKVILLE: How long should we take, Ms Eastman?

30 MS EASTMAN: I'm in your hands, Chair.

COMMISSIONER SACKVILLE: This is within your sphere of speciality.

MS EASTMAN: It may not be, but I think an hour is what was - - -

COMMISSIONER SACKVILLE: Well, it's now 10 to 1. We shall resume at 2 o'clock.

5 MS EASTMAN: Thank you.

COMMISSIONER SACKVILLE: Okay. Thank you very much.

ADJOURNED

[12.46 pm]

10 **RESUMED**

[2.00 pm]

COMMISSIONER SACKVILLE: Yes, Ms Wright.

MS WRIGHT: Commissioners, the next witness is Dr Rebecca Kelly.

15 COMMISSIONER SACKVILLE: Please come forward. Thank you. Please do sit down. I will ask you to take the oath or affirmation as the case may be. Thank you.

<REBECCA ANNE KELLY, AFFIRMED

[2.01 pm]

<EXAMINATION BY MS WRIGHT

20

COMMISSIONER SACKVILLE: Thank you very much.

DR KELLY: Thank you.

COMMISSIONER SACKVILLE: Ms Wright will now ask you some questions.

MS WRIGHT: Thank you. Would you please state your full name.

25 DR KELLY: Rebecca Anne Kelly.

MS WRIGHT: And, Rebecca, are you the mother of three children?

DR KELLY: I am.

MS WRIGHT: And does that include your son Ryan?

DR KELLY: Yes, it does.
MS WRIGHT: How old is Ryan?
DR KELLY: He's eight.
MS WRIGHT: And in what grade is Ryan at school?
5 DR KELLY: He's just started grade 2.
MS WRIGHT: Okay. And I think we have some photos of Ryan - - -
DR KELLY: I think you do.
MS WRIGHT: - - - that we can show.
DR KELLY: Yes. He's particularly cute. I just want you to notice that. I do make
10 gorgeous children.
MS WRIGHT: I think they're showing on the screen down here.
DR KELLY: Yes. I can see it on here.
MS WRIGHT: Yes. And how would you describe Ryan as a boy?
DR KELLY: Ryan is an all-round delightful human being. He's – he's got a great
15 sense of humour. He's very affectionate, he's incredibly cheeky. Yes. He's just a
really rough and tumble little boy. He loves his bike, he loves big stuff, but, you
know, he's all about living. He loves Shaun the Sheep with a passion that's hard to
describe. He has a toy baby that he takes everywhere, including to school every day.
So, you know, he's a – a delightful person, I think.
20 MS WRIGHT: Rebecca, do you have a PhD from the Australian National
University?
DR KELLY: Yes, I do.
MS WRIGHT: And are you an environmental scientist?
DR KELLY: Yes, I am.
25 MS WRIGHT: Did you work as an academic for many years?
DR KELLY: I did, yes. I was a fellow at the Australian National University.
MS WRIGHT: And you now run your own consultancy company?

DR KELLY: Yes, I do.
MS WRIGHT: Are you also currently the Chair of Down Syndrome Tasmania?
DR KELLY: I am.
MS WRIGHT: Is that since 2013?
5 DR KELLY: I've been on the board since 2013. I've been in the chair's position for – this is my third year now.
MS WRIGHT: Okay. And were you previously the director of a disability service provider
DR KELLY: Yes, I was on the board.
10 MS WRIGHT: Do you live in Launceston, Tasmania?
DR KELLY: I do.
MS WRIGHT: And have you provided a statement to the Commission dated the 9th of February 2020?
DR KELLY: Yes, I have.
15 MS WRIGHT: And there has been a development since you made your statement which you wish to inform the Commission about. And we'll come to that.
DR KELLY: Yes.
MS WRIGHT: Are the contents of your statement true and correct?
DR KELLY: Yes, they are.
20 MS WRIGHT: Commissioners, Dr Kelly's statement is found at tab 4 of tender bundle A. And, Rebecca, you've also provided to the Commission a number of documents in support of your statement.
DR KELLY: Yes, I have.
MS WRIGHT: And those are at tabs 5 to 15. Now, in your statement, Rebecca, you
25 describe Ryan as very medically complex.
DR KELLY: Yes, he is.
MS WRIGHT: And can you briefly explain that. He's required over his eight years specialist medical care - - -

DR KELLY: Yes. So - - -

MS WRIGHT: - - - in a number of areas.

DR KELLY: So Ryan has a cleft palate. He has – and that’s required two surgeries to repair that palate. He has a repaired defect in his heart. So he had three holes in
5 his heart when he was born. He had leukaemia when he was one. So he went through seven months of treatment for leukaemia. He had – he has issues with his eyes and required surgery to straighten his eyes and to move his mole spot for nystagmus. He’s had a bunch of other sort of surgeries along the way. He’s got very chronic issues with his ears, which I will no doubt talk a lot about today, but he’s had
10 persistence with fluid behind his ears for a long time and recurrent infections that are now causing us greater grief going forward.

He went very suddenly deaf in one ear two years ago and has developed a mixed loss in his other ear. So we’re looking at cochlear implants at the moment as a way forward. What else does he have? And he was diagnosed with complex trauma and
15 takes medication for anxiety as a result of that. And that’s kind of – some of the things we deal with are consequences of other things that we’ve done. So - - -

MS WRIGHT: And does he live with Down syndrome?

DR KELLY: Yes. So he has Down syndrome.

MS WRIGHT: Okay. And about how many surgeries – about how many surgeries
20 has he had in his eight years?

DR KELLY: Do you know, I’ve actually lost count of the number. We definitely had two or three surgeries a year for the first five years. I can’t tell you how many general anaesthetics. I’ve probably blocked a lot of them out, but it would be 50 plus
25 times that he’s gone to theatre for various sorts of procedures. He had a lot of admissions in the early days for things like pneumonia and croup and still is very vulnerable to those acute interactions with the health care systems where things go wrong very quickly. So, yes, that’s kind of the chronic ongoing things and then there’s the acute things that happen.

MS WRIGHT: So complex care needs across multiple medical specialties?

DR KELLY: Definitely, yes.
30

MS WRIGHT: Yes. And you’ve described in your statement a number of challenges that Ryan and you have experienced in navigating the health system.

DR KELLY: Yes, definitely.

MS WRIGHT: Most recently, you’ve had difficulties arranging important surgery.

DR KELLY: Yes.

MS WRIGHT: Is that for Ryan's ear.

DR KELLY: Yes. So that's – there's chronic issues that we've had with Ryan's ear and a very long-running difficulty with trying to get adequate care and proper
5 diagnosis, and a very long-running situation that's sort of blown out and been very difficult to get surgery. So we – we do now have a surgical date, which is good, but it sort of started over 12 months ago, the process of getting to that point. So - - -

MS WRIGHT: Okay. So the ear infection has been a regular feature of Ryan's life.

DR KELLY: Yes.

10 MS WRIGHT: And surgery was recommended in about March of last year; is that the case?

DR KELLY: Yes. So about March of last year we went in for a procedure to have a look and see – really, to start to plan for a cochlear implant on his left and see
15 whether he would be a candidate. When they were in there they found that the constant retraction in ear infections on his eardrum had caused what you call a cholesteatoma. So at the very early stages of this it's almost like a cyst that develops behind your eardrum. And as it grows it takes out all the things that it touches, so it's very damaging. And it can be life threatening if it sits there long enough, because it grows into the brain eventually if you leave it there.

20 So when we had that procedure in March last year, I was told that it was very urgent. They cleaned up what they could find, but it was very urgent at that point that we have surgery and that they would get back to me in a couple of weeks with a plan. That didn't happen. And I spend a lot of time – it's in the notes – about the various interactions. And it turns out that we were lost in the system. And eventually I made
25 my way back in and was told that no, that was wrong; we didn't need surgery at that point.

A whole pile of other things happen in the meantime. There's a very long, very detailed account of all the steps, but, essentially, we went back in for another look and see in October and were told that what I had been warned would happen without
30 the surgery had, as far as I could tell, happened. So he had a large polyp that was blocking their look to his eardrum. He had a very persistent infection there and they felt that this cholesteatoma had formed and caused damage. They said we would need to operate urgently again. The conversation was that he would need a mastoidectomy and clean this up, so that it didn't cause more damage to his own
35 hearing, because this is his good ear.

We had the CT scan to plan for that. I asked – I got back – because we had had so many troubles, I got back to them two days later and said, "What's the plan?" and got a phone call from a resident, so the most junior doctor, saying, "The consultant's

looked at it and she doesn't think it's that bad and she will get back to you." And then she never did. And he in the meantime got very significant infections and ended up hospitalised twice with sort of the side effects of all the things we were doing to treat the constant infection and the pain. He had taken Nurofen for many months and ended up vomiting blood right before Christmas.

5 He had four weeks of antibiotics and got a really severe oral thrush infection. So we sort of had this ongoing thing. We got to January and I managed after throwing – I was, obviously, not happy after that and got back into Melbourne and had a plan for surgery, which, again, didn't go anywhere, but, fortunately, the chief of surgery has now intervened and organised an operating slot for him in March. So it's – it's been needed for a long time, but it's a very complex sort of winding story as to how we got there.

10 MS WRIGHT: One of the difficulties you've spoken of is that you're based in Tasmania, his specialist care is in Melbourne, and you've had to go back and forth between places.

15 DR KELLY: Yes. I think our system – our health system is very fractured. And as soon as you move away from those major centres and the tertiary operation – like, the tertiary hospitals, the link between our local hospital and that tertiary centre is not good and the communication is very poor. And the way of being able to escalate – there's no way as an outpatient that I could escalate that situation and get us back into the system easily. So, yes, that's been a big challenge.

20 MS WRIGHT: And one of the issues you raised in your statement to the Commission and also in a complaint which you made to the hospital concerns the importance of information sharing - - -

25 DR KELLY: Yes.

MS WRIGHT: - - - between doctors and other health professionals.

DR KELLY: Definitely.

MS WRIGHT: And is that particularly important for a patient with complex care needs such as Ryan, in your experience?

30 DR KELLY: Yes. I think it's very important. So Ryan's got six or seven different specialist clinics that we're operating across. And those are, obviously – he's got very complex needs in most of those clinics. And often there's no letters, there's no information that passes in an official way between those – those doctors. And I am the conduit of that information. Often, what I'm relaying is the verbal conversation I had at the end of the procedure. So that procedure we had in March there was no record of any of that conversation. And I was even told in the end it wasn't in the notes that were written that day, and so I spent many months, you know, "What's

going on with Ryan?” “Well, I’ll tell his paediatrician what I was heard and what I was told.”

I tell the emergency doctor what I was told. But there was nothing for me to actually hand over and say, “Well, this is what’s going on with Ryan. This is the current
5 situation with his ears. This is what we should do if he gets an infection.” You know, there was no care plan there for him and no basic information to hand to any of the doctors that we interacted with. And there were a lot of them over those months in between.

MS WRIGHT: So Ryan, he had an audiologist.

10 DR KELLY: Yes.

MS WRIGHT: He has a GP.

DR KELLY: Yes. So Ryan has an audiologist, a GP, a paediatrician, an ophthalmologist, an ENT, an oncologist, a cardiologist. He has plastic teams, he has a speech therapist, OT. And then we have schools. So we have all of these different
15 people that are providing care or providing education to Ryan and the need for them to communicate with each other. And then we have acute admissions. So we still front up at emergency. So we have a whole rolling procession of doctors that we don’t know and don’t know us that we have to communicate to.

COMMISSIONER SACKVILLE: Are they – the ones you’ve mentioned, are they
20 in Tasmania or Victoria or both?

DR KELLY: A bit of both. So we have – our paediatrician’s local, our GP is local, audiology is local. The main specialist around cardiology and things like that, they’re over in Melbourne. And then we’re – we’re kind of frequent flyers through emergencies. We like to try out every state’s health system when we go on holidays.
25 We have a tendency to front up at emergency in every state. So, you know, we access the health system Australia-wide sometimes, whenever we go places. We might use your New South Wales system last year, too.

MS WRIGHT: And you give an example at paragraph 65 of just that. When you were on holiday in New South Wales, Ryan had to be hospitalised.

30 DR KELLY: Yes.

MS WRIGHT: You attended at an emergency department at New South Wales.

DR KELLY: Yes.

MS WRIGHT: But you and the treating health carers, doctors and nurses - - -

DR KELLY: Yes.

MS WRIGHT: - - - experienced some difficulties, because you didn't have any overarching care plan or records to give them.

5 DR KELLY: Yes. So he – we ended up on a holiday, taking an ambulance to the local emergency department where we were and three weeks earlier I had been told he had mastoiditis and he urgently required surgery, but I had no documentation of that and I had to recount that to multiple – so I had to tell the ambulance officers and the emergency doctors and the consultants on the ward and everyone was, “Well, what was the plan? Should he be on antibiotics?” We didn't know if part of the infection was because of that. His paediatrician only knew what I had told him. So
10 the paediatrician at that hospital we were at actually was quite good friends with our paediatrician. So they were talking but he didn't know anything that I didn't know. So he didn't have any formal information about what had happened in that procedure to pass over to that hospital in New South Wales to inform his care there.

MS WRIGHT: One of the issues you speak about in your statement is your role in
15 facilitating communication among Ryan's - - -

DR KELLY: Yes - - -

MS WRIGHT: - - - various health carers. Now, what do you mean by that? You've described in your statement - - -

DR KELLY: Yes.

20 MS WRIGHT: - - - a number of times when you have had problems accessing Ryan's test results - - -

DR KELLY: Yes.

MS WRIGHT: - - - images, reports, other medical records. How would you describe the amount of time that you've spent following up on those sorts of things
25 and attempting to obtain access.

DR KELLY: Enormous. Absolutely enormous. I've spent weeks and weeks and weeks of last year particularly, but this is a – it's almost like a job in its own right, the job of managing the records and the information. It's very – if we go to – when I had my youngest daughter, I had to send – I was still breastfeeding. I sent Ryan to
30 emergency with his father and I sent four pages of notes along with him and I had phone calls because he's that complex. There's so much going on with him. And most of it – the only sort of record of most of it is in my head because it's not in all these notes and there's no simple easy place to find all of these things. And it changes all the time too, because obviously things are changing, every appointment
35 we go to, things change.

And so the role of – my role is really to constantly have all of that in my head, to be able to see the linkages, to do enough research that I can ask the right question when

I get to the next appointment and that's really fundamentally important. I often walk away from an appointment, go and start asking and finding things and know that I should have asked something else. And so they're often not bringing information to me as a parent. I'm bringing them ideas and questions, which then create the next

5 care plan moving forward. So that role that I play around facilitating communication between medical professionals, but also bringing research in to that care, that caring situation, and having to constantly be sort of hypervigilant, doing research, pulling it in, making sure everyone knows what's going on, it's a really large role and it's one that tends to be played, I think, by mothers more than anyone in the health system.

10 MS WRIGHT: Did you even at one point have to make a freedom of information request - - -

DR KELLY: Yes.

MS WRIGHT: - - - to obtain access to some of Ryan's medical records.

DR KELLY: Yes. So I've had a lot of difficulties, particularly in the last 12

15 months. Because I wasn't getting information, I started to request records. And that means I wanted operation notes. And things are often – some of the specialties will actually give me operation notes, that's no problem, or they will put them up on the portal system, for example, from The Royal Children's. But others when I asked, it was like, "No, you're just a parent. We don't give those to parents. That's policy".

20 You know, that idea that I wouldn't be able to understand or shouldn't have access to that detailed information, which when I got – when I got it was actually fundamental. There were things buried in those notes that I needed to know because no one else had been told them and they were vital in terms of his ongoing care to have that information. So – and yes, we've had to do freedom of information requests to get

25 some of that information.

MS WRIGHT: What do you think medical professionals and the health system generally can do to facilitate your role in communicating between his team of medical - - -

DR KELLY: Yes.

30 MS WRIGHT: - - - and health carers?

DR KELLY: I think – for one thing, the notes are often full of errors, if there are notes at all. I feel like out of all of those appointments, after those procedures, we should have walked away with a half-pager saying, "We saw Ryan today. These are the things that we saw. This is his current situation. If he gets an infection, this is

35 the first line of treatment. And here's a phone number for you to contact if you need to if" – you know, so if we fronted up at emergency, someone should have – there should have been a number there for them to call back, so that they could actually get more information. So that information there that any parent can take – and you don't need high levels of literacy to take that to emergency with you and hand it over to the

doctor – that’s missing. That doesn’t happen in the health system and it should happen. So that’s part of it.

I think the issues with notes – notes are full of errors. Whenever I do get access to notes, they’re full of mistakes and errors that are actually really important. And
5 having full access to those but also having a right of reply on them, so that I can actually read them and say, “No, that was actually his left ear that was infected and not his right”, because that matters going forward or, you know, “No, that’s not my recollection”. And at least note that down, so that moving forward we don’t have this error-filled record of his history. That is what doctors are going to rely on going
10 forward.

MS WRIGHT: Now, Rebecca, another matter you raise is that you feel you should be included in discussions about Ryan’s care. And you’ve made some observations about that. Just focusing on Ryan, there have been times – and you’ve given some evidence in your statement – where your observations of him as a parent, you feel,
15 have not been taken on board.

DR KELLY: Yes, definitely.

MS WRIGHT: Now, there’s an example I think you wish to tell the Commission about - - -

DR KELLY: Yes.

MS WRIGHT: - - - that occurred at Christmas when you’ve had to attend an emergency department.

DR KELLY: Yes.

MS WRIGHT: And you made your views about Ryan’s admission known to the staff and you felt they weren’t listened to and Ryan’s health did subsequently
25 deteriorate.

DR KELLY: Yes, definitely. So as I mentioned, he got admitted with a very severe oral thrush infection over the Christmas period. We presented the first time on Christmas night. So it took a few days. He sort of stopped drinking and stopped eating. It’s very difficult sometimes for me to figure out what’s going on. And it
30 takes me a couple of days to sort of go why. And then I looked in his mouth and it was white. And I went, “He’s got thrush”. So I kind of went, “I know what the problem is now”. And I went to emergency. And don’t go to emergency on a public holiday is probably the first lesson of the medical system but I went to emergency. And the first doctor that we hit was, “Yes, that’s oral thrush. Here’s a topical
35 treatment. Go home”.

And I stood there and I went, actually, he hasn’t eaten or drunk much for two or three days. You know, he has probably had a couple of hundred mls. I am concerned

about dehydration. He has had severe pain. I can't get him to drink. I can't give him Nurofen because he was vomiting blood last week. So you know, my pain options were limited. And so I said to her, I said, "I'm not comfortable going without a paediatric review. And she said, "They're not going to tell you anything I told you". And I went, "No, I'm not going without a paediatric review". And the paediatric registrar came down and she was good and she sent us home with lignocaine.

And then the next day we came back because he was still not drinking. And I was concerned that it wasn't just his mouth and that a topical treatment wasn't going to be enough because it wasn't the first day of the infection. We're on day 4, maybe. You know, it was already really well advanced by the time we present there. And then when we got there he was very ill and he was very dehydrated. And I said to him, his peripheral access is always really hard. It's hard to get a vein on him at the best of times and he's dehydrated and it's going to get harder and harder the longer that we wait here.

And they got us around the back quickly but they left us for two hours then without attempting to get an IV in. While he was lying there he was de-saturating, but in a way that nurses don't tend to pick up. So my observation of nurses is – so when he desaturates, he sort of – 98 per cent he looks good, then he gradually drifts down and he kind of gets to 94, 95, and then he kind of stirs himself up and his heart rate goes up and he gets himself back up again and then he drifts down. And the tendency of most nurses is to stand there and wait until the number goes up and then write the top number down. I don't know, there's some temptation to get the best score rather than the lowest score. And I kept pointing out to her, I said, "Look he's crashing. See how he's doing that, that's a sign that he's crashing and he's going to crash hard soon." Every time I said it she sort of – a bit dismissive.

And I said, "You really need to get someone here to do an IV". And eventually a doctor came and he had two goes at it and he couldn't get one in. And then said, "I will go get the ultrasound", and then disappeared. And disappeared for 40 minutes. And to the point I ended up calling the nurse back and said, "Well, can you just go and get the paediatrics? Like, this isn't going to get any easier". By this stage he was really sick. His ketones were 4-3. He was crashing really badly and he was very sick. And eventually they sort of said, "We've spoken to the paediatrician and they usually just put a nasogastric tube in". But even then, they hadn't done that. No one had made any effort to get fluids into this child.

And eventually we – the paediatrics came and took us up to the ward. And it was only a registrar because it's a public holiday. And it took him four shots with the ultrasound. He couldn't even see a vein on the ultrasound by the time he went to do that. That meant it was really, really traumatic. So we had a child that probably the night before could have been given fluids and it would have been okay. By the time we were there, he was really, really sick.

When I said to the paediatric registrar – he came down and I said, “Look, he’s been crashing”. The nurse said, “No, his saturations are fine, he was just moving and the trace was bad”. And I said, “No, the trace was excellent”. I’ve spent a year of my life watching this child in hospital. I know what a good trace looks like. You know,
5 that devaluation of my knowledge of what he looks like when he’s crashing, you know, it was that situation that we could have avoided that turning into. And in the end, he needed a systemic fungicide, so – and that’s what fixed it because it was everywhere, it wasn’t just topical. But that took several days to get to that point of properly diagnosing it and properly treating him.

10 MS WRIGHT: And you’ve said in your statement at 17 that Ryan’s care has been good when health carers have treated him as an equal to other children - - -
DR KELLY: Yes.
MS WRIGHT: - - - in their care, not as Ryan with Down syndrome.
DR KELLY: Definitely.

15 MS WRIGHT: What are the things they can do to treat him as an equal? And then I will ask you to read part of your statement.
DR KELLY: Yes.
MS WRIGHT: Someone will provide it to you.
DR KELLY: Someone will provide that to me. Yes. Look, I mean the first thing is
20 that they treat him like a child. And I always have that sense when someone comes in, you know, when they start to use the label “the Down syndrome child”, you go, okay, we’re going to have a problem here because you’re seeing the label and not the child. The doctors that we’ve got who are great – and we do have some really great doctors – are the ones that – they love Ryan. They see Ryan as a really unique
25 individual. And it’s really clear that they value him and they think he’s worth everything that their other patients are worth. And those doctors are great and they give him the best quality care. They also tend to listen to me. So they know that he can be harder to read. And if I say he’s in pain, well, he’s in pain. You know, if I translate for them what I see his behaviour as meaning, they listen to that. So those
30 sorts of doctors are brilliant. And we’ve got a great GP and we’ve got a great paediatrician and some of our specialists are brilliant. And when that’s like that, the care works really well. And they’re very experienced and that helps as well.
MS WRIGHT: All right. Do you have your statement - - -
DR KELLY: I do now.

35 MS WRIGHT: - - - there, Rebecca? And if – could I ask you to start at paragraph 156. And read your statement until paragraph 181.

DR KELLY: I can. So I wrote about trauma and impacts of trauma. So:

5 *I have deep regrets about my own failure to advocate effectively for Ryan in terms of minimising the effects of trauma associated with medical procedures on his life. What I know now that I did not know in the beginning is that people with intellectual disability are likely to develop more trauma from the same experience and that even newborns can experience lifelong impacts from traumatic experiences. This is knowledge I've gained through experience of parenting a medically complex child with an intellectual disability and my own research.*

10 MS WRIGHT: Rebecca, sorry, if I could just pause you there, you're quite a fast speaker.

DR KELLY: Sorry, I thought I was doing really well and being slow.

MS WRIGHT: If you could try and slow down somewhat.

DR KELLY: I will slow down.

15 MS WRIGHT: Thanks.

DR KELLY:

20 *Ryan has had painful and invasive procedures since he was a newborn. Some of the earliest traumatic memories I have are of when he was a newborn and a registrar attempted four separate times to get a vein, twisting the needle trying to get access. During this procedure I could see the pain on Ryan's face and knew he was distressed but his low tone meant that screaming and crying were hard for him. It was incredibly hard to watch my newborn baby be put through that pain. I recall that partway through the procedure the registrar said out loud the words to the effect of, "Look, it's not even hurting him." It was my first experience of someone assuming that Ryan was less than human and that his reactions to pain and discomfort were less than those of a typical child. Over the following years, Ryan had lots of procedures, usually with little pain relief and never with any type of pre-med that would mean he wouldn't remember the procedure. Even now that I'm aware of the need for this, I often struggle to get this request taken seriously.*

30 *During one of Ryan's procedures in 2018 I recall asking for a pre-med three times prior to a procedure and each time was reassured that it would be given when we got to theatre. When we got to theatre, the anaesthetist said no one had told her, it wasn't in Ryan's medical notes and she was not aware that*
35 *Ryan was not a 'typical boy'. Instead of stopping and slowing down to discuss his anaesthetic risks and allow time for a pre-med to be administered, she moved quickly to push Ryan through the process. When he woke he was*

extremely upset and withdrawn. He experienced a significant escalation in his anxiety and regression in his behaviour over a whole term at school as a result.

5 *When Ryan was little, he was always a friendly, chatty baby and toddler. He loved interacting with everyone and would chat away. He also used Auslan signs to express himself as he spoke. He was a friendly, outgoing little boy. Sometime around Ryan's sixth birthday, I noticed he gradually started to withdraw into himself. Over a period of months he stopped talking and signing and gradually became angry and disengaged. He also struggled to sleep,*
10 *waking frequently during the night. Ryan's lack of eye contact and interaction had some of the therapists and educators around him flagging an autism diagnosis.*

I took Ryan to see a clinical psychologist who specialises in autism and explained that my gut feeling was that Ryan was traumatised and anxious, rather than autistic. After observing him, she agreed and said that complex trauma as a result of the many invasive medical procedures he has experienced was the most likely cause. Ryan has less control over situations and less capacity to demand procedures are done in a way he prefers, as well as less ability to clearly communicate his distress and debrief after a bad experience.
20 *Ryan does not communicate pain and distress in the same ways as other children, which can be misinterpreted as him not experiencing pain. Ryan is now scared of friendly people, no doubt because most of the people he met in his early life were paediatric nurses and doctors, who are always lovely and friendly and usually went to do something painful and intrusive shortly after they met him. After seeking help from the psychologist, we began changing the way we interacted with Ryan at home, at school and in therapy sessions, implementing trauma-informed practices in all settings.*

Over the course of months, Ryan gradually began talking again and interacting with people, though not to the same level as he had when he was younger. Trauma is an ongoing issue and something I'm now much more mindful to minimise and manage. I asked for Ryan to be given a pre-med before procedures which I know will be traumatic. We minimise unnecessary investigations or observations and, where possible, we respect the boundaries he sets and his bodily autonomy. Major investigations are left until he is under anaesthetic and after a pre-med to minimise his memories of these procedures.
35 *All these things have made a huge difference to him. Regardless, trauma has had a significant and ongoing impact on his life, both in terms of his enjoyment in life and his development.*

The impacts on me and my family. As for myself, I am frustrated and exhausted by the fight for care for my son and have lost my trust that the system will put my son's needs first. Over the battle that has been the last year, I have had periods of total despair and powerlessness and in many ways lost much of

myself through this process. Any time I have for self-care is now sunk into chasing care and I spend much of my time worrying about Ryan. Ryan wakes multiple times every night, meaning I never get a good night sleep, which makes both parenting and running a business challenging most days.

5 *The level of vigilance required at every step has put an enormous burden of stress on me and my family and has put Ryan's health and development in danger. The time put into emails and phone calls to push things along is a job in itself. To have to go through this is just extraordinary. It is frustrating, exhausting and terrifying that every single step in Ryan's care appears to*
10 *depend on me ringing and emailing constantly to ensure that the next step is taken.*

I am well aware of the level of privilege that I have in navigating the complexities of the health system. I am well educated, I am organised and articulate and have excellent advocacy skills and I still find this task incredibly
15 *difficult. What on earth happens to the child whose parents who do not have the education, who are intellectually disabled themselves, who place their full trust into the medical practitioners or for whom English is not a first or even a second language?*

My ability to work and my business have both been impacted and I estimate
20 *we're at least \$15,000 out of pocket in terms of lost income, with additional costs associated with Ryan's care, as most of the things like antibiotics we use are not on the PBS and hospital days are always expensive.*

My daughters are both stressed and anxious. My eldest was incredibly fearful that her brother would be admitted to hospital in the lead-up to Christmas and that our family Christmas would be lost to another hospital admission. I was
25 *too exhausted by all the stress of waiting for surgical dates to organise her a birthday party in November. My youngest is now clingy and cries when I leave the room. When I said I had to take her brother to emergency on Christmas night, she became hysterical, crying and begged me not to go. It is hard for her*
30 *to understand that we don't always get to choose. She is becoming increasingly anxious as time goes on.*

And my suggestions for change. In terms of acute care and appropriate triaging of children with intellectual disabilities, I believe there are significant
35 *gaps in knowledge for most medical professionals in assessing acute care for people with intellectual disabilities and significant communication challenges. These people will almost always present with much more advanced and complex situations than would be the case for other patients. Appropriate triaging of a child with an intellectual disability and communication challenges*
means assuming the worst, rather than hoping for the best.

40 *Care needs to be more proactive and medical practitioners need to understand that issues will be more advanced and that they can escalate very quickly, due*

5 *to the delays and diagnosis caused by communication issues. They need to understand that for these children pain is communicated differently and signs of pain may not be as clear as in other children. It is important to listen to parents and carers about their observations; they're an essential and informed source of knowledge and experts in their children's care. Wait and see is not the right approach, as that phase has already happened usually days earlier. Requirement for consistent and quality care. The public health outpatient system involves a revolving door of junior doctors seeing even very complex patients in clinic appointments. It is rare for a patient to see the same doctor at two consecutive appointments, meaning they have to go back over the full history and, essentially, start again with each new doctor, who is often too junior to have in depth knowledge or to feel confident in making a strong plan for managing the patient's medical condition.*

10 *Notes are very poor and full of errors, so these doctors largely rely on the verbal accounts from parents and carers at each appointment, but often disregard their recollections in favour of what's written in those notes. This results in no comprehensive care plan, inconsistent advice and information and poor implementation of proposed actions. It also encourages a system of wait and see and pushing difficult decisions on to the next clinic, so that they're the problem of the next doctor, rather than the current doctor.*

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MS WRIGHT: Rebecca, could I just stop you there.

DR KELLY: Yes.

MS WRIGHT: You were involved in a program at the University of Tasmania in which you speak to some undergraduate – medical undergraduate students.

25 DR KELLY: Yes. So I'm a volunteer with the patient partner program at the University of Tasmania in Launceston. It's a really wonderful program where they bring people with lived experience of various illnesses or disabilities or carers in to talk to fourth year medical students. And I've done that for, I think, seven years now, so - - -

30 MS WRIGHT: And you talk about your experience having a child with disability?

DR KELLY: Yes. It's – I talk about the experience of parenting Ryan. I think one of the things I try and do is make sure I put front and centre his humanity first. And so a lot of them have never met a child with an intellectual disability. So it sounds bizarre, but some of the most powerful moments, I think, are the things I share about him as a child, rather than as a patient, and allowing them to see him as a child first. But then I talk about the system and the issues with the system and their role in that and how they can help.

35

I talk about how to deliver a pre or a postnatal diagnosis and the words they should use are, about the importance of, I guess, understanding that child is communicating and that they are – whether they’re talking to you or not, they are understanding things that are going on in that room and they are communicating to you. Ryan’s a really powerful communicator. He doesn’t use a lot of words, but if you’re willing to stop and look and listen to what his body is telling you, he’s a very powerful communicator. And those sorts of lessons for doctors, young medical students, are really important, I think.

MS WRIGHT: You say in your statement at page – at paragraph 207 that life with an intellectual disability is often seen as a life better avoided, through screening and pregnancy termination, rather than a life of value, meaning and purpose.

DR KELLY: Yes.

MS WRIGHT: You had a positive experience - - -

DR KELLY: I did.

MS WRIGHT: - - - with the birth of Ryan. I wonder if you could share that briefly with the Commission.

DR KELLY: Yes. So Ryan had a postnatal diagnosis of everything. I made a very active decision not to have screening. I had thought about it and decided that I would accept and love and embrace the children that I had, and whatever form they came in. And that was good to have made that active decision and then end up with that child. Quite fortunately on that day, we had a wonderful obstetrician, who has seen me through three pregnancies. And, just by luck, our current paediatrician was the one that was there present in the room that day. And that set me up very well, because both of those professionals advocated very heavily for Ryan to room in with me right from the beginning.

So all those basic things that mothers and babies need to bond in those early days, they were both strong advocates for that. They made it clear that they understood that this would be challenging news, but they never painted it as bad news. They weren’t, you know, that sort of, “I’m really sorry.” That didn’t happen. We had – it was really clear right from the beginning they thought he was beautiful and that there was congratulations there. And that they understood we had a lot of things to get our head around, but – and that they were there to support us through that, and they would sit and talk with me and give me those quiet moments, but also not be overly negative. They weren’t negative in that experience; they were empathetic.

Yes. There was a lot of really good moments there when I look back and I reflect on that experience. And it’s a really – most parents can remember how they heard the news and what words were given. And it’s really powerful to hear, “Congratulations, your baby’s beautiful” instead of, “I’m really sorry. Your baby has Down syndrome.” They lead you off on two very different parenting paths,

those two sets of phrases. And I was very fortunate that I had the right people there with me that actually gave me us positive experience.

MS WRIGHT: That was a positive experience. And you say in your statement you've since Ryan's birth had some negative - - -

5 DR KELLY: Yes.

MS WRIGHT: - - - experiences involving doctors and nurses saying things to you such as, "Didn't you have the test?"

DR KELLY: Yes.

MS WRIGHT: You speak about a medical model of disability - - -

10 DR KELLY: Yes.

MS WRIGHT: - - - and ableism in your statements. Could you expand on what you mean by that?

DR KELLY: So, I guess, coming – so, obviously, the medical model of disability is the model that says that this is something to be cured. It's that someone with a disability is in some way broken and that we need to come in and fix them to make them as "normal" as possible. And I think that that underpins still most medical training. So this concept that you're starting with a broken child and that the – the effort is to in some way cure them. And I think when you bring that into that medical setting, doctors are all about curing stuff, and – and at the end of the day if you can't cure it under that model, then you eradicate it under that model.

15 And it sets up a really bad dynamic about how you consider that person and their value and their life. And if you see that, particularly Down syndrome – and we see this a lot, because we're at the front line of being able to detect these things before birth – if you think that that person's life is a tragedy and that they "suffer" from this condition, then you start to believe that it's an act of kindness or, you know, that it's a responsible act to do all you can to prevent that birth. And that becomes quite coercive. And I see this with women all the time. We support a lot of women. And I help support them through various support groups where their autonomy in that decision is taken away, because that medical model really sits there. It's there right from the beginning.

20 And then you see it go through life, where when you're facing that need for care, if you have a doctor that thinks that possibly your life is going to be a little bit better if your child doesn't make it because they're taking that burden away from you, that has horrible implications for the level of care that you're going to get. That child isn't going to be valued in the same way that another child who isn't seen under that medical model to be some sort of burden. It just sets up such a terrible way of viewing that child's life and that child's value. And it affects all the care that they

get going forward. And often I don't think many people when they hold that belief deep down, if you questioned on it, they probably wouldn't admit it, it's such an unconscious bias but it's right there and it's central to medical training, I think, but it needs to change because it's very dangerous.

5 MS WRIGHT: So you're a strong advocate for improved training - - -

DR KELLY: Yes.

MS WRIGHT: - - - for medical and health professionals about intellectual disability and disability more broadly, as well as systemic change within the system for things such as – you've mentioned at paragraph 215 of your statement, such as longer

10 appointments - - -

DR KELLY: Yes.

MS WRIGHT: - - - the need to focus more on the child, communication methods that the child uses, listening to parents and carers, to interpret what the person with intellectual disability is trying to say.

15 DR KELLY: Yes, definitely.

MS WRIGHT: And given your experience with Ryan's health care, what would you like to see come out of the Royal Commission?

DR KELLY: A lot. You guys have got a big job ahead of you. I would like to see fundamental change in the way that medical schools work in terms of training

20 doctors. Firstly, we've got to break this idea that age or disability devalues you as a human. And that's a really big first task. So until you break that concept very early on, you're always going to run into issues. So we need to change training so that we make sure that people are exposed to all these parts of life and actually realise that

we want Ryan. We love Ryan. We want him to have a really full life and they're not doing us a favour by not treating him.

25 Then obviously there's specific knowledge that they need to have around the medical conditions he can have, they need to understand pain, they need to understand trauma and the prevention of trauma in children. So there's lots of very technical things that they need to do. They need to follow their own guidelines. So there are good

30 guidelines already in existence for most of the things that I'm talking about, but they're not implemented. So the IV access is a good example. I went and found the guidelines the other day and realised they've almost never been followed for him in emergency. So it's not the system's not there, it's just not enacted. So all of those things need to come together and be done and they need to be aware of them.

35 There needs to be better transparency and accountability. The system needs to be accountable for the care that it provides to people. And I think the complaint that I put in last year really showed me, very vividly, the total lack of accountability. You

know, I wrote a 10 page complaint to a hospital and nothing happened. Nothing happened and his care didn't get any better. And I didn't get a response. And then I escalated that and still nothing happened. And then I escalated it again and nothing happened. And then I got the Health Complaints Commissioner in and I got a phone call.

5 And you know, when we got there, that 10 pages, there were systemic issues in there they need to address, but at the end of the day the urgent bit was give my son good care tomorrow. They could have done that the next day. That didn't take four months to get there. And so that lack of accountability is huge, and there's no – I'm
10 kind of horrified at the lack of governance that goes through these systems that actually makes people accountable for implementing the right processes.

I think communication. Communication within hospitals between teams within hospitals, but cross-border issues with communication are enormous. So as soon as you move away from that tertiary treatment centre and you're living in Tasmania and you're relying on your local paediatrician and your local GP and your local hospital,
15 and if nothing's coming out of that tertiary treatment centre, we're all stuck. We're lost wandering around in the wilderness. So actually fixing those really systemic issues around communication across those systems is really fundamental to getting good care.

20 MS WRIGHT: Thank you, Rebecca. Commissioners, unless there's any matters which the Commissioners wishes to ask Rebecca, those are my questions.

COMMISSIONER SACKVILLE: You've raised a large number of issues that are very important.

DR KELLY: Yes.

25 COMMISSIONER SACKVILLE: Can I just ask you about the last one, coordination - - -

DR KELLY: Yes.

COMMISSIONER SACKVILLE: - - - and particularly cross borders.

DR KELLY: Yes.

30 COMMISSIONER SACKVILLE: Has the My Health Record system made any difference to that?

DR KELLY: Not that I've noticed. No. So I don't – to be honest, I'm not even sure what's in Ryan's My Health Record. I haven't checked. I don't know that other people check. I don't know what goes in there. I think part of the problem is if it's
35 not written in the first place. So if that ENT doesn't write a letter at the end of a procedure or at least, you know, a half page memo, it's not in there. So unless the

information's actually documented, you know, very much straight away and put in a form that it's then accessible, it doesn't happen. So, yes, I haven't noticed that that's made any benefit in terms of a system.

5 COMMISSIONER SACKVILLE: And as far as a central place where records – and I understand your point that the records are often incomplete or inaccurate – is that a role that the local GP or local paediatrician can or do play?

10 DR KELLY: Yes and no. So as far as I understand – and talking to the people at the Royal Children's the other day – they all use different systems. So there's no universal system by which various doctors and people in the health profession actually keep records and there's no shared platform. They've all developed their own platforms. And some of them talk to each other a little bit and most of them don't. Some things do go back to the GP and I've used the GP to get notes sent to him which then come to me.

15 But, yes, that kind of – it's not a good – it's not a functioning system. There is no good integrated information system across which medical professionals Australia-wide can actually see what's happened in our history. And, I mean, no one – Ryan has folders and folders full of notes, so no one's going to wade through those anyway. What they need is where are we at now and who do I talk to if I need more information. They need that précis summary of his – you know, they don't want to read hundreds of pages on his heart when they just need to read the last letter, so - - -

20 COMMISSIONER SACKVILLE: Thank you. Thank you very much for coming - - -

DR KELLY: Thank you.

COMMISSIONER SACKVILLE: - - - and talking to us.

25 DR KELLY: I appreciate it.

COMMISSIONER SACKVILLE: It's been very helpful and you have made a lot of suggestions that we will take very seriously. Thank you.

DR KELLY: Thank you.

30 MS WRIGHT: I tender Rebecca Kelly's statement, which I understand is exhibit 4-4, as well as the supporting documents, which will be exhibits 4-4.1 to 4-4.11.

EXHIBIT #4-4 STATEMENT OF DR REBECCA ANNE KELLY DATED 09/02/2020 (STAT.0042.0001.0001)

35 **EXHIBIT #4-4.1 PHOTOGRAPHS OF RYAN KELLY (IND.0009.0001.0105)**

**EXHIBIT #4-4.2 LETTER FROM AUDIOLOGIST TO ENT DATED
28/11/2017 (IND.0009.0001.0118)**

5 **EXHIBIT #4-4.3 EMAIL TO HEAD ENT AT ROYAL CHILDREN'S
HOSPITAL DATED 15/04/2019 (IND.0009.0001.0047)**

**EXHIBIT #4-4.4 EMAIL TO END CO-ORDINATOR 23/11/2019
(IND.0009.0001.0034)**

10 **EXHIBIT #4-4.5 EMAIL TO ENT CO-ORDINATOR RE FOLLOW-UP PLAN
25/10/2019 (IND.0009.0001.0057)**

15 **EXHIBIT #4-4.6 EMAIL REQUESTING REPORTS AND NOTES DATED
31/10/19 (IND.0009.0001.0115)**

**EXHIBIT #4-4.7 EMAIL RESPONDING TO REQUEST DATED 16/12/19
(IND.0009.0001.0090)**

20 **EXHIBIT #4-4.8 COMPLAINT TO ROYAL CHILDREN'S HOSPITAL
DATED 23/09/19 (IND.0009.0001.0106)**

**EXHIBIT #4-4.9 EMAIL FROM CONSUMER LIAISON RE COMPLAINT
DATED 31/10/19 (IND.0009.0001.0030)**

25 **EXHIBIT #4-4.10 EMAIL FORWARDING COMPLAINT TO ENT
(IND.0009.0001.0092)**

EXHIBIT #4-4.11 EMAIL TO ENT CO-ORDINATOR (IND.0009.0001.0054)

30 COMMISSIONER SACKVILLE: Okay. Thank you.
DR KELLY: Thank you.

<THE WITNESS WITHDREW

[2.52 pm]

COMMISSIONER SACKVILLE: Are we going to move directly to something else or should we take - - -

MS EASTMAN: Commissioners, we've made very good time today, so that completes the witnesses who will be giving evidence today.

5 COMMISSIONER SACKVILLE: Right.

MS EASTMAN: So it means that there will be an early adjournment to today's proceeding.

COMMISSIONER SACKVILLE: So we get an early mark.

MS EASTMAN: You do.

10 COMMISSIONER SACKVILLE: Excellent. Thank you very much. We will adjourn until 10 o'clock tomorrow.

**MATTER ADJOURNED at 2.53 pm UNTIL
WEDNESDAY, 19 FEBRUARY 2020**

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