



Chair's Opening Address – Ronald Sackville AO QC

Public hearing 4: Health care and services for people with cognitive disability

Sydney, 18 February 2020

Acknowledgement of Country

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 present today.

We further acknowledge the profound contributions First Nations culture and traditions make 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 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.

Bushfires

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 by the catastrophic bush fires in so many parts of this beautiful country. We know that among those that 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.

Introduction

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 and abuse by or within the health system for people with cognitive disability are as disturbing as they are profound. They should 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 well as differences in learning, awareness or decision-making. “Cognitive disability” therefore includes (but is not limited to) intellectual disability, learning disability, autism, acquired brain injuries 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, when they try to access health care.

I do not intend to repeat what was said in opening the public hearings on Education in Townsville in November and Accommodation 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 webcast of the proceedings.

I want to address just two matters. I shall then say something briefly about the subject matter of today’s hearing. I shall leave the details to Ms Kate Eastman SC, Senior Counsel Assisting the Royal Commission, who appears today together with Ms Simone Fraser and Ms Georgina Wright, both of whom are Counsel Assisting the Royal Commission.

The two matters I want to address are these:

First, in what ways is the Disability 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 not only this week but throughout 2020.

How is the DRC distinctive?

In recent times we have heard 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 challenging 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 the Commonwealth Government has recently announced its intention to set up a Royal Commission to investigate the causes of the recent catastrophic bushfires.

There is nothing new about the use of Royal Commissions in Australia to investigate significant policy questions. There have been hundreds of Royal Commissions established at 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. 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 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 stress 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 the Aged Care Royal Commission since many older people within its terms of reference are people with disability. We have arranged matters so that our 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, submissions and original research, its scope was actually considerably 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 2020 (bearing in mind that there will be multiple hearings on some issues):

- Education of students with disability.
- The experiences of people with cognitive disability within the health system.
- 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. (This will be done with 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.
- Limitations on opportunities for economic participation by people with disability.
- The experiences of people with disability in the criminal justice system, whether as accused persons, witnesses or victims of crime.

This is not by any means an exhaustive list. Furthermore we are acutely conscious that the life experiences of people with disability cannot be neatly compartmentalised into self-contained categories or domains. 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 social attitudes towards disability – that transcend boundaries.

I do not 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.

A second unusual feature of this Royal Commission is that the terms of reference direct 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 direction 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. 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 Commission’s 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 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 have 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 diagnosis and treatment of serious health problems. It is vital that we hear first-hand from people who have had experience of the kinds of neglect and abuse and that we benefit from their insights as to what can be done to make things better.

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 by two advocates with intellectual disability – Jane Rosengrave and Colin Hiscoe – in the First Progress Report of the Commission 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 safer and more inclusive and accessible. We are extremely grateful for their advice. The steps that have been taken to support witnesses who will give evidence at this hearing include:

- Extensive discussions with 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 the hearing room to remove barriers and make the room more comfortable for the witnesses. People present today can see the differences between this set up and the usual appearance of a hearing room.
- A familiarisation session held yesterday to make people with cognitive disability comfortable with the environment in which they will be giving evidence.

Progress of the Royal Commission

The Royal Commission is committed to transparency in communicating to the disability community and the Australian community at large the progress of our work. For that reason, we published in December the “First Progress Report” of the Commission. The Report summarises the major activities of the Commission since commencement of operations, including the public hearings, workshops, community forums, issues papers and research projects.

The First Progress Report is available on the website and in Easy Read format. I suggest that anyone who is interested in the work of the Commission should if possible, read one or other versions of the document. I will not repeat the information in the Report.

However, I do want to refer to some developments that post-date the Report.

The Progress Report recorded that by 10 December 2019, 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. In addition, we have received 72 responses, some extremely detailed, to the four Issues Papers released so far, which concern:

- Education;
- Health (the subject of this hearing);
- Homes and Accommodation; and
- the Criminal Justice System.

(The last of these was released in January, after the Progress Report was released.)

Many submissions 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, exploitation and neglect of people with disability, including children. These submissions not only inform us, but can provide a platform for further investigations, for example to gather evidence to be presented at public hearings 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.

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 our recommendations.

We encourage people with disability, advocates and all interested parties to continue making submissions. The 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 Andrea Mason.

The Progress Report also referred to the recent amendments to the Royal Commissions Act 1902 (Cth) 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, a little ahead of schedule. This is an important development, both for the Royal Commission and for people wishing to recount their experiences to a Commissioner in private.

You can 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. As I have mentioned, last week three Commissioners attended First Nations people community engagements in Darwin, Alice Springs and Papunya.

I should also mention that the Commission now has 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 busy year.

The hearing

The human rights framework for this hearing is provided by Article 25 of the Convention on the Rights of Persons with Disabilities, to which Australia is a party. Article 25 is quite lengthy but in essence 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.

Ms Eastman will say more about the human rights approach required by the Convention. During the hearing, as Ms Eastman will explain, we shall hear from people with cognitive disability and their families about their experiences, 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 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. The background is that in 2007 Commonwealth, State, Territory and local

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.

Unfortunately the process has not been as successful as had been hoped. For example, according to the latest Closing the Gap report the life expectancy of indigenous males is still 8.6 years less than non-indigenous males, while the gap for indigenous females is 7.8 years. It is acknowledged that the target to close the life expectancy gap by 2031 is not on track.

The important point for present purposes is that it is accepted by all Governments – as it should be – that the present 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.

Now consider the experiences of people with disability in the health system. Ms Eastman will provide more details so I shall refer to only two pieces of evidence 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) – **27 years**. People with intellectual disability in New South Wales aged between 5 and 69 years have three times the number of deaths than would be expected in the general population. People on the autism spectrum who reside in New South Wales 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 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% 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, Senior Advocate with the NSW Council for Intellectual Disability in his statement refers to this evidence. He says that the health inadequacies facing people with cognitive disability constitutes 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 those of the other witnesses at this hearing. Most of all we have to pay special attention to the experiences of people with cognitive disability and their families.