Chair's Opening Address – Ronald Sackville AO QC

Public hearing 6: Use of psychotropic medication, behaviour support and behaviours of concern

Sydney, 22 September 2020

Acknowledgement of Country

As with all our hearings we commence with an acknowledgment of Country. I wish to acknowledge the Gadigal people of the Eora Nation, the traditional custodians of this land. I also acknowledge the Turrbul and Jagera nations, upon whose lands is our hearing room in Brisbane. I pay my respects to their Elders past, present and emerging, as well as to all First Nations People viewing this public hearing on the public livestream.

Welcome

This is the sixth public hearing of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. It is the fifth hearing in which evidence is presented on a topic within the Royal Commission's terms of reference. The hearing this week will examine the ways in which people with intellectual disability are treated when they display, or are thought likely to display, so-called "behaviours of concern". The responses often involve the administration of psychotropic medication. This hearing will examine whether responses of this kind, as distinct from positive behavioural support, cause or increase the risk of people with intellectual disability experiencing violence, abuse, neglect or exploitation.

As I noted at the commencement of Public hearing 5 (which dealt with the impact of the COVID-19 pandemic on people with disability) ordinarily any member of the community is free to attend and observe a public hearing of a Royal Commission. As we all know only too well, these are not ordinary times. We will still be conducting a public hearing this week, but it will be a virtual hearing. For reasons of safety during the COVID-19

pandemic no member of the general public can be present in the hearing room. The proceedings will of course be live streamed so that anyone interested can follow the proceedings by going to the Royal Commission's website.

I extend a warm welcome on behalf of the Royal Commission to everyone who is following or who will follow these proceedings on the live stream or in some other way.

Justice Ginsburg

Before explaining how this hearing will be conducted I want to pay tribute to and honour the memory of Justice Ruth Bader Ginsburg who died last week.

It may seems strange to mourn the in Australia the death of a Justice of the Supreme Court of the United States, but her commitment to equality transcended national borders. She is of course best known as a champion of women's rights and she was mightily influential in advancing the cause of women's equality far beyond the borders of the United States.

What is less known is that Justice Ginsburg was also a champion of the rights of people with disability. A Disability Rights Organisation in the United States said on her death that no other Supreme Court Justice has played a larger role in the disability rights movement. Her opinion in the foundational case of *Olmstead v L.C.* in 1999 which greatly expanded the scope of the *Americans with Disability Act,* has been described as "legendary". It has also been said to be the equivalent in the area of disability rights of *Brown v Board of Education* (the famous School Desegregation Case in 1954) in the field of civil rights.

Justice Ginsburg's life is perhaps best described in a portion of the Hebrew Bible known as Shofetim or Judges:

"Tzedek, tzedek tirdof"

"Justice, Justice, you shall pursue"

This also describes what this Royal Commission is attempting to do.

The Virtual Hearing

I would like to explain briefly how this virtual hearing will be conducted. We have a hearing room in Sydney which is a courtroom within the premises occupied by the Fair Work Commission. We are using the courtroom with the kind permission of that

Commission. As it happens, there are two Royal Commissions holding hearings at the Fair Work Commission's premises today, the other being a hearing of the Aged Care Royal Commission.

Three Commissioners are participating this hearing. Commissioner Alastair McEwin AM is with me in Sydney, but keeping at a safe distance. Commissioner Roslyn Atkinson AO is participating by video link with the Royal Commission's hearing room in Brisbane.

Ms Kate Eastman SC is the Senior Counsel Assisting the Royal Commission and she is present in the Sydney hearing room Ms Eastman is appearing with two Counsel Assisting the Royal Commission, Dr Hayley Bennett and Ms Melinda Zerner. Dr Bennett is in Sydney hearing room while Ms Zerner is in the Brisbane hearing room together with Commissioner Atkinson. Some members of the Royal Commission's staff are in the Sydney hearing room or nearby, others are in the Brisbane hearing room.

As with our recent hearing on the effects of the COVID-19 pandemic on people with disability, this remote hearing has involved meticulous preparation in setting up the information technology and video link systems. We have been told that there is every reason to be confident that all will proceed smoothly, but please bear with us if we have the occasional glitch.

We will hear from 26 witnesses over the course of 4 hearing days. Most witnesses will give evidence remotely, but some will do so from one or other of the hearing rooms. The evidence of certain witnesses will be pre-recorded.

The evidence will include witnesses who can speak of the experiences of people with intellectual disability and autism to whom psychotropic drugs have been administered, sometimes over very long periods, in order to control what is usually described as "challenging behaviour" or "behaviours of concern". We shall hear from medical practitioners (including psychiatrists and general practitioners) about the benefits and risks of administering psychotropic drugs to people with intellectual disability and autism. We shall also hear from other health professionals, advocates and academic experts (including researchers in the field of disability studies). In addition, evidence will be given by representatives of Commonwealth and State agencies such as the NDIS Quality and Safeguards Commission, the Queensland Public Guardian and the Queensland Department of Communities, Disability Services and Seniors.

Witnesses will use expressions that may not be familiar to everyone but have particular meanings in this area. They include expressions such as "restrictive practices", "chemical

restraints" and "off-label prescribing". Ms Eastman will explain most if not all of these terms in her opening and others will become clearer as the witnesses give their evidence.

Without intruding too much on Ms Eastman's opening, I think it is important to explain at the outset what is meant by "challenging behaviour" or "behaviours of concern". I appreciate that there is considerable sensitivity about the use of language and that some people interpret these terms as implying that people with intellectual disability are responsible for their own behaviour. However, these terms are used consistently by experts, including experts in disability studies who understand nuances in language.

For example, Professor Leanne Dowse, who is Professor of Disability Studies and Chair in Intellectual Disability and Behaviour Support at the University of New South Wales adopts the definition of "behaviours of concern" advanced in the literature. The expression refers to:

> "Behaviour of such an intensity, frequency or duration as to threaten the life or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion."

Behaviours of concern can include – or at least can be said to include – verbal, physical or sexual aggression; self-injury; and destruction of property. As the evidence will make clear, challenging behaviour can have severe consequences both to the person exhibiting that behaviour and to those who are providing care, treatment or support.

Professor Dowse explains that complex support needs arise in the interaction between the individual and their potential or actual support systems. In other words, the needs reflect the relationships between the individual, their service providers and agencies and the context which shapes their relationships. This highlights that:

"Behaviours of concern are not simply an individual pathology, but rather exist in the complex interplay of bio-medical function, social and environmental which also shape the interventions made in response to those behaviours of concern."

The term "psychotropic drugs" refers to any drug capable of affecting the mind, behaviour or emotions of the person to whom the drug is administered. This hearing will be concerned with psychotropic drugs that can be administered legally, although such drugs are subject to stringent controls under Commonwealth, State and Territory laws. The three main classes of psychotropic drugs are anti-depressants, anxiolytic hypnotics (such as benzodiazepines like Valium and Xanax which are used to manage anxiety) and anti-psychotic or anti-convulsive drugs.

Ms Eastman will address in more detail the evidence that will be given this week. I want to make just a few general observations.

On the basis of the statements that will be tendered in evidence, there seems to be widespread agreement on certain matters:

- Psychotropic medications have an important part to play in treating mental illness and, if properly administered, can improve health outcomes for patients with those illnesses.
- Psychotropic drugs, particularly antipsychotics, can detrimentally affect the person's health and well-being if administered inappropriately. Sometimes the consequences can be very serious indeed. The evidence will provide examples of adverse consequences that can even include death. According to Dr Catherine Franklin, a Consultant Psychiatrist and Research Fellow at the Queensland Centre for Intellectual and Developmental Disability, about 80 percent of people taking anti-psychotic medication experience side effects and one third of these have moderate to severe impairment due to medication-related side effects.
- There is a clear distinction between using psychotropic drugs appropriately to treat mental illness and administering them to control the behaviour of people with intellectual disability or autism who do not necessarily have any mental illness. In practice, as we shall hear, the distinction is blurred and psychotropic drugs are often used to control challenging behaviour of people with intellectual disability and not truly for the purpose of treating mental illness, although the medical records may suggest otherwise.
- Psychotropic drugs are over used in Australia as a response to behaviours of concern by people with intellectual disability. For the most part, this form of behavioural control is administered without the person having a meaningful say in what is to happen.
- Some data is available that may suggest that psychotropic drugs are overused. For example, Mr Graeme Head, the NDIS Quality and Safeguards Commissioner, states that there were 177,611 reports of unauthorised use of chemical restraints on NDIS participants in 2019-2020. An unauthorised use of psychotropic medication is not necessarily improper, for example where drugs have to be administered without prior approval in an emergency. Nonetheless, these figures are suggestive and perhaps receive support from other data. However, there are no reliable national statistics on the extent to which psychotropic drugs are used to

control the behaviour of people with intellectual disability, the majority of whom are not NDIS participants.

- Official bodies have formulated key principles designed to limit the use of psychotropic drugs. The overriding and generally accepted principle is that psychotropic medication – and other restrictive practices – should be administered only as a last resort to prevent imminent and serious harm to the person or others and only where less restrictive options have been exhausted. Even then, the least restrictive option should be used. The difficulty that witnesses will point to is the absence of enforceable national standards regulating the administration of psychotropic drugs to people with intellectual disability and autism as a form of chemical restraint, although some initiatives are underway to formulate national standards.
- Positive behaviour support is an effective tool for responding to behaviours of concern and should be more widely used as a means of reducing reliance on chemical restraints provided that the support is of the requisite quality.
- The overuse or misuse of psychotropic drugs as a form of behavioural control raises significant issues concerning Australia's compliance with the CRPD. The provisions that are relevant include these:
    - Article 12 of the CRPD provides that States Parties such as Australia shall recognise that people with disability enjoy legal capacity on an equal basis with others in all aspects of life.
    - Article 14 requires States Parties to ensure that people with disability enjoy the right to liberty and security of person on an equal basis with others and are not deprived of their liberty arbitrarily.
    - Article 15, which reflects the terms of other International Conventions, says that no-one shall be subjected to cruel, inhuman or degrading treatment.
    - And of course Article 16 states that States Parties must take appropriate measures to protect people with disability from all forms of violence, abuse, neglect and exploitation.

The issues we are examining this week therefore have a significant human rights dimension.

May I make two final comments.

First, as I have frequently pointed out, our Terms of Reference require us to inquire into an extraordinarily wide range of issues, many of which raise policy questions of considerable difficulty and complexity. Sometimes the answers to the policy questions may seem to be relatively straightforward, at least in principle, but the difficulty and complexity lie in translating those principles into everyday practice. It is the practical implementation of good ideas that can be the key to reducing, if not completely particular forms of abuse directed at people with disability. This may be one such area.

Secondly, the Royal Commission is committed to providing a forum for people with disability to recount their experiences and express their views. However, some people with disability, despite the best efforts of advocates, are unable or perhaps unwilling to make their voices heard in a public hearing. Even so, it is essential for the Royal Commission to understand their experiences. As Ms Eastman will explain, in some respects this hearing is concerned with the experiences of hidden or voiceless people with disability. One way or another, their stories must be told.