



Australian
Human Rights
Commission

Guidelines on the rights of people with disability in health and disability care during COVID-19

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Disability Discrimination Commissioner's Foreword

The COVID-19 pandemic has highlighted the systemic disadvantage that people with disability face in Australia and around the world.

The interaction between people with disability and the health care and disability support systems may lead to significant human rights issues. People with disability may be placed in situations where they are vulnerable and profound power imbalances exist. This is particularly the case for people with disability with complex support needs, a cognitive or intellectual disability, or who have a communication disability.

Sometimes human rights issues arise inadvertently when health care professionals or disability support workers may be unaware of their unconscious biases. This is especially the case when resource shortages exist or during times of emergency. At other times, conduct may occur as a result of discriminatory points of view or policies. In all situations, however, there is a possibility that people with disability may be exposed to serious harm.

A critical justification for the creation, signing and ratification of the *Convention on the Rights of Persons with Disabilities* (CRPD) throughout the international community was to acknowledge the specific issues faced by people with disability in society. In particular, there was a need, on occasion, to treat difference differently to achieve substantive equality. There was also a recognised need to plan explicitly for emergency or crisis situations.

The Australian Government Advisory Committee for the COVID-19 Response for People with Disability (Advisory Committee) was formed in April 2020 to deal better with the effect of the coronavirus pandemic on people with disability in Australia and as a reflection of the Australian Government's commitment to the CRPD. The Advisory Committee has as members: representatives of government, civil society, medical professionals and people with disability. I sit as a member of the Advisory Committee in my capacity as Disability Discrimination Commissioner at the Australian Human Rights Commission.

These Guidelines have been drafted to support the implementation of the *Advisory Committee's Management and Operational Plan for People with Disability* (the Plan), which focuses on broad clinical, public health and communication actions by Commonwealth, State and Territory governments. The actions suggested under the Plan, and implemented by health authorities and disability service providers, need to be informed by human rights considerations.

These Guidelines are designed to ensure that human rights considerations inform the decisions made by health care and disability workers when supporting people with disability.

Dr Ben Gauntlett

Disability Discrimination Commissioner
Australian Human Rights Commission

1 Introduction

Policy responses to the SARS-CoV-2 virus and associated disease, COVID-19, including isolation and social distancing measures, may in certain circumstances have a greater impact on some people with disability, particularly those who rely on carers and other support people, and those who live or work in high-risk environments.

Treatment protocols for medical practitioners, health and disability support workers may, in certain circumstances, also have the potential to discriminate against people with disability. This occurs when unwarranted assumptions are made about people with disability or when their needs and preferences are not adequately taken into account. This discrimination may be unintentional and undertaken unknowingly.

In some cases, it may be necessary to treat people with disability differently in order to ensure 'disability neutrality'.¹ That is, to ensure that they enjoy their human rights, including the right to health, on an equal basis with other people. This is consistent with the concept of 'substantive equality'. It requires rules to be questioned, differences acknowledged, and reasonable accommodations made rather than ignored, so as to enable equality of opportunity and not just merely equality of treatment.

2 Role of the Guidelines

These Guidelines are issued under section 67(1)(k) of the *Disability Discrimination Act 1992* (Cth) (the DDA) and section 11(1)(n) of the *Australian Human Rights Commission Act 1986* (Cth). These provisions give the Australian Human Rights Commission the power to publish guidelines ‘for the avoidance of discrimination on the ground of disability’² and for the avoidance of acts or practices that may be inconsistent with or contrary to any human right.³

These Guidelines have been developed to **support** the Advisory Committee for the COVID-19 Response for People with Disability (Advisory Committee) *Management and Operational Plan for People with Disability* (the Plan). The Plan was developed in accordance with the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) and has been endorsed by the Australian Health Protection Principal Committee.

About the Advisory Committee

In recognition of the significant impact of the COVID-19 pandemic on people with disability, the Australian Government established the Advisory Committee in early April 2020.

The Advisory Committee advises the Chief Medical Officer. The primary aim of its current work is to ensure the health and safety of people with disability during the COVID-19 pandemic.

The intended **audience** for the Guidelines is health care workers, including medical practitioners, nurses and allied health professionals, and disability services and support workers particularly in the health and disability support systems where individuals with complex support needs are being assisted. The Guidelines may also be a useful resource for people with disability, their families and carers, to assist them to understand their rights in a health care setting.

The **purpose** of the Guidelines is to provide practical guidance on how to apply a human rights-based approach to decision-making within the health system in the context of the current pandemic, that takes the rights of people with disability properly into account. Health care and disability support providers can use these Guidelines as the basis for developing publicly available medical and treatment protocols which uphold the human rights principles outlined.⁴

“A human rights approach is critical to response and recovery efforts not only in relation to the COVID-19 pandemic, but also to ensure that States take action now to build equitable, sustainable and resilient societies that have the mechanisms to prevent and respond rapidly to future public health emergencies and to ensure that ‘no-one is left behind’.”⁵

Committee on the Rights of Persons with Disabilities⁶
9 June 2020

3 Disability in Australia

'Disability' in the *Disability Discrimination Act 1992* (Cth)

Disability, in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future (including because of a genetic predisposition to that disability); or
- (k) is imputed to a person.

To avoid doubt, a **disability** that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability.⁷

People with disability in Australia

- There are 4.4 million people with disability in Australia.⁸
- Almost one-in-five Australians have a disability.⁹
- People born in 2015 can expect to live one-fifth of their life with some level of disability.¹⁰
- The prevalence of disability generally increases with age. While 3.7% of 0-4 year olds are reported as having a disability, this increases to 84.6% of those aged 90 years and over.¹¹
- The National Disability Insurance Scheme provides funding to support individuals with permanent and significant disability, who comprise approximately 460,000 people in Australia.¹²

Australians with disability can be disadvantaged in accessing health services because of:

1. barriers to communication
2. attitudes, values and assumptions concerning an individual's quality of life and life expectancy
3. unconscious bias
4. delayed diagnoses and misdiagnoses of people caused by diagnostic overshadowing¹³ or assumptions about health outcomes
5. decisions to refuse access to critical care being based on an individual's age, or mental or physical disability, in circumstances where that is not clinically relevant
6. specific issues for First Nations and culturally and linguistically diverse people with disability with respect to cultural norms and health care
7. specific issues for women with disability with respect to accessing health care
8. failing to consider the need for, or provide, reasonable adjustments to allow a person with disability to access the same level of health care as a person without disability
9. failing to recognise the decision-making capacity of a person with disability or to take their will and preferences about their health care into account
10. failing to consider the need for support for decision-making, particularly in times of crisis.

In a particular case, the reason that a person with disability is disadvantaged in accessing health care services may be because the person or organisation providing the service is not aware of the relevant issues that give rise to the disadvantage. However, even when the disadvantage is unintentional, the effect upon people with disability interacting with the health care system can be devastating.

“[T]he consequences of neglect and abuse by or within the health system for people with cognitive disability are as disturbing as they are profound ... the extent and consequences of neglect and abuse should shock the conscience of all Australians.”¹⁴

Commissioner Sackville AO, hearing of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
28 February 2020

4 Human rights issues and COVID-19

The COVID-19 pandemic has raised a number of significant human rights concerns for people with disability.¹⁵ This has been identified by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability,¹⁶ independent experts commissioned by Disabled People's Organisations Australia,¹⁷ the United Nations (UN) Special Rapporteur on the rights of persons with disabilities,¹⁸ UN human rights experts,¹⁹ the Secretary-General of the UN,²⁰ the UN High Commissioner for Human Rights,²¹ the UN Sustainable Development Group,²² the World Health Organization,²³ human rights organisations,²⁴ and leading universities and commentators.²⁵

"While the COVID-19 pandemic threatens all members of society, persons with disabilities are disproportionately impacted due to attitudinal, environmental and institutional barriers that are reproduced in the COVID-19 response."²⁶

Office of the United Nations High Commissioner for Human Rights
29 April 2020

When seeking to protect the human rights of people with disability in the context of COVID-19, the following human rights principles outlined in article 3 of the *Convention on the Rights of Persons with Disabilities* (CRPD),²⁷ are important:

(i) Respect for the inherent dignity of a person

Dignity sits at the core of most UN human rights instruments, and is often intertwined with other human rights concepts.²⁸ It has been described as the 'anchor norm of human rights'.²⁹

The principle of 'respect for inherent dignity' points to the inherent value of the human dignity of all people.³⁰

This is particularly important to articulate in the context of vulnerable groups (including groups with intersectional characteristics³¹) where stigma can lead to discrimination and value judgements regarding the value of one life compared to another.

(ii) *Individual autonomy, including the freedom for a person to make their own choices*

Autonomy refers to the ‘freedom of being in charge of one’s own life and of making one’s own choices’.³² When an individual has autonomy they have a greater ability to make ‘reasonable life choices’.³³ Autonomy also underpins the right to independent living.

Article 12 of the CRPD reinforces the importance of autonomy through its recognition of the principle of equal recognition of the legal capacity of people with disability, and the role of supported decision-making. Importantly, support ‘must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making’.³⁴

“... persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age.”

“[Decisions] concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”³⁵

Office of Civil Rights, US Department of Health and Human Services
28 March 2020

(iii) *Non-discrimination*

Non-discrimination is a ‘basic and general principle relating to the protection of human rights’.³⁶ Non-discrimination underpins a number of key rights in the CRPD and supports the concept of equality.

‘Discrimination’ is defined in article 2 of the CRPD as:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.³⁷

In addition to these international human rights principles, there are also specific Australian laws dealing with discrimination on the ground of disability. The DDA makes it unlawful to treat a person less favourably because of their disability in a range of areas of public life, including in relation to the provision of medical services and facilities.

(iv) *A person’s ability to be fully included, participate and be in society*

Participation in a human rights context generally refers to a person’s ability to exercise both their civil and political rights and their economic, social and cultural rights.³⁸

At its core, participation is about being able to fully engage with all aspects of life without impediment.

Participation is also a key design feature of the monitoring processes of the CRPD and the composition of the CRPD Committee, which signals a move away from a medical model of disability, towards a social model.³⁹

(v) *Equality of opportunity*

Equality of opportunity focuses on the removal of institutional and environmental barriers.⁴⁰ This also incorporates making reasonable adjustments to ensure that people with disability can take advantage of opportunities on an equal basis with others. It is the first step in facilitating substantive equality—equality of outcomes.

(vi) Accessibility

Accessibility plays a key role in facilitating the ‘full and effective participation of people with disability in society’.⁴¹ Accessibility refers to the right of people with disability to access the physical environment, transport, information, systems and any other elements of daily life to support their participation and the realisation of their rights.

These principles are echoed in the DDA.⁴²

A key part of ensuring the equality of people with disability is through the principle of ‘reasonable accommodation’. Article 5(3) of the CRPD provides that parties shall actively take all appropriate steps to ensure that reasonable accommodations are made to ensure the promotion of equality and prevention of discrimination.⁴³

The PANEL model

The PANEL model⁴⁴ provides guidance on the key elements of a human rights-based approach and is a useful analytical tool. It includes the following elements:

- **Participation**—everyone has the right to participate in decisions that affect their human rights.
- **Accountability**—effective monitoring of compliance with human rights norms, and remedies to address non-compliance.
- **Non-discrimination and equality**—all forms of discrimination must be prohibited and prevented, and priority should be given to the most marginalised in our society.
- **Empowerment**—everyone is entitled to claim and exercise their rights and freedoms.
- **Legality**—when laws and policies are developed, they recognise human rights as enforceable entitlements, and are consistent with human rights.

Human rights and health care

Health professionals are guided by a range of different protocols, and use a variety of different assessment tools, in a health care setting. By their nature these tools and protocols are designed with a primary focus on positive health care outcomes. It is important that these tools and protocols also ensure the protection of the rights of people with disability.

Clinical Frailty Scale

The Clinical Frailty Scale⁴⁵ (CFS) is a tool that was developed to help assess the frailty of older people (over 65 years) for clinical purposes. It allows clinicians to rate an individual on a scale from 'very fit' to 'terminally ill'. Some of the factors that are used to assess frailty under the CFS include:

- the amount of assistance an individual requires with outside activities and personal care
- whether they have symptoms which limit activities.

Given the factors used to determine where an individual sits on the CFS there is a risk that people with disability will be discriminated against when it is applied. With this in mind, the UK National Health Service Specialised Clinical Frailty Network issued the following guidance on the use of the CFS:

The [Clinical Frailty Scale] has not been widely validated in younger populations (below 65 years of age), or in those with learning disability. It may not perform as well in people with stable long term disability such as cerebral palsy, whose outcomes might be very different compared to older people with progressive disability. We would advise that the scale is not used in these groups. However, the guidance on holistic assessment to determine the likely risks and benefits of critical care support, and seeking critical care advice where there is uncertainty, is still relevant.⁴⁶

It is also relevant to note that a recent publication on the application of the CFS in the context of COVID-19 has cautioned against its use as the sole component of any assessment regarding the allocation of limited resources.⁴⁷ Rather, it should be viewed as a 'rapid component of a person-centred approach'.⁴⁸

ANZICS Guiding Principles

The *Guiding principles for complex decision making during Pandemic COVID-19* developed by the Australia and New Zealand Intensive Care Society (ANZICS Guiding Principles)⁴⁹ were developed to:

[provide] a framework to support intensive care specialists who are required to make decisions about the ethical allocation of critical care resources when demand exceeds capacity during a global pandemic.⁵⁰

The ANZICS Guiding Principles identify disability as an ‘irrelevant and discriminatory consideration’:

In the situation where patients are otherwise similarly ranked in terms of clinical priority, access to intensive care must not be based on irrelevant and discriminatory considerations such as gender, sexual orientation, religion, disability, social status, personal connections, wealth, citizenship, insurance status, ethnicity or race.⁵¹

5 Which human rights are relevant?

This section outlines the key rights captured within the CRPD which are most relevant in the context of a pandemic.⁵²

- **Right to protection during times of risk**⁵³

The government has an obligation to take measures to protect people with disability in times of risk. These include armed conflict, humanitarian emergencies and natural disasters.

- **Right to health**⁵⁴

People with disability have the right to the enjoyment of the highest attainable standard of health without discrimination.

- **Right to life**⁵⁵

People with disability have a right to life. The life of a person with disability is of equal value to the life of any other person.

- **Right to equality and non-discrimination**⁵⁶

Everyone is entitled to the equal protection and benefit of the law without discrimination. This may include the provision of reasonable accommodation for a person with disability in order to achieve substantive equality.

- **Right to equal recognition before the law**⁵⁷

People with disability have the right to recognition as persons before the law. This includes the right to make decisions about their own health care, including providing or declining consent to medical treatment. They also have the right to access any support they require to exercise their legal capacity.

- **Right to accessible information**⁵⁸

People with disability have the right to express themselves, including the freedom to give and receive information and ideas through all forms of communication, including through accessible formats and technologies, sign languages, Braille, augmentative and alternative communication, mass media and all other accessible means of communication.

6 Practical examples

This section outlines practical examples of the role of human rights in a health care setting.⁵⁹ Some of the examples below outline the potentially catastrophic consequences that may result if the rights of people with disability are not central to health care responses.

6.1 Access to mobility aids

Riva has presented to the emergency department of a large public hospital with symptoms of COVID-19. To minimise the spread of the virus the hospital has strict physical distancing protocols in place.

Riva has a vision impairment and uses a cane to navigate.

The hospital has a policy in place that patients who are being tested for COVID-19 cannot bring any items into the hospital that the virus may have attached to. This includes mobility aids.

The policy also explicitly provides the following:

- where a person requires a mobility aid they will be provided with an aid by the hospital for use while they are in the emergency ward or when they are admitted
- if the hospital does not have the mobility aid that the person requires, the hospital will disinfect the person's aid so they are able to use it in the hospital.

The triage nurse notices Riva's cane leaning against the counter and explains the policy to her. Riva is happy to use a hospital cane but explains that she finds it easiest to navigate with a pencil tip cane. The triage nurse checks and the hospital does not stock these types of canes. She offers to disinfect Riva's cane so that she can continue to use a mobility aid that best suits her needs.

Human rights considerations

The emergency department has put in place a process that addresses the risk of infection but still ensures people with disability are able to use their mobility aids.

Riva has the right to be treated without discrimination based on her disability,⁶⁰ including the right to maintain her mobility in a manner of her choice.⁶¹ Access to a suitable cane at the hospital is essential to her ability to realise her right to health.⁶²

Realising rights in practice

When an emergency department puts in place a policy regarding patients' possessions in the context of infection control, the following steps will assist in protecting the rights of people with disability:

- recognising within triage policies that where a person with disability requires a mobility aid or other support that this is a key component in providing them with health care
- ensuring that the emergency department has ready access to a range of mobility aids and supports
- ensuring that people with disability are made aware of the policy on arrival
- educating staff about different types of mobility aids.

6.2 Accessible communication

Sebastian has been admitted to hospital with COVID-19. Sebastian is deaf and uses Auslan to communicate. Sebastian has been on the ward for three days and has not had access to an Auslan interpreter. He understands that these are unique times and has been muddling by in communicating with the ward nurses. He has raised his need for an interpreter multiple times.

The doctor visited Sebastian this morning and explained that he will require two negative swab tests before he can leave hospital. Without an Auslan interpreter Sebastian is not aware that he has been told this and does not know the requirements for his discharge. Based on the time he has been on the ward and the fact that the nurses have understood his care requests, made through hand gestures and other means, the nurses have assumed that Sebastian can lipread.

Human rights considerations

The ward nurses' assumption that Sebastian can lipread has resulted in his communication needs not being met.

Sebastian has a right to be treated without discrimination based on his disability.⁶³ This right includes the provision of reasonable adjustments,⁶⁴ such as access to an Auslan interpreter. Sebastian also has a right to be provided with accessible information about his medical needs.⁶⁵ Providing reasonable adjustments and information in an accessible form are essential to Sebastian's ability to fully realise his right to health.⁶⁶

Realising rights in practice

When a person who needs accessible communication is admitted to hospital, the following steps will assist in protecting their rights:

- asking the person at the point of admission if they have any accessibility requirements in relation to communication
- putting in place a process that ensures the information gathered at the point of admission is provided to the hospital staff who will be treating the person and any hospital administrators who have responsibility for supporting the communication needs of patients
- providing each hospital ward with a list of key contacts for accessible communication needs (for example, internal hospital contacts and external contacts such as the National Relay Service)
- ensuring that hospital staff are aware if a person uses non-verbal cues to communicate (like head banging or wakefulness to indicate pain levels).

6.3 Access to visitors and family

Lucia, age 17, has not been able to attend school due to the home learning policy in place as a result of COVID-19. She has woken with a fever. Her mother, Angela, with whom she lives, calls the nearest medical centre that is offering COVID-19 testing to make an appointment.

Lucia has Autism and is already distressed as she is out of her normal school routine. Being in unfamiliar surroundings and near people she does not know is likely to increase her distress. Her paediatrician has been able to provide her with regular appointments via telehealth during this time of increased stress, and has increased her anti-anxiety medication dose, which has helped her to be more settled at home.

In her call to the medical centre, Angela explains that she is concerned that Lucia may have COVID-19. She also explains Lucia's care needs, that she will need to stay close to her as a support person, and that Lucia is on medication to help manage her anxiety.

When they arrive at the medical centre they speak with the receptionist. She explains that it is the medical centre's policy that suspected COVID-19 patients must wait in a separate waiting area and that, as an infection control measure, family are not permitted to wait with them. However, based on Angela's earlier call, and information provided to the medical centre by Lucia's paediatrician, she has found a spare office for them to wait in that is away from the busy waiting room. The receptionist has spoken to the general practitioner who will be seeing Lucia and she has confirmed that she is happy for Angela to stay with Lucia during the consultation, and practise the calming strategies that have been developed by Lucia's care team. All of the infection control measures that are maintained in relation to the patients waiting in the waiting room are also maintained in relation to the spare office.

The receptionist makes sure that Angela is able to make a follow-up appointment with Lucia's paediatrician to review her progress. Angela makes a telehealth appointment to ensure that Lucia remains in isolation until her test results are available.

Human rights considerations

The medical centre has put in place a policy to maintain the safety of patients and staff. The receptionist's initiative and good communication between the care team members has resulted in Lucia having her needs met in this case.

Lucia has the right to be treated without discrimination based on her disability.⁶⁷ This right includes the provision of reasonable adjustments that take into account her particular needs arising from her disability,⁶⁸ such as access to a family member and being able to wait in a quiet area. Providing reasonable adjustments is essential to Lucia's ability to fully realise her rights.

While the receptionist understood the need to take Lucia's disability into account when implementing the policy, the fact that allowing Angela to stay with Lucia was an 'ad hoc' decision rather than a core part of the policy could have affected Lucia's ability to seek medical attention and realise her right to health.⁶⁹

Realising rights in practice

When a person who requires a support person attends a medical centre for medical attention in the context of a pandemic, the following steps will assist in protecting their rights:

- providing a separate waiting area where the person who may have COVID-19 can wait with family members or other support person, away from other patients
- allowing the person to wait away from the medical centre (for example, in their car) and contacting them or their support person when the doctor is ready to see them
- ensuring any policy developed by the medical centre specifically refers to the requirement to make reasonable adjustments for people with disability and provides practical guidance on how this can be achieved
- ensuring the individual with a disability is able to access appropriate and ongoing specialist medical and developmental care even when physical distancing and isolation measures need to be in place (for example, via telehealth).

6.4 Involuntary hospital discharges

Genevieve was recently admitted to hospital after a change of medication caused serious side effects. Genevieve has bipolar disorder.

To taper off the medication fully and begin a new regimen under supervision, Genevieve's psychiatrist suggested she stay in hospital for another four weeks. Although Genevieve was feeling much better and doing well, she agreed with this approach as she had been traumatised by her recent experience.

In the third week of her hospital stay Genevieve was provided with voluntary discharge forms by the nurse unit manager. Genevieve explained that the original advice was that she should stay under supervision for four weeks. The nurse unit manager explained that the hospital's triage policy had been revised to ensure that physical distancing could be maintained. Part of this policy revision included discharging patients who may find it difficult to comply with these protocols due to 'behavioural challenges'.

Human rights considerations

The hospital appears to have made assumptions about Genevieve's ability to adhere to physical distancing protocols on the basis of her disability.

Genevieve has the right to be treated without discrimination based on her disability.⁷⁰ Genevieve has a right to the highest attainable standard of health.⁷¹ This includes 'health-related rehabilitation' and health services designed to 'minimize and prevent further disabilities'.⁷²

Realising rights in practice

When a hospital puts in place a discharge policy designed to minimise in-hospital disease transmission, the following steps may assist in ensuring the rights of people with disability are protected:

- clearly articulating within the policy that the decision to discharge should:
 - be clinically based
 - include an assessment of the physical and mental health of the individual patient
 - require dual sign-off, by two senior doctors
- where a decision is reached to discharge a person with disability, the discharge process should include confirmation of at-home supports and a follow-up plan. Where consent is provided this should include direct communication between the hospital and support persons.

6.5 Limited resources

Kenji has COVID-19 and has been in hospital in regional Australia for ten days. Overnight his condition has worsened and he has been moved into one of the hospital's ten intensive care beds. Kenji is 12 years old and has Down syndrome.

After two days in the intensive care unit (ICU), Kenji's condition has continued to decline and it is likely he will require ventilation. The hospital has three ventilators, with two already in use. In addition to Kenji, there are two other children in ICU who are also likely to require ventilation if they deteriorate any further.

In anticipation of having to allocate the last ventilator the hospital's two most senior intensive care specialists meet to discuss prioritisation. All patients are a similar age. Kenji receives a lower priority than the other two patients in relation to access to a ventilator.

Human rights considerations

Kenji's family are concerned that the specialists have made an assumption about Kenji's likelihood of surviving ventilation based on his Down syndrome diagnosis.

Kenji has the right to be treated without discrimination based on his disability.⁷³ Kenji also has the right to the highest attainable standard of health,⁷⁴ and most importantly the right to life.⁷⁵ Kenji has a right to the effective enjoyment of life 'on an equal basis with others'.⁷⁶ In addition, as a child, Kenji has a specific right to enjoy all of his human rights, including the right to life, on 'an equal basis with other children'.⁷⁷

Realising rights in practice

When a hospital and its senior intensive care specialists prioritise the provision of limited life-saving resources, like ventilators, the following steps may assist in ensuring the rights of people with disability are protected:

- clearly articulating within any applicable policy (including one derived from the ANZICS General Principles) that all decisions must:
 - be clinically based
 - include a medical assessment of the individual patient
 - not be based on assumptions about the quality of a person's life after treatment because of their disability
- providing for an independent review of any decision not to allocate lifesaving resources to a person with disability or otherwise
- providing patients with access to an independent health advocate.

6.6 'Do not resuscitate' directions

Sean lives in an aged care facility. There has recently been an outbreak of COVID-19 in another facility owned by the same operator. The operator has asked all its facilities to support residents to 'get their affairs in order' including providing template advance care directives which include 'do not resuscitate' directions in the event of a COVID-19 outbreak at the facility.

The operator has taken this step on the basis that most of the facility's residents are near the end of their life and having a 'do not resuscitate' direction in place will allow them to avoid a traumatic medical intervention.

Sean has cerebral palsy and uses a wheelchair. He is 55 years old.

The manager of Sean's facility has followed up with him twice to collect the signed form. Sean does not want to sign the form and has made this clear to the manager, but the manager continues to insist.

Human rights considerations

The manager of Sean's facility appears to have made an assumption about his right to life saving intervention based on his residence at the facility, which is directly connected to his disability. The operator may also have made improper assumptions about the wishes of the residents as a whole, in the way in which 'do not resuscitate' directions have been solicited. Aside from any breaches of professional conduct rules or legal regulations that may apply to the conduct of the manager or the operator, the manager's conduct is potentially a breach of Sean's human rights.

Sean has the right to be treated without discrimination based on his disability.⁷⁸ Sean also has the right to the highest attainable standard of health,⁷⁹ and most importantly the right to life.⁸⁰ Sean has a right to the effective enjoyment of life 'on an equal basis with others'.⁸¹ A key part of Sean's being able to realise all of these rights is his right to be able to exercise his legal capacity without 'undue influence' and with appropriate communication support.⁸² If Sean needs support in exercising his legal capacity he has a right to access that support.⁸³

Realising rights in practice

Providing residents with a pre-prepared treatment direction of any type and asking them to sign it is likely to raise a presumption of undue influence.

To support the protection of the rights of people with disability, and others, in a residential care setting it should be clear in the operator's policies that residents should not be asked to sign any documentation without access to an independent advocate who can communicate in an accessible manner and support them in making a decision.

7 Additional resources

Information about COVID-19

For additional information and resources relating to the impact of COVID-19 on people with disability please refer to the dedicated webpages of the following agencies and organisations:

- [Department of Health](#)⁸⁴
- [Department of Social Services](#)⁸⁵
- [Australian Human Rights Commission](#)⁸⁶
- [Ideas](#)⁸⁷
- [Queenslanders with Disability Network](#).⁸⁸

State and territory human rights commissions

Links to the websites of each of the state and territory human rights commissions or agencies can be found on the [Australian Human Rights Commission's website](#). These provide information on the anti-discrimination and human rights legislation in place around Australia.

Endnotes

¹ Samuel Bagenstos, 'May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing' (2020/2021) 130 *Yale Law Journal Forum* 1.

² *Disability Discrimination Act 1992* (Cth) s 67(1)(k).

³ *Australian Human Rights Commission Act 1986* (Cth) s 11(1)(n).

⁴ It should be noted the field of bioethics is distinct from international human rights law. This distinction is beyond the scope of these Guidelines but further information may be found in Catalina Devandas Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, UN Doc A/HRC/43/41 (17 December 2019) and the papers referred to therein.

⁵ Committee on the Rights of Persons with Disabilities, 'Statement on COVID-19 and the human rights of persons with disabilities', *UN Office of the High Commissioner for Human Rights* (Web Page, 9 June 2020)

<<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25942&LangID=E>>.

⁶ 'The Committee on the Rights of Persons with Disabilities (CRPD) is the body of independent experts which monitors implementation of the CRPD by the States Parties. All States parties are obliged to submit regular reports to the Committee on how the rights are being implemented.' See the CRPD Committee's website for further information:

<<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>>.

⁷ *Disability Discrimination Act 1992* (Cth) s 4(1).

⁸ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Summary of Findings 2018* (Catalogue No 4430.0, 24 October 2019).

⁹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Summary of Findings 2018* (Catalogue No 4430.0, 24 October 2019).

¹⁰ Australian Institute of Health and Welfare, *People with Disability in Australia* (Cat no DIS 72, September 2019) <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/personal-factors>>.

¹¹ Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Summary of Findings 2018* (Catalogue No 4430.0, 24 October 2019).

¹² Australian Institute of Health and Welfare, *People with Disability in Australia* (Cat no DIS 72, September 2019) <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/social-support>>.

¹³ 'Diagnostic overshadowing' in the context of disability refers to a situation where a health professional makes an assumption that a patient's symptoms are related to their disability, rather than exploring alternative causes. This may result in a delay in appropriate treatment.

¹⁴ Transcript of Proceedings, *Public Hearing – Day 9 – Health care*, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (28 February 2020), <<https://disability.royalcommission.gov.au/publications/transcript-day-9-health-care-sydney>>.

¹⁵ 'Community update: COVID-19', *Australian Human Rights Commission* (E-Bulletin, 8 April 2020) <<https://www.humanrights.gov.au/about/news/e-bulletin/community-update-covid-19-8-april-2020>>.

¹⁶ 'Statement of Concern: The response to the COVID-19 pandemic for people with disability' *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Publication, 26 March 2020) <<https://disability.royalcommission.gov.au/system/files/2020-03/COVID-19%20Statement%20of%20concern.pdf>>.

¹⁷ Robin Banks et al, 'Statement of concern-COVID-19: human rights, disability and ethical decision making', *Disabled People's Organisations Australia* (Publication, 14 April 2020) <https://dpoa.org.au/wp-content/uploads/2020/04/Statement-of-Concern-COVID-19-Human-rights-disability-and-ethical-decision-making_Final.pdf>.

¹⁸ Catalina Devandas Aguilar, Special Rapporteur, 'COVID-19: Who is protecting the people with disabilities? – UN rights expert', *UN Office of the High Commissioner for Human Rights* (Web Page, 17 March 2020) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725&LangID=E&fbclid=IwAR0BtrEp7xOtFIARx_MRhcdxTyNJCvymIS0eBi55zc8Q4P9QysdtzvZDS3k>.

¹⁹ "No exceptions with COVID-19: "Everyone has the right to life-saving interventions" – UN experts say', *UN Office of the High Commissioner for Human Rights* (Web Page, 26 March 2020) <<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25746&LangID=E>>.

²⁰ Antonio Guterres, 'We have a unique opportunity to design and implement more inclusive and accessible societies', *United Nations COVID-19 response* (Web Page, 6 May 2020) <<https://www.un.org/en/coronavirus/we-have-unique-opportunity-design-and-implement-more-inclusive-and-accessible-societies>>.

²¹ 'COVID-19: Bachelet urges States to take extra steps to include people with disabilities', *UN Office of the High Commissioner for Human Rights* (Web Page, 30 April 2020), <<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25847&LangID=E>>.

²² 'Policy Brief: Disability-Inclusive Response to COVID-19', *UN Sustainable Development Group* (Publication, May 2020) <<https://unsdg.un.org/resources/policy-brief-disability-inclusive-response-covid-19>>.

²³ World Health Organization, 'Addressing human rights as key to the COVID-19 response', (Publication, 21 April 2020) <<https://www.who.int/publications-detail/addressing-human-rights-as-key-to-the-covid-19-response>>.

²⁴ 'COVID-19: Ethical decision-making for First Peoples Living with Disability', *First Peoples Disabilities Network Australia* (Publication, April 2020) <<https://fpdn.org.au/wp-content/uploads/2020/04/COVID-19-Ethical-decision-making-for-First-Peoples-Living-with-Disability.pdf>>.

²⁵ See for example: Hannah Kuper et al, 'Disability-inclusive COVID-19 response: What it is, why it is important and what we can learn from the United Kingdom's response', [version 1; peer review: 2 approved] *Wellcome Open Research* (Kuper et al Open Letter, 28 April 2020) <<https://doi.org/10.12688/wellcomeopenres.15833.1>>; and 'Disability, COVID-19 and Triage: Exploring Resource Allocation and the Framing of Disability', *Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School* (Web Page, 14 April 2020) <<https://petrieflom.law.harvard.edu/events/details/book-launch-disability-health-law-and-bioethics>>.

²⁶ Office of the High Commissioner for Human Rights, 'COVID-19 and the Rights of Persons with Disabilities: Guidance' (Publication, 29 April 2020) <https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf>.

²⁷ The CRPD is applicable to all levels of government by virtue of Article 4(5).

²⁸ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 90.

²⁹ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 91.

³⁰ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 92.

³¹ 'Intersectionality' refers to the overlapping characteristics of a person's identity (for example, race, gender, sexual orientation, disability) which may combine to result in discrimination and disadvantage.

³² Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 93.

³³ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 93.

³⁴ Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12: Equal Recognition before the Law*, UN Doc CRPD/C/GC/1 (11 April 2014) [17].

³⁵ 'OCR Issues Bulletin on Civil Rights Laws and HIPAA Flexibilities That Apply During the COVID-19 Emergency', *US Department of Health and Human Services* (Press Release, 28 March 2020) <<https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html>>.

³⁶ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 95.

³⁷ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 2.

³⁸ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 97.

³⁹ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 98.

⁴⁰ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 101.

⁴¹ Ilias Bantekas et al *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 102.

⁴² *Disability Discrimination Act 1992* (Cth) ss 3, 5, 6.

⁴³ *Disability Discrimination Act 1992* (Cth) ss 5(2), 6(2). The concept of 'reasonable adjustments', as referenced in the *Disability Discrimination Act 1992* (Cth), is similar to the concept of 'reasonable accommodation' in the CRPD. *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁴⁴ 'Human rights-based approaches', *Australian Human Rights Commission* (Web Page, 18 June 2013) <<https://www.humanrights.gov.au/our-work/rights-and-freedoms/human-rights-based-approaches>>.

⁴⁵ 'Clinical Frailty Scale', *Dalhousie University* (Web Page, 25 June 2020) <<https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale.html>>.

⁴⁶ 'Clinical Frailty Scale', *Specialised Clinical Frailty Network* (Web Page, 25 June 2020) <<https://www.scfn.org.uk/clinical-frailty-scale>>.

⁴⁷ Ruth Hubbard et al 'Frailty in the Face of COVID-19' (July 2020) 49(4) *Age and ageing* 499, 500.

⁴⁸ Ruth Hubbard et al 'Frailty in the Face of COVID-19' (July 2020) 49(4) *Age and ageing* 499, 500.

⁴⁹ 'Guiding principles for complex decision making during Pandemic COVID-19', *The Australian and New Zealand Intensive Care Society* (Publication, undated) <https://www.anzics.com.au/wp-content/uploads/2020/04/ANZI_3367_Guiding-Principles.pdf>.

⁵⁰ 'Guiding principles for complex decision making during Pandemic COVID-19', *The Australian and New Zealand Intensive Care Society* (Publication, undated) 4 <https://www.anzics.com.au/wp-content/uploads/2020/04/ANZI_3367_Guiding-Principles.pdf>.

⁵¹ 'Guiding principles for complex decision making during Pandemic COVID-19', *The Australian and New Zealand Intensive Care Society* (Publication, undated) 6 <https://www.anzics.com.au/wp-content/uploads/2020/04/ANZI_3367_Guiding-Principles.pdf>.

⁵² See also CRPD article 4(3) (duty to consult with people with disability), article 6 (women), article 7 (children), article 14 (right to liberty and security of the person), article 17 (physical and mental integrity), article 23 (family), article 31 (collection of data): *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

⁵³ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 11.

⁵⁴ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁵⁵ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 10.

⁵⁶ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5; Committee on the Rights of Persons with Disabilities, *General Comment No 6: Article 5: Equality and non-discrimination*, UN Doc CRPD/C/GC/6 (26 April 2018).

⁵⁷ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 12.

⁵⁸ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) arts 9, 21; Committee on the Rights of Persons with Disabilities, *General Comment No 2: Article 9: Accessibility*, UN Doc CRPD/C/GC/2 (22 May 2014).

⁵⁹ Please note that real names are not used.

⁶⁰ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁶¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 20.

⁶² *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁶³ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁶⁴ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁶⁵ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) arts 9, 21; Committee on the Rights of Persons with Disabilities, *General Comment No 2: Article 9: Accessibility*, UN Doc CRPD/C/GC/2 (22 May 2014) [40].

⁶⁶ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁶⁷ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

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⁶⁹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008). art 25.

⁷⁰ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁷¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁷² *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁷³ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁷⁴ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁷⁵ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 10.

⁷⁶ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 10.

⁷⁷ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 7.

⁷⁸ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 5.

⁷⁹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 25.

⁸⁰ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 10.

⁸¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 10.

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⁸³ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 12.

⁸⁴ 'Coronavirus (COVID-19) advice for people with disability', *Australian Government Department of Health* (Web Page, 17 July 2020) <<https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability>>.

⁸⁵ 'Information and referrals for people with disability and their supporters about coronavirus (COVID-19)', *Australian Government Department of Social Services* (Web Page, 21 July 2020) <<https://www.dss.gov.au/disability-and-carers/information-and-referrals-for-people-with-disability-and-their-supporters-about-coronavirus-covid-19>>.

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