

Elizabeth's Scenario

Facts

Elizabeth is a 64-year-old recent retiree who has been receiving dialysis. She is refusing further treatment, which will ultimately result in her death. Given the nature of the decision, the treating team questions her capacity to refuse treatment. Elizabeth's capacity has not previously been impaired.

Issue

There are two key human rights questions that arise in Elizabeth's scenario: could any of the possible assessors amount to a public entity for the purposes of the HRA, and if so, what human rights would likely be engaged?

In general, a human right is engaged when a law or the act of a public entity interferes with or limits the enjoyment or exercise of a human right by a person.¹

Thus, any decision-maker that amounts to a public entity under the HRA is legally obligated to act compatibly, both in a substantive and procedural sense, with any of Elizabeth's human rights protected by the HRA that would likely be interfered with or limited by their conduct.

This legal obligation will not arise, however, if a law permits the decision-maker to limit the human right in a way that is reasonable and justifiable² or any of the potential exceptions to the public entity obligations arise.³

In order to determine whether a right is engaged, it is necessary to identify and understand the meaning and content of the right in a purposive way by reference to the values and interests that it represents and protects.⁴ Ascertaining the meaning and content of the right in this way establishes the defined scope of the right.⁵ Once the boundaries of the right are delineated, it can be said that public entities must respect all the freedoms that the right affords the individual person within its defined boundaries.⁶

Analysis

Elizabeth's scenario consists of two categories of decision-makers: those undertaking a capacity assessment and those acting as a substitute-decision maker.

Capacity Assessment

Persons undertaking a capacity assessment

A capacity assessment can be carried out by a family member, friend or colleague, health professional, social worker, support worker or advocate, person who works in the law, including a lawyer or a justice of the peace (JP), worker in a financial institution or an Aged Care Assessment Team worker.⁷ A public entity is defined as an organisation in and for Queensland.⁸ This would include public hospital but may exclude many other important health organisations.⁹ This includes exempting federal public services and entities.¹⁰ Additionally, private hospitals and private healthcare providers will be exempt unless they are treating public patients.¹¹

Anyone who carries out a capacity assessment in a private capacity, such as a family member, friend or colleague, would not amount to a public entity.¹²

However, anyone undertaking a capacity assessment in their position as an employee of an organisation that performs a function of a public nature on behalf of the state of Queensland such as a health professional employed by a public residential aged care service facility (since it is operated by the Queensland Government), would amount to a public entity.

Notably as well, a JP would amount to a functional public entity because they provide services to the community on behalf of the government.¹³

Human Rights engaged?

Undertaking a capacity assessment and the results of such an assessment can engage several human rights.¹⁴

These include, but are not limited to, the right to equality before the law,¹⁵ the right not to be treated in a cruel, inhuman or degrading way,¹⁶ the right not to be subjected to any medical treatment without full, free and informed consent,¹⁷ the right to not have one's privacy unlawfully or arbitrarily interfered with,¹⁸ the right to liberty and security of the person¹⁹ and the right to humane treatment when deprived of liberty^{20, 21}

¹ *PBU & NJE v Mental Health Tribunal and Others* [2018] VSC 564 [105].

² HRA s 13.

³ *Ibid* s 58(2) – (4).

⁴ *PBU & NJE v Mental Health Tribunal and Others* [2018] VSC 564, [105].

⁵ *Ibid* [108].

⁶ *Ibid*.

⁷ Attorney-General and Minister for Justice, *Queensland Capacity Assessment Guidelines 2020* (Guide, Version 1, 2020) 6.

⁸ HRA s 9(5).

⁹ https://www.qhrc.qld.gov.au/data/assets/pdf_file/0008/19907/QHRC_factsheet_HRA_WhatIsAPublicEntity.pdf

¹⁰ *Ibid*; HRA s58(2).

¹¹ *Ibid*.

¹² HRA s 58(3).

¹³ HRA s 9(1)(h); <https://www.publications.qld.gov.au/dataset/human-rights-in-decision-making-guide-for-jps-and-cdecs>.

¹⁴ Attorney-General and Minister for Justice, *Queensland Capacity Assessment Guidelines 2020* (Guide, Version 1, 2020) 8.

¹⁵ HRA s 15(3)-(4).

¹⁶ *Ibid* s 17(b).

¹⁷ *Ibid* s 17(c).

¹⁸ *Ibid* s 25(a).

¹⁹ *Ibid* s 29(1).

²⁰ *Ibid* s 30(1).

²¹ *PBU & NJE v Mental Health Tribunal and Others* [2018] VSC 564, [110].

Of these rights, three particularly relevant human rights include the right to equality before the law, the right to not be subjected to medical treatment without consent and the right to not have one's privacy unlawfully or arbitrarily interfered with.²²

Right to equality before the law

Meaning and content of the right

The right to equality before the law is located in s 15(3)-(4) of the HRA as part of the broader right to recognition and equality before the law.

Section 15(3) and (4) state:

- (3) Every person is equal before the law and is entitled to the equal protection of the law without discrimination.
- (4) Every person has the right to equal and effective protection against discrimination.

The purpose of this right is to protect the inherent and universal dignity of human persons.²³

The right under s 15(3) and (4) has three elements.²⁴ In relation to questions of capacity, the right to equal protection of the law without discrimination and the right to equal and effective protection against discrimination are particularly relevant (i.e. last two limbs).²⁵

Application

A capacity test similar to the one in question has been framed as a functional test where the question is whether the person has the *ability* to remember and use or weigh relevant information and communicate a decision and not whether the person has *actually* done so.²⁶ Framing the test this way respects the right to equality before the law, namely, it ensures people with mental illness (i.e. those whose capacity are in question) are afforded the same respect for their inherent dignity and autonomy that people without illness whose capacity is not in question are afforded.²⁷

Right to not be subjected to medical treatment without consent

Meaning and content of the right

The right to not be subjected to medical treatment without consent is located in s 17(c) of the HRA as part of the broader right to protection from torture and cruel, inhuman or degrading treatment.

The general starting point of this particular right has been explored in a Victorian Supreme Court case and found to be "the paramount consideration that a person is entitled to make his own decisions about his life".²⁸

Forcing a person of full mental capacity to have unwanted medical treatment seriously undermines their personal dignity and autonomy.²⁹ Personal dignity underpins this right.³⁰

Whether treatment is medically warranted is not relevant at this point.³¹ The person in question is presumed to have full mental capacity.³² The right to refuse unwanted medical treatment enables the person to choose what should happen to them and thereby protects that person's individuality, dignity and autonomy.³³

Application

In undertaking a capacity assessment, while the presumption that Elizabeth retains full mental capacity remains in effect, forcing Elizabeth to receive further treatment that she has rejected would amount to an absolute violation of her right to not be subjected to medical treatment without consent on the basis it seriously undermines her personal dignity and autonomy.

Right to not have one's privacy unlawfully or arbitrarily interfered with

Meaning and Content of the Right

The right not to have one's privacy unlawfully or arbitrarily interfered with is located in s 25(a) of the HRA as part of the broader right to not have one's privacy, family, home or correspondence unlawfully or arbitrarily interfered with.

The right to privacy protects people from unjustified interference with their personal and social individuality and identity.³⁴

It has been interpreted to include protection of self-determination and personal inviolability.³⁵

²² Ibid [111].

²³ Ibid [113].

²⁴ HRA s 15(1) – (5).

²⁵ *PBU & NJE v Mental Health Tribunal and Others* (2018) 56 VR 141 [114]-[116].

²⁶ Ibid [206].

²⁷ Ibid.

²⁸ *Re Kracke v Mental Health Review Board* (2009) 29 VAR 1 [569].

²⁹ Ibid.

³⁰ Ibid.

³¹ Ibid.

³² Ibid.

³³ Ibid.

³⁴ Ibid [125].

³⁵ Ibid [127]-[128].

Self-determination relates to the capacity of people to determine who they are, how they will live their lives and what should be done to them.³⁶ Notably, since the exercise of self-determination requires personal autonomy, often a term used interchangeably with self-determination, it is also said the right to privacy protects personal autonomy.³⁷

Personal inviolability relates to the freedom of all persons not to be subjected to physical or psychological interference, including medical treatment, without consent.³⁸

While it has been stressed these rights are not absolute and may be limited by the law when reasonable and justifiable,³⁹ the starting point is that people with a mental disability have the same right of self-determination and the same right to personal inviolability as everybody else.⁴⁰

Application

In assessing capacity, the assessor must respect the person's right to privacy and its encompassing values of self-determination and personal inviolability.

One central consideration is that a finding of impaired capacity should not be made simply because, in the decision-makers view, the person made a decision that was bad, unwise, the person may not have engaged in the assessment process, unreasonable or not sensible, rational or well-considered.⁴¹ Making such a finding on one of these grounds directly offends the person's right to self-determination, and in turn, the individual dignity of the person in question.⁴² The person has the right to make their own decisions that accord with their own values due to the consideration and acceptance of the value of dignity of risk.⁴³

Understandably, there is a natural tendency to make a decision in the best interests of vulnerable persons and thus assess capacity on the grounds of whether the decision made by the person was reasonable.⁴⁴ Despite these good intentions, however, the decision made is irrelevant to whether the person has capacity and the focus must be upon the ability of the person to exercise a decision-making process itself.⁴⁵ Focusing on the outcome is said to 'penalise individuality and demand conformity at the expense of personal autonomy'.⁴⁶ In any event, a decision to consent to or refuse medical treatment is inherently subjective thereby making it difficult if not impossible for another to objectively characterise it as unreasonable or not.⁴⁷

Ultimately therefore, the capacity test must be applied in a way that is 'criteria-focused, evidence-based, patient-centred and non-judgemental'.⁴⁸

More generally, in undertaking a capacity assessment, there are several 'do's' and 'don'ts' that must be understood by the decision-maker to respect the adult's privacy.⁴⁹

The assessor *should* only ask the adult for their information, this information must be relevant to the decision, the information collected should only be used for the purposes of the assessment and the adult's permission should be obtained before sharing their information with others.⁵⁰

The assessor *should not* obtain the adult's personal information from others without first seeking their consent, seek information that doesn't relate to the assessment, use information for other purposes without first seeking the adult's consent and disclose the adult's personal information to others not related to the assessment process.⁵¹

Substitute decision-making

Persons acting as a substitute decision-maker

If Elizabeth is found to have impaired capacity and in the absence of any advanced health directive it may be necessary to appoint a substitute decision-maker, that is, a Queensland Civil and Administrative Tribunal (QCAT) appointed guardian, an enduring power of attorney or a person such as Elizabeth's close family members maybe considered to exercise automatic health care decision making power on Elizabeth's behalf (called a Statutory Health Attorney).

For any person appointed as a QCAT guardian, an enduring power of attorney or a statutory health attorney that amounts to a 'public entity' for the purposes of the HRA, they would be subject to the public entity obligations (for example, the Public Guardian or delegate).

However, even if the person appointed does not amount to a public entity, they are still legally obligated to apply a set of 'general principles'.⁵² Notably as well, they must apply a set of 'health care principles' whenever they are called upon to make a decision about a health care matter.⁵³

One important general principle is that the human rights of all adults, regardless of their particular capacity, must be recognised and taken into account.⁵⁴ In addition, another principle states the human rights of the adult in question be empowered.⁵⁵

Accordingly, any person acting a substitute decision-maker in Elizabeth's scenario are likely obligated to recognise and take into account Elizabeth's human rights in making a decision on the health care issue.

³⁶ Ibid [127].

³⁷ Ibid.

³⁸ Ibid [128].

³⁹ HRA s 13.

⁴⁰ *PBU & NJE v Mental Health Tribunal and Others* (2018) 56 VR 141 [127]-[128].

⁴¹ Ibid [164]-[166].

⁴² Ibid [165].

⁴³ Ibid [164].

⁴⁴ Ibid [167].

⁴⁵ Ibid [168].

⁴⁶ Ibid.

⁴⁷ Ibid [169].

⁴⁸ Ibid [172].

⁴⁹ Attorney-General and Minister for Justice, *Queensland Capacity Assessment Guidelines 2020* (Guide, Version 1, 2020) 14.

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² *Guardianship and Administration Act 2000* s 11B.

⁵³ Ibid s 11C.

⁵⁴ Ibid s 11B(3).

⁵⁵ Ibid.

Human Rights engaged

A variety of human rights are potentially relevant for a substitute-decision maker in this context.⁵⁶

However, it is particularly important to recognise and respect the person's right to self-determination protected under their right to privacy.⁵⁷

It is recommended that the decision-maker ascertain the views and preferences of the person, provide information about the decision and options available to the person and try support the person to reach a decision themselves which you can then make.⁵⁸

If they cannot obtain the person's views and preferences, it is advisable that they 'stand in their shoes' and make the decision that they believe the person would have made, having regard to anything they said or indicated in the past, the views of family and friends and sometimes views of service providers, health care professionals and carers.⁵⁹

If there are several available options, the option that should be favoured is the option that least restricts the person's freedom of action.⁶⁰ The main priority should be acting in the welfare and interests of the person even if it means acting in a way that the family or carers disagree with.⁶¹

Once the substitute-decision maker has made a decision their obligation does not end there. It is important for the substitute-decision maker to include the person by: explaining to them the decision made, the impact it will have on their life, the reasons why it was made and what they can do if they disagree with the substitute-decision maker's decision.⁶²

Finally, throughout the whole decision-making process, the substitute-decision maker must only exercise the powers and functions conferred to the substitute-decision maker by the relevant law to respect the person's right to make decisions about other areas of their life.⁶³

QCAT

In the context of capacity and decision-making for adults, QCAT has the power to make decisions on a range of matters, such as making a declaration about the person's decision-making capacity or about the execution and appointment of an enduring power of attorney, appointing a guardian to make some or all personal and health care decisions or making temporary decisions to deal with an urgent situation.⁶⁴

Under the HRA, a court or tribunal will amount to a public entity only when they are acting in an administrative capacity.⁶⁵ Tribunals, such as QCAT, often act in an administrative capacity by, for example, reviewing administrative decisions made by government departments, conducting disciplinary proceedings, appointing guardians and administrators and reviewing involuntary treatment orders.⁶⁶

Accordingly, QCAT would be subject to the public entity obligations under the HRA in deciding to appoint a healthcare guardian for Elizabeth's healthcare matters.

⁵⁶ National Association of Community Legal Centres, *How guardians and attorneys can promote, respect and protect human rights* (Fact Sheet, 2013) 2.

⁵⁷ National Association of Community Legal Centres, *How guardians and attorneys can promote, respect and protect human rights* (Fact Sheet, 2013) 4.

⁵⁸ *Ibid.*

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

⁶¹ *Ibid.*

⁶² *Ibid.*

⁶³ *Ibid.*

⁶⁴ <https://www.qcat.qld.gov.au/matter-types/guardianship-for-adults-matters/qcat-decisions-about-adults>

⁶⁵ HRA s 9(4)(b).

⁶⁶ Queensland Human Rights Commission, 'The role of courts and tribunals under the Human Rights Act 2019', *The role of courts and tribunals* (Fact Sheet, July 2019) <<https://www.qhrc.qld.gov.au/your-rights/human-rights-law/the-role-of-courts-and-tribunals>>.