

This submission will emphasise the importance of avoiding a “one size fits all” approach when considering policy options relating to people with different levels of intellectual disability. Many of the contributions so far have emphasised the circumstances of people with mild intellectual disability, who may have the capacity to consent but are not encouraged to exercise their autonomy. The result of this focus is the denial of the rights of those who have more severe intellectual disability, and are unable to consent to any medical procedures (as is the case in many of the stories told by parents in submissions to this inquiry).

The idea of “forcibly” sterilising people is, at first glance, patently reprehensible. But to view this issue in an even-handed way, we also need to conceptualise a total ban on non-therapeutic sterilisation as “forcing” some people to retain their fertility. If the law were to prevent all non-therapeutic sterilisations for people lacking the capacity to consent, this would curtail “autonomy” in the same way as forced sterilisations would.

It is not discrimination to allow people with severe intellectual disability to undergo a sterilisation procedure, where it is in their best interests to do so. It may seem discriminatory because, on the face of it, in the absence of their intellectual disability, sterilisation would not be contemplated. However, this is not the case. Even without an intellectual disability, if I were told that any children I produced would be removed by Community Services, I would elect to be sterilised. I tolerate a monthly period only because I wish to have children. It is absurd to suggest that people who have little capacity to manage menstruation and no capacity to care for children, should nevertheless suffer menstruation. Those advocating that they should maintain their fertility even where it detracts from their quality of life have not advanced any reasons why they should be forced to do so, other than relying on an assertion that sterilisation is violence, and violence is always bad.

People with mild intellectual disability, who, with support, are able to make informed decisions about their fertility, should be encouraged to do this. Their right to autonomy should not be curtailed, and should be supported by law. People with mild intellectual disability, who, with support, are able to care for children they have produced, should also be assisted in this, in every way that society can manage. However, for people with more severe intellectual disability, this form of support is irrelevant. They will not be able to exercise their “right to decide freely and responsibly the number and spacing of their children”. The mention of this “right” in relation to individuals with severe intellectual disability paints the authors as manifestly out of touch with the realities of severe intellectual disability.

In Marion’s case, the High Court said that where a person is unable to provide consent, it is the responsibility of the court to decide whether it is in a person’s best interests to undergo a sterilisation procedure. Some people have expressed concern that if courts are charged with making decisions about a person’s best interests, such decisions would be arbitrary. Jurisdictions such as the ACT and Tasmania have implemented comprehensive guidelines on

how a court is to make decisions according to a person's best interests. They include a consideration of a person's wishes, to the extent that these can be ascertained. If a total ban were to be adopted, the views of those who were deemed technically incapable of providing consent, but who were close to meeting the threshold, would be completely disregarded. In "standing up for" the rights of people with intellectual disability, therefore, rights organisations are saying that the only opinions that matter are those of the people who are declared to have full decision-making capacity.

Deciding cases according to each individual's best interests will not be arbitrary if an appropriate legal test is adopted. The following approaches could therefore be implemented nationally:

In **Victoria**, the Victorian Civil and Administrative Tribunal must decide according to the principles in s 4(2) of the *Guardianship and Administration Act 1986*:

- The means which is least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted; and
- The best interests of a person with a disability are promoted; and
- The wishes of a person with a disability are wherever possible given effect to.

In **Tasmania**, the Guardianship and Administration Board must consider the principles outlined in s 6 of the *Guardianship and Administration Act 1995*:

- The means which is the least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted; and
- The best interests of a person with a disability or in respect of whom an application is made under this Act are promoted; and
- The wishes of a person with a disability or in respect of whom an application is made under this Act are, if possible, carried into effect.

To determine best interests, matters to be taken into account by the Board include those set out in s 45:

- The wishes of that person, so far as they can be ascertained; and
- The consequences to that person if the proposed treatment is not carried out; and
- Any alternative treatment available to that person; and
- Whether the proposed treatment can be postponed on the ground that better treatment may become available and whether that person is likely to become capable of consenting to the treatment.

In the **ACT**, under the *Guardianship and Management of Property Act 1991*, the ACT Civil and Administrative Tribunal may give consent where:

- The person is not competent to give consent and is not likely to become competent in the foreseeable future; and
- The procedure would be in the person's best interests.

The Tribunal must take into account:

- The wishes of the person, so far as they can be ascertained; and
- What would happen if it were not carried out; and
- What alternative treatments are available; and
- Whether it can be postponed because better treatments may become available.