By Catherine Carroll and Gemma McGrath

Intellectual disability and the right to family life

Equality under the law

In July 2013, the Senate Standing Committee on Community Affairs issued the report of its inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia.[1] This offered an opportunity to revisit the complex and challenging issue of the rights of a person with an intellectual disability, particularly rights relating to fertility and the ability to procreate.

The committee received 91 submissions from a broad range of organisations and individuals. One of the most remarkable features of this issue is that, while the views of interested parties vary enormously as to the appropriate approach that should be taken by lawmakers in this country, the starting point of all the submissions was almost universal. That is, the debate is based on a common commitment to create or preserve rights for a person with an intellectual disability commensurate with the rights available to a person without a disability. The divergence occurs when considering how this should best be achieved.

CURRENT POSITION IN AUSTRALIA

The complexity of this issue starts with the current legislative and common law regime in Australia. While there are some common themes throughout the common law and in legislation, there is currently no uniformity in the legislation from one state to the next. Similarly, the laws and procedures affecting minors differ in certain respects from those relating to adults who are deemed to have a decision-making incapacity.

Adults

The rights of an adult who may, by reason of an intellectual disability, have a decision-making incapacity, are subject to guardianship legislation, which varies between states. Most of the state Guardianship Acts afford some protection of adult women's rights and interests by requiring an application to the Guardianship Tribunal (or its equivalent) before any sterilisation procedure can lawfully be performed.[2] There are exceptions in most states for emergency sterilisation procedures that are required to save the person's life or prevent serious damage to health.

The legislation also goes some way to outlining the circumstances in which the Tribunal (or its equivalent) may consent to the sterilisation of individuals. Except for that of NSW, the Acts import some notion of determining what is in the 'best interests' of the affected person. There is substantial variation in what this expression means.[3]

Minors

The High Court decision in *Marion's Case*[4] reflects the common law that applies to decisions affecting minors. The case was an application for an order permitting the sterilisation of 'Marion', a teenage girl with an intellectual disability. It involved the distinction between a therapeutic and a non-therapeutic sterilisation. Therapeutic sterilisation is either a 'by-product of surgery appropriately carried out to treat some malfunction or disease' or 'an incidental result of surgery performed to cure a disease or correct some malfunction'.[5] The High Court stated that therapeutic sterilisations do not require court authorisation. The case does not provide further guidance on the distinction between therapeutic and non-therapeutic sterilisations, and this is a point of some concern, as there is potential ambiguity in those terms between their legal and medical meanings.

Leaving aside this definitional problem, *Marion's Case* sets out a decision-making pathway for the lawful sterilisation of an intellectually disabled minor. First, if the child has the decision-making capacity to fully understand the type of medical treatment and its consequences, then the child must provide her informed consent to the procedure.

Second, if the child does not have that capacity and the sterilisation is classed as therapeutic sterilisation, then the parent or carer may consent to the procedure.

Third, if the child does not have that capacity and the sterilisation is categorised as non-therapeutic, then the Family Court must authorise the procedure, in order to ensure that it is in the best interests of the child. This involves a consideration of side-effects on the child, available alternatives, and whether the procedure is 'necessary to enable her to lead a life in keeping with her needs and capabilities'.[6]

PROBLEMS ARISING FROM THE CURRENT LEGISLATIVE AND JUDICIAL FRAMEWORK

The inconsistency in laws between the states means that the rights of a disabled person vary according to the jurisdiction in which they live. In some states, there is a pronounced difference between the stringency of tests applied to adults compared with those for minors. Furthermore, the legislative frameworks do not usually involve sanctions or criminal penalties for people who carry out an unlawful sterilisation. It follows that the remedy from a breach of the law in this regard is either civil proceedings or disciplinary proceedings against a medical or legal practitioner. Some submissions to the Senate inquiry argued that there ought to be a criminal sanction for unlawful sterilisation procedures.

WHAT RIGHTS EXIST IN LAW?

The starting point for any discussion about improving the decision-making regime needs to be a consideration of the rights that currently exist in law. The question that follows closely from this is whether all of those rights can be protected and, if so, how?

Australia has rights and obligations under international laws and treaties; in particular, the *Convention on Rights of Persons with Disabilities* (CRPD), which was ratified by Australia in 2008. Specifically, article 23(c) of the CRPD provides that people with disabilities, including children, will retain their fertility on an equal basis with others. Similarly, article 12 of the CRPD provides that people with disabilities have the right to legal recognition, and to enjoy legal capacity, on an equal basis with others. Importantly, this right includes access to the support necessary to exercise their legal capacity.[7]

The Senate report acknowledged that as a signatory to this treaty (and others), Australia has chosen to be bound by the treaty requirements. It follows that Australia must give effect to their terms in good faith.[8] In particular, Women With Disabilities Australia (WWDA) submitted that sterilisation in the absence of the person's free and informed consent is a clear violation of Australia's obligations under international law.[9] Similarly, the Australian Lawyers for Human Rights, the Women's Legal Service of New South Wales, and

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People with Disabilities Australia all attached significance to recommendations by the United Nations *Committee on the Elimination of all forms of Discrimination Against Women* (CEDAW Committee). These recommendations had called on Australia to prohibit the sterilisation of women with disabilities and all girls, other than where there is a serious threat to life or health, in the absence of their fully informed and free consent.[10] These concerns are reflected in calls for Australia to enact legislation that prohibits the involuntary sterilisation of adults with disabilities and children.[11]

The Senate committee accepted the view of the Commonwealth Attorney-General's Department that Australia's obligations are found in the text of international treaties to which it is a party. Commonwealth, state and territory laws are reviewed prior to Australia entering treaties, to ensure their compliance with the proposed international obligations.[12] However, that there are considerations other than the strict application of the law was also acknowledged.

In an excellent article in the *Victorian University Law and Justice Journal*,[13] John Toven and Elliot Luke describe the origins of the rights-based approach to disability, and how this informs Australia's obligations under international law. Their view is that international law is an expression of legal rights, which reflects a particular moral conception of human rights. This involves:

> 'a profound commitment to the dignity and worth of every individual who is endowed with rights purely by virtue of his or her humanity. Under this model, a woman or girl with an intellectual disability is not defined by her disability. Nor is she undeserving of rights because of her reduced cognitive capacity. She is first and foremost a person who is entitled both to respect for her dignity and to protection of her human rights. As such, a consideration of human rights is relevant to the sterilisation of such women and girls not simply because of the legal and political significance of this discourse... but also because of its consequences for the moral conceptualisation of this issue.'[14]

PROTECTING THE RIGHTS OF PEOPLE WITH DISABILITIES

Those who favour an outright prohibition on sterilisation in the absence of fully informed consent usually start from a position of wishing to preserve the right of the disabled person to have fertility on the same basis as people living without a disability. However, there is a real possibility that in preserving this right, other rights may be ignored, breached or destroyed. A careful consideration of each of these rights is required in order to arrive at a solution that is sufficiently flexible to meet the needs of each individual.

The right to dignity and quality of life

The Senate report quoted the view of Dr Wendy Bonython that international human rights law affirms and protects *multiple* human rights, which should be equally respected. Specifically, the right to have a family is not the only human right, and the right to dignity and quality of life is just as important to an individual.[15] The shift in focus from the absolute right of fertility to the right of the individual to enjoy quality of life brings the individual's needs more to the fore of the discussion.

It is easy to envisage a situation where a female with a painful or debilitating condition associated with her fertility (severe dysmenorrhea, endometriosis) might safely and reasonably explore the option of sterilisation by way of hysterectomy to improve her quality of life. There is a grave risk that an absolute prohibition on the sterilisation of women with a decision-making incapacity would preclude a woman with a disability from gaining an improved quality of life in that way. In some instances, the right to fertility, if enforced by an outright ban on sterilisation, would be mutually exclusive with a right to quality of life.

The right to support for decision-making capacity

The outright prohibition of sterilisation would also fail to recognise the right of people with a disability to be supported in their decision-making capacity. Substituted decision-making is an essential means of protecting human rights, in order to ensure that people with decision-making incapacity can exercise their rights. In effect, without substituted decision-making, the right to access medical care and treatment is worthless because there is no capacity to exercise the right.

This argument encapsulates the real difficulty with an excessively rigid enforcement of the right to fertility. People with a disability who might, if given the choice, favour their right to receive medical treatment over their right to unfettered fertility, are at risk of being locked out of the ability to exercise that right, by reason of their decision-making incapacity.

Discrimination?

Perhaps the most challenging and contentious question in this debate is whether the outright prohibition of forced sterilisation would constitute discrimination against a person on the basis of their disability. The Adult Guardian of Queensland and the Public Advocate of Queensland submitted to the Senate committee that if society and the law allow an adult without a disability to undergo a medical sterilisation procedure, then adults with a decision-making incapacity should be given the same right. This is so because eliminating discrimination means not only ensuring that people with disabilities are not forced to undergo procedures that would not be forced on those without disabilities, it also means that people with disabilities must have the right to choose from the same range of options that are available to people without disabilities.[16]

An interesting view expressed by Queensland Advocacy Inc to the Senate committee summarises the question as follows:

> 'It is crucial to consider whether sterilisation would be offered to a person without disability in the same circumstances or given the same medical indications. For this reason, we're reluctant to say that sterilisation should never be authorised for someone with decision-making incapacity (given that such an option would be available to someone with capacity who is able to give informed consent). We concede that it may be possible that, in rare circumstances, the complex health needs of a person with a disability and the lack of other appropriate alternatives may make sterilisation a legitimate option.'[17]

This argument is compelling. The Senate committee attached much weight to the need to focus on the ability to look at the rights of an individual, rather than to confer rights on the group as a whole. In order for a right to be meaningful, it is essential that it can be exercised in a way that meets an individual's needs.

CONCLUSION

The current legislative and judicial framework in Australia undoubtedly leaves scope for the rights of disabled individuals to preserve their fertility to be neglected or overlooked. But it is also clear that a careful review of the rights of a disabled person in their entirety requires a more nuanced and balanced approach than would be available if Australia enacted an outright ban on involuntary sterilisation. It is axiomatic that in order for a right to be meaningful it must be able to be exercised. One right should not obliterate another, as far as is reasonably possible. Any legislative framework needs to consider the individual's particular circumstances in order to give effect to that individual's rights.

A number of the recommendations made in the Senate report are based on the importance of ensuring that the disabled person is entitled to a presumption of decision-making capacity, and that sterilising a person who has, or in the future may have, decision-making capacity should be banned.[18]

The report also recommends that Australian jurisdictions adopt the same definition of capacity, so that a person's rights do not vary according to the jurisdiction in which they reside. Following on from this, and arising from the extensive discussion on a rights-based approach to this issue, there is a recommendation that all jurisdictions adopt uniform laws that are based on the 'best protection of an individual's rights', rather than the 'best interest' test that is currently in place.

While there is little doubt that the refinement and application of the law that protects these rights will continue to challenge law-makers and care-givers alike, the recommendations represent a positive attempt to safeguard the entirety of the rights of a person with a disability, in relation to their body, health and wellbeing. ■

Notes: 1 Senate Standing Committee on Community Affairs, 'Involuntary or coerced sterilisation of people with disabilities in Australia', 17 July 2013, Commonwealth of Australia ISBN 978-1-74229-897-9. Accessible at www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs. **2** *Guardianship Act* 1987 (NSW) s35 (1); *Guardianship and Administration Act* 1993 (SA) s61 (2); *Guardianship and Administration Act* 1990 (Tas) s38(1); *Guardianship and Administration Act* 2000 (Qld) s79; *Guardianship and Administration Act* 1986 (Vic) s42G(1); *Guardianship and Administration Act* 1990 (WA) s57(1); *Adult Guardianship Act* 2011 (NT) s21. *Guardianship and Management of Property Act* 1991 (ACT) s70(1). **3** *Guardianship Act* 1987 (NSW) s42(2); *Guardianship and Administration Act* 1993 (SA) s61(2); *Guardianship and Administration Act* 1990 (Tas) s45(1) & (2); *Guardianship and Administration Act* 2000 (Qld) s70; *Guardianship and Administration Act* 1986 (Vic) ss42E and 38(1); *Guardianship and Administration Act* 1990 (WA) ss63(1) and 51(2); *Adult Guardianship Act* 2011(NT) s20. *Guardianship and Management of Property Act* 1991 (ACT) s70(2). **4** (1992) 175 CLR 218. **5** *Ibid*, 250, 253. **6** *Ibid*, 251,259. **7** CRPD Article 12(4). **8** Senate report, see n1 above, s3.2, p65. **9** *Ibid*, s4.3, p83. **10** *Ibid*, s4.5, p84. **11** *Ibid*, s4.11, p86. **12** *Ibid*, para 4.13, p87. **13** John Toven and Elliot Luke, 'The involuntary, non-therapeutic sterilisation of women and girls with an intellectual disability: can it ever be justified?' (2013) 3 (1) *VULJ* 27 at 31. **14** *Ibid*, at 32. **15** Senate report, see n1 above, at 4.22, p90. **16** *Ibid*, para 4.32, p93. **17** Queensland advocacy Inc, submission to the Senate Standing Committee on Community Affairs, number 65, p6. **18** Senate report, see n1 above, recommendations 6, 7, 8 & 9, ppix, x.

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