

At the intersection of law and medicine: promoting the inherent dignity and human rights of persons with disabilities

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According to United Nations estimates, around 10% of the world's population, or 650 million people, live with a disability.¹ On 3 May 2008, the rights of these persons living with disabilities was given significant additional protection when the *Convention on the Rights of Persons with Disability* (the Convention) came into force. Article 1 of the Convention, which was ratified by Australia, states that its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

This article discusses the rights of persons with disabilities, with a focus on the potential impact of the law on community perceptions of the value of the lives of persons with disabilities. It assesses how successful the law has been in affirming the value of persons with disabilities through focusing on some recent cases, bills and legislation. Where the conclusion is that the human rights and inherent dignity of persons with disabilities have not been adequately promoted, recommendations for improvement have been made.

Wrongful life

A "wrongful life" action involves a plaintiff with disabilities claiming compensation from a negligent doctor or other health service provider for both the pain and suffering and the expenses involved in living a life with disabilities. An excellent example of a court affirming the inherent dignity of the life of a person with disabilities can be found in *Harriton v Stephens*,² the leading case on wrongful life claims in Australia.³ The High Court denied compensation to a profoundly disabled young woman who was born as a result of the negligence of her mother's doctor in failing to diagnose rubella infection during the pregnancy and causing her mother to lose the opportunity to undergo an abortion.

The majority of the High Court found against the appellant due to, among other things, the impossibility of comparing a life with disabilities to non-existence, the uncertainty about the class of persons who would be owed such a duty of care, and the sanctity of all human

life.⁴ On the dignity of the life of persons with disabilities and the respect that the community should show the disabled, Crennan J stated that:

... it is odious and repugnant to devalue the life of a disabled person by suggesting that such a person would have been better off not to have been born into a life with disabilities. In the eyes of the common law of Australia all human beings are valuable in, and to, our community, irrespective of any disability or perceived imperfection ... Statutes advancing equality of treatment in our legal system prohibit differential treatment of the disabled, which may have as its wellspring, or be otherwise connected with, eugenic anxieties ... differential treatment of the worth of the lives of those with ill health or disabilities has been a mark of the societies and political regimes we least admire.⁵

Wrongful birth

Although *Harriton v Stephens* rejected the possibility of a person being able to personally claim damages for the costs arising from being born, the ability of parents of a child born as a result of negligence to obtain damages on the basis of a "wrongful birth" claim was recognised by the High Court in *Cattanach v Melchior*.⁶ However, some Australian jurisdictions responded to this decision by enacting legislation to limit damages for wrongful birth actions except in relation to parents of a disabled child.⁷ An example of such a provision is s 71 of the Civil Liability Act 2002 (NSW):

- (1) In any proceedings involving a claim for the birth of a child to which this Part applies, the court cannot award damages for economic loss for:
 - (a) the costs associated with rearing or maintaining the child that the claimant has incurred or will incur in the future, or
 - (b) any loss of earnings by the claimant while the claimant rears or maintains the child.
- (2) Subsection (1)(a) does not preclude the recovery of any additional costs associated with rearing or maintaining a child who suffers from a disability that arise by reason of the disability.

This exception has been perceived as a legislative statement that the life of a child with disabilities is of less worth than that of a child without disabilities. Thus,

the provision is criticised for violating the sanctity of life argument by implicitly asserting that, despite any benefits that a disabled child might provide to his or her parents, the burden of a disabled child is such a significant detriment that it is appropriate for the parents to be able to obtain compensation on the basis that the child should never have been born.

One approach to these kinds of provisions that would be consistent with the aim of promoting the human rights and inherent dignity of persons with disabilities would be to simply remove the exemption granted to children with disabilities, so that all parents in such situations are treated equally regardless of whether their child has a disability. Some would be critical of such an approach as it may produce a number of undesirable consequences, especially the possible impairment of the development of children with disabilities, as the parents of these children would be denied significant financial resources that could be used to help these children reach their full potential.

An alternative approach that could both promote the dignity of persons with disabilities and avoid denying financial resources to parents of children with disabilities could be to insert an additional subsection into the relevant legislation affirming the value of persons with disabilities. For example, an additional subsection could be added to s 71 of the Civil Liability Act 2002 (NSW) along the lines of "Nothing in Section 71 should be taken to suggest that the life of a person with disabilities is inferior or in any way less worthy of dignity and respect than the life of a person without disabilities".

Treatment of infants with disability

The rights and dignity of persons with disabilities is raised directly in cases involving decisions not to treat preterm infants, as courts will often address the issue of whether death is preferable to a life with disabilities. Generally speaking, when deciding whether to withhold or withdraw treatment to an infant, the courts will look at a number of criteria including the futility of the treatment, the burden imposed by the treatment compared to the expected benefits, and the quality of life that can reasonably be expected for the child. The latter criterion is probably the most contentious and difficult for courts to decide. In these cases the courts have demonstrated that they are often willing to intervene in decisions about the withdrawal of life-saving measures for children suffering from a disability.

For example, *Re B (a minor) (Wardship: medical treatment)*⁸ involved a baby living with Down Syndrome who required an operation to remove an intestinal blockage. The parents of B did not consent to the surgery, arguing that it was not in their child's best interests to live another 20 to 30 years with severe

physical and mental handicaps. Although confirming that the child's quality of life was a relevant factor to be taken into consideration when making the decision, the Court of Appeal denied the parent's application and ordered that the surgery be performed. *Re B* is a case that clearly demonstrates the willingness of the judiciary to affirm the value of the life of a child with disabilities even if this involves overruling the decision of the child's parents.

Adults with disabilities

Another area where the law can express a judgment about the value of the lives of persons with disabilities is in the area of end-of-life decisions. A recent case which considered the law in this area was *Brightwater Care Group (Inc) v Rossiter*⁹. This case involved Mr Rossiter, a mentally competent man suffering from spastic quadriplegia, who requested that the operators of his nursing home stop feeding him. An application was made by Mr Rossiter and the nursing home to the WA Supreme Court to make a declaration as to whether it was legally permissible for the nursing home to comply with the request. The court held that the nursing home was under a common law duty to not provide any medication to Mr Rossiter without his informed consent.¹⁰ The court further declared that any person who complied with the request of Mr Rossiter would not be liable to criminal sanctions. Mr Rossiter died shortly after the matter was heard when he reportedly refused medical treatment for an infection.

The court in delivering its judgment clearly expressed its compassion for the tragic circumstances in which Mr Rossiter found himself, stating that the "clinical description of Mr Rossiter's condition fails to adequately convey the tragedy of his present circumstances. Nor does it recognise the sympathy which any reasonable person would properly have for Mr Rossiter and the predicament in which he finds himself".¹¹

However, there were no statements in the court's judgment that affirmed the dignity of the lives of persons with disabilities and the important contribution that they can make to society even if only through continuing to struggle in a dignified way against their illness. A statement like this in such judgments, in addition to statements of compassion for the often tragic lives that some persons lead, could play a key role in effectively affirming the dignity and human rights of persons with disabilities. Including statements like these in judicial decisions might also play a significant role in helping to avoid a situation where individuals with disabilities refuse life-saving or life-preserving treatment solely on the basis that they consider that they are unable to make a valuable social contribution and have simply become a burden on society.

Euthanasia

At the time of writing, the SA Parliament is considering bills to legalise voluntary euthanasia within SA. The Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill 2008 (SA) (Voluntary Euthanasia Bill 2008) is of particular concern to the rights of persons with disabilities as it would appear to permit persons with disabilities to consent to euthanasia. The proposed legislation specifically allows adult persons “who have an illness, injury or other medical condition that ... irreversibly impairs the person’s quality of life so that life has become intolerable to that person, to end their suffering by means of voluntary euthanasia”.¹²

Although voluntary euthanasia is presented by its proponents as a compassionate solution, there are many arguments against legalising voluntary euthanasia, especially in relation to the harm that it can cause to persons with disabilities. A key argument against legalising voluntary euthanasia is that it may devalue the lives of the disabled, as it can be viewed as a legislative statement that their lives are of such low quality that the government will allow them to end their lives. Further, there is a concern that, regardless of how the legislation legalising voluntary euthanasia is drafted, there will inevitably be some persons with disabilities who consent to euthanasia after being pressured by family and friends. Even in the absence of actual pressure, some individuals will consider themselves under an obligation to consent to euthanasia after incorrectly concluding that they are perceived by family and friends as a burden on society.

It is also important to consider the social impact of legalising voluntary euthanasia which may produce significant negative outcomes for persons with disabilities. Legalising euthanasia could play a key role in changing the current community approach of affirming human life as inherently valuable, with each life being no more or less valuable than another, to a situation where a person’s life is judged according to arbitrary criteria with those individuals who have lives judged as inferior provided with the legal option of ending their lives.

If despite these and the other significant arguments against voluntary euthanasia the practice is legalised in SA then it is important to ensure that there are sufficient safeguards within the legislation to minimise the possible harmful impact that the legislation may have for persons with disabilities. The drafters of the Voluntary Euthanasia Bill 2008 have aimed to minimise the chances of the possible adverse consequences that might be produced from legalising voluntary euthanasia through including safeguards such as that the request for volun-

tary euthanasia must normally be in writing, there is a “cooling off” period of at least 24 hours, a psychiatrist can be required to certify that the person is able to give valid consent, and the person requesting euthanasia is provided with information about their illness, palliative care and the process involved in administering voluntary euthanasia.¹³

In addition to these safeguards, a general statement similar to that suggested for inclusion in s 71 of the Civil Liability Act 2002 (NSW), which clearly affirms the human rights and inherent dignity of persons with disabilities, should also be included in the legislation. Such a statement would play a significant role in reducing the likelihood that the proposed legislation might negatively impact on both the self-perception of persons with disabilities and the appreciation by family members, friends and the wider community of the value of the lives of persons with disabilities.

Conclusion

Parliament and the courts can play a key role in assisting Australia fulfil its obligations to protect and affirm the lives of persons with disabilities. Law makers have demonstrated their ability to fulfil this role, although there is a need for greater consistency so that when any issue relevant to the value of the lives of persons with disabilities is addressed, a clear message is sent to the community which affirms the human rights and inherent dignity of all persons with disabilities.

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Footnotes

1. United Nations Department of Public Information, *Some Facts about Persons with Disabilities* (2006) at www.un.org/disabilities/convention/facts.shtml.
2. *Harriton v Stephens* (2006) 226 CLR 52; 226 ALR 391; [2006] HCA 15; BC200603032.
3. Some commentators have argued that the label “wrongful life” is inappropriate and that some other term should be used for these actions, such as “wrongful suffering”. See, for example, Kirby J in *Harriton v Stephens* (2006) 226 CLR 52 at 58–61; 226 ALR 391; [2006] HCA 15; BC200603032.
4. For a response to these criticisms and a discussion of the arguments in favour of wrongful life actions, see the judgment of Kirby J in *Harriton v Stephens* (2006) 226 CLR 52 at 58–101; 226 ALR 391; [2006] HCA 15; BC200603032.



5. *Harriton v Stephens* (2006) 226 CLR 52 at 128–30; 226 ALR 391; [2006] HCA 15; BC200603032 (footnotes omitted).
6. *Cattanach v Melchior* (2003) 215 CLR 1; 199 ALR 131; [2003] HCA 38; BC200303801.
7. Civil Liability Act 2002 (NSW) s 71; Civil Liability Act 2003 (Qld) ss 49A and B; Civil Liability Act 1936 (SA) s 67.
8. *Re B (a minor) (Wardship: medical treatment)* [1990] 3 All ER 927.
9. *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229; BC200907548. For a detailed overview of this case see Markovich D, “Duties relating to the preservation of human life: the interface between civil and criminal law” (2009) *HLB* 17 (9 & 10) 172.
10. The provision of nutrition and hydration was held to fall within the definition of medication as Mr Rossiter was unable to receive food and water by mouth and was being kept alive through a tube inserted into him by surgical means which supplied a mix of nutrition and hydration in accordance with medical principles and protocols: see above n 11 at [35].
11. Above n 8 at [10].
12. Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill 2008 (SA) s 3.
13. Above s 19.