INTERNATIONAL DISABILITY LAW

A PRACTICAL APPROACH TO THE RIGHTS OF PERSONS WITH DISABILITIES

JITIN BISWAS

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Protection for Privacy under the United Nations Convention on the Rights of Persons with Disabilities

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Abstract: Article 22 of the Convention on the Rights of Persons with Disabilities (CRPD) protects personal and family privacy and reputation. This paper examines the antecedents of the CRPD privacy article in other international instruments and selected domestic law. It traces the history of the article through the deliberations that led up to the final version of the CRPD, which has now been ratified by 173 nations. It analyzes the text of the article and discusses its limited administrative and judicial applications. Finally, it describes the article's place in current thinking about disability human rights.

Keywords: disability rights; disability; privacy; Convention on the Rights of Persons with Disabilities; reputation

1. Introduction

Article 22 of the Convention on the Rights of Persons with Disabilities (CRPD) protects personal and family privacy and reputation. Article 22 reads:

> Respect for Privacy
>
> 1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.
>
> 2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others (UNGA 2006)[1].

International Human Rights Law protections for privacy are generally thought to include privacy of personal information, privacy of communications, privacy of personal environment, such as one's dwelling and other personal spaces, and freedom from attacks on personal honor or reputation (UMHRC 2012). United States Supreme Court Justice Louis Brandeis described privacy—in his words "the right to be let alone"—as the "most comprehensive of rights and the right most valued by civilized men."[2] A recent commentary on data privacy states: "The values thought to be protected by privacy . . . include physical security, liberty, autonomy, intimacy, dignity, identity, and equality" (Francis and Francis 2014[3], p. 2 of 25). Privacy is a value in itself, and its protection furthers other values that human beings cherish (Wachter 2017).

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[1] Hereafter, CRPD.

[2] *Olmstead v United States*. 1928. 277 U.S. 438, 478 (Brandeis, J., dissenting).

[3] Hereafter Francis and Francis, Privacy.

2. Relation to Other International and National Privacy Protection Regimes

The privacy article of the CRPD aligns closely with privacy protections in other international human rights instruments; those instruments served as inspiration for the CRPD provision (United Nations Ad Hoc Committee n.d.a). The International Covenant on Civil and Political Rights states: "(1). No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. (2). Everyone has the right to the protection of the law against such interference or attacks." (UNGA 1976). The language of the Universal Declaration of Human Rights is similar (UNGA 1948).[4] The Convention on the Rights of the Child states: "(1). No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation. (2). The child has the right to the protection of the law against such interference or attacks." (UNGA 1990a). The Convention on Migrant Workers provides: "No migrant worker or member of his or her family shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home, correspondence or other." (UNGA 1990b). Various regional and other instruments also protect a person's private information and reputation (ICRC n.d.). The CRPD itself, in its article on statistics and data collection, requires that state parties will collect appropriate information to implement policies in accordance with the Convention, but in collecting and maintaining the information state parties must obey safeguards to ensure confidentiality and respect for the privacy of people with disabilities.[5]

The connection between the CRPD's privacy article and the terms of the other human rights instruments distinguishes the CRPD's treatment of privacy from its treatment of some other rights. The point has been made that although the United Nations' own materials on the CRPD stress that it does not create new rights and instead applies existing rights in a way that responds to the situation of persons with disabilities (Kayess and French 2008[6], p. 20), in fact the treaty does contain new rights for people with disabilities, for example, rights to research and development (Article 4), raising of awareness (Article 8), poverty reduction and economic security (Article 28), and other entitlements not found or not expressed as affirmative rights in other pacts (Kayess and French 2008, pp. 32–33). The privacy article only modestly expands on the language found in other instruments. The consistency of the language, however, should not be taken to mean that the article requires mere formal equality of treatment between people with disabilities and others, as discussed at greater length in Section 6, below.

Many regional and national legal regimes afford protection for privacy rights. The European Convention on Human Rights guarantees privacy (Council of Europe 2010). A celebrated recognition of privacy in European Union law is the "right to be forgotten" case, *Google Spain SL v. Agencia Española de Protección de Datos* (*Google v. Spain*), in which the European Union Court of Justice ruled that European citizens have the right to request search engine firms that gather personal information for profit to remove links to private information if the information is no longer relevant (The Court (Grand Chamber) (2014).[7] The court relied on European Union Directive 95/46, implementing Articles 7 and 8 of the Charter of Fundamental Rights of the European Union. It ruled that Google may be forced to de-link its search engine from personal information searched for by a person's name even when the information is true and was lawfully published. The court required a balancing of the conflicting interests of the subject of the information and the general public.[8]

National privacy legislation is found in many places. For example, Argentina enacted a wide-reaching *Personal Data Protection Act* in 2000.[9] New Zealand's *Privacy Act* establishes principles

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[4] For a discussion see (Hurley 2015).

[5] CRPD, Art. 31(1)(a).

[6] Citing UN online sources.

[7] For a critical review, see (Perotti 2015).

[8] Case C-131/12, para 99. For discussion of the privacy jurisprudence of the European Court of Human Rights and how it might be applied in the interpretation of Article 22, see (Della Fina 2017).

[9] Act 25,326 (30 October 2000).

for the collection, use, and disclosure of individuals' information by private and public agencies, as well as access by the individuals affected to the information held by the agencies.[10] Sweden's *Personal Data Act* protects people against violation of personal integrity when personal data is processed.[11] Privacy protections exist in Canadian law, although the position has been advanced that existing domestic law is insufficient to protect against employer misuse of genetic information (Labman 2004). In the United States, constitutional protections exist against unreasonable searches by government actors[12] and many legal sanctions exist for nongovernmental intrusions into individuals' privacy (Dobbs 2000). In U.S. constitutional law, privacy concepts are closely linked to bodily autonomy and fundamental rights to make decisions about sexuality,[13] medical treatment,[14] abortion[15] and other matters,[16] free from government prohibitions. The idea of privacy rights being connected with rights to bodily autonomy surfaced in the comments of a number of contributors to the drafting of Article 22.

As with other aspects of the CRPD, any overlap with other international human rights instruments and national legislation does not diminish the need for particularized protections for individuals with disabilities, given the unique nature of much disability discrimination. In the words of one commentator, "the reality of persons with disabilities' rights experience in most contexts is more complex than simply outright denial. Even when their entitlement to rights has been formally recognized and uncontentious, their disability has often effectively excluded them from rights enjoyment." (Mégret 2011, p. 263).[17] The CRPD provides a means to challenge the barriers to the realization of basic human rights for persons with disabilities.

3. The History of Article 22

During the Second Session of the Ad Hoc Committee on the Convention in 2003, the Secretary General appraised the World Programme of Action, acknowledging advances in medical research, genetics, and biotechnology, and discussing implications for the privacy rights of individuals with disabilities (United Nations Ad Hoc Committee 2003a).[18] The Second Session also considered a letter from Morten Kjaerum, the Executive Director of the Danish Institute for Human Rights concerning the "concept of autonomy" (United Nations Ad Hoc Committee n.d.b). The letter pointed out that autonomy rights include: "[1.] right to personal development, to create ideas and goals for life; [2.] right to privacy; [3.] right to integrity, liberty and freedom from coercion; [4.] right to inclusion in community life; and, [5.] right to participate actively in political process" (United Nations Ad Hoc Committee n.d.b). The letter went on to state: "Issues of privacy are also highly relevant for persons with disabilities whose dependence on technical and personal aids may lead to situations of vulnerability" (United Nations Ad Hoc Committee n.d.b). The Bangkok delegation referred to respect for privacy in its initial proposals for the Convention (United Nations Ad Hoc Committee 2003b). The delegation's discussion mentioned the link between respect for private and family life, freedom of expression, and the right to sexuality for individuals with disabilities.

Following the Second Session, the Ad Hoc Committee established a Working Group. The Working Group's proposed text included an article establishing protection for privacy, home, and family. The portion of the text relating to privacy and reputation was close to what would become the final wording of Article 22:

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[10] Privacy Act 1993 (assent 17 May 1993).

[11] Personal Data Act (1998:204) (issued 29 April 1998).

[12] *Bivens v Six Unknown Named Agents of the Federal Bureau of Narcotics*. 1971. 403 U.S. 388; Mapp v Ohio. 1961. 367 US 643.

[13] *Lawrence v Texas*. 2003. 539 U.S. 558.

[14] *Parham v JR*. 1979. 442 US 584.

[15] *Roe v Wade*. 1973. 410 US 113.

[16] *Griswold v Connecticut*. 1965. 381 US 479.

[17] The truth of Mégret's observation should not, of course, diminish the attention paid to outright denial of rights.

[18] UN Doc CRPD/A/AC 265/2003/1. For an account of the history of the CRPD as a whole, see (Degener and Begg 2017).

> 1. Persons with disabilities, including those living in institutions, shall not be subjected to arbitrary or unlawful interference with their privacy, and shall have the right to the protection of the law against such interference. States Parties to this Convention shall take effective measures to protect the privacy of the home, family, correspondence and medical records of persons with disabilities and their choice to take decisions on personal matters (United Nations n.d.).

The Working Group suggested that the Ad Hoc Committee consider replacing the word "correspondence" in the first paragraph with the broader term "communications." (United Nations n.d.).

Various Working Group participants submitted commentaries and proposals concerning the privacy language to be included in the Convention (Martin and Lachwitz n.d.). Great Britain suggested protecting privacy under a provision covering autonomy in general (Martin and Lachwitz n.d.). The United States highlighted the need for privacy with regard to voting and employment (United Nations 2004). The nongovernmental organization (NGO) Inclusion International noted the threat to privacy from institutional living arrangements imposed on people with mental disabilities and discussed the need to protect privacy rights of individuals with disabilities (United Nations 2003). Another NGO suggested a specialized article on the privacy of records (WNUSP 2003).

The Third Session of the Ad Hoc Committee for disability rights discussed proposals for the privacy article extensively (United Nations Ad Hoc Committee n.d.c). Costa Rica's draft entitled "Respect for Privacy" read:

> 1. Persons with disabilities shall not be subjected to arbitrary or unlawful interference with their privacy, and have the right to the protection of the law against such interference in all fields. States Parties to this Convention shall take effective measures to protect the privacy of the communications, information and documents of persons with disabilities (United Nations Ad Hoc Committee n.d.c).

The European Union's early draft was somewhat more detailed:

> 1. Persons with disabilities, including those living in institutions, shall not be subjected to arbitrary or unlawful interference with their privacy, and shall have the right to the protection of the law against such interference. States Parties to this Convention shall take effective measures to protect the privacy of the home, family, correspondence and medical records of persons with disabilities and their choice to take decisions on personal matters (United Nations Ad Hoc Committee n.d.c).

Wording changes to this draft were discussed. Kenya suggested including the term "communication" (United Nations Ad Hoc Committee n.d.c). South Africa suggested the article should provide protection of "all forms of privacy of an individual" and "reflect the full range of human rights protection" (United Nations Ad Hoc Committee n.d.c). An Australian NGO suggested separating privacy and family into separate articles and broadening the scope of the language used in the Committee's draft concerning medical records (United Nations Ad Hoc Committee n.d.c). The materials from the Fourth Session of the Ad Hoc Committee in 2004 continued to combine privacy and family rights, but added protection for privacy in government data collection activities (United Nations Ad Hoc Committee 2004).

During the Fifth Session of the Ad Hoc Committee, privacy was split off from family rights and became its own article, as reflected in the final version of the Convention (United Nations Ad Hoc Committee 2005a). The committee said, "There was broad support to split the substance of the text prepared by the Working Group for draft article 14 into two separate articles." The privacy draft now read:

> No persons with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home

> or correspondence or other types of communication, or to unlawful attacks on his or her honour and reputation. All persons with a disability have the right to the protection of the law against such interference or attacks (United Nations Ad Hoc Committee 2005a).

There remained an active draft concerning the privacy of medical records, and there was concern about providing for advances in communication technologies (United Nations Ad Hoc Committee 2005a). On behalf of the EU, Luxemburg favored the broad language "regardless of their place of residence or living arrangements" over language that specified institutional settings (United Nations Ad Hoc Committee 2005b). Yemen and Serbia and Montenegro expressed support for the language on arbitrary and unlawful interference and revived the proposal to replace correspondence with "communications" (United Nations Ad Hoc Committee 2005b). Serbia and Montenegro suggested covering all records pertaining to people with disabilities. The United Arab Emirates favored retaining language about persons living in institutions to make sure that privacy rights are protected while the institutions are monitored (United Nations Ad Hoc Committee 2005b). Japan favored conforming usage to that in the Covenant on Civil and Political Rights, and supported the broader language about place of residence over that specifying institutional settings (United Nations Ad Hoc Committee 2005b). Russia opposed the splitting of family rights and privacy rights into two articles, stating that the issues were closely related, but it supported some of the changes to the language while suggesting modified versions of others (United Nations Ad Hoc Committee 2005b). At the Seventh Session, Article 22 appeared in its final version (United Nations Ad Hoc Committee 2006, pp. 17–18).

4. The Text of Article 22

Several features of Article 22's text merit comment. As indicated above, the language "regardless of place of residence or living arrangements" was the product of extensive discussions over whether to single out institutional arrangements or to embrace broader terminology that would avoid reinforcing the stereotyped idea that people with disabilities will reside in institutional settings. The broader language should not be taken as minimizing the unique threats to personal privacy that life in institutions poses for the people with disabilities who live in them. Article 22 may provide authority by which to challenge the use of large institutions that not only make privacy impossible but also breed abusive conditions (Perlin 2007, p. 344). The CRPD elsewhere addresses the opportunity of individuals to choose where they live and to have access to resources that support living an inclusive life in the community rather than a segregated or isolated institutional existence.[19]

The textual provision "arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication" is also noteworthy. The drafters opted for breadth of coverage for privacy protections by explicitly addressing both correspondence and other forms of communication, expanding the terms of earlier human rights instruments. As illustrated by the rise of social media communication in the present era and the temptation for both public and private actors to make use of personal information on social media platforms, making rights protection keep pace with communications technology remains a continuing, even an increasing, challenge.[20]

The language "or to unlawful attacks on his or her honour and reputation," which echoes that in other human rights instruments, holds promise for efforts to diminish the stigma that frequently is imposed on persons with disabilities.[21] The protections in the other instruments inspired the drafters of Article 22 to include parallel provisions regarding defense against attacks on honor and reputation. State-sponsored segregation of people with disabilities and the history of eugenics and other attacks on those with disabilities make them uniquely subject to reputational harm.[22]

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[19] CRPD, Art 19.

[20] e.g., (Horowitz 2016).

[21] See (Goffman 1963, p. 5).

[22] See (Weber 2007, pp. 18–20).

The term of Article 22 recognizing "the right to the protection of the law against such interference or attacks" imposes an affirmative duty on the state to prevent and remedy interference with privacy and attacks on reputation. Of course, nations will differ in the domestic law they create to effectuate this duty and the avenues of enforcement available. In countries influenced by the English Common Law, private suit is the default method by which victims of intrusion or damage to reputation may obtain redress.[23] States with other traditions will address violations of the norms of privacy and reputation protection in other ways,[24] although, as noted below, even in places that do not follow common law approaches, individual litigation has included claims under Article 22.

The language in Article 22 providing that "States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others" reflects special concerns about health-related information and the potential that its disclosure will lead to discrimination against persons with disabilities. The same concern inspired the *Genetic Information Nondiscrimination Act*[25] in the United States and the present debate in the U.S. over the collection and use of medical information in employee wellness programs (Abelson 2016). Aisling De Paor and Charles O′Mahony have declared: "By implication, the right to genetic privacy is . . . protected under the UN CRPD and other human rights instruments . . . " (De Paor and O'Mahony 2016, p. 13). They note that Article 22 rights may be interpreted to require states to prohibit employers from genetically testing employees (De Paor and O'Mahony 2016, p. 19). Questions linger whether people with disabilities should be afforded special protections given their vulnerability to the misuse of personal, health, and rehabilitation information, but the language of Article 22 simply provides that the protection for people with disabilities shall be "on an equal basis with others."

The dominant approach in affording protection of health information privacy is to ensure that no personally identifiable information is disclosed without the informed consent of the individual. Recent research has criticized that approach as incomplete, however, because individuals may be subject to discrimination based on correlations between characteristics they have and aggregate predictions of risk of disease or disability. As two prominent authorities state: "For example, employers or insurers might learn from [data analytics] that particular demographic categories of patients have especially high rates of chronic conditions (including HIV) or especially high costs of treating these conditions and alter plan design accordingly."[26]

5. Article 22 Applications and Interpretations

Application and interpretation of Article 22 may be found in the reports of the Committee on the Rights of Persons with Disabilities reviewing the progress of the parties adopting the CRPD, as well as in administrative and judicial decisions in cases involving the CRPD. As an example of Committee observations, Denmark's 2014 review led to an expression of concern that psychiatric hospitals continued to be allowed to transfer private information about patients without the patients' consent (UNCRPD 2014). Reports by internal authorities in countries that have ratified the CRPD also describe challenges and responses with regard to implementing Article 22.[27] The report from Argentina, for example, noted the nation's law protecting the rights of persons living with HIV infections (UNCRPD 2010a). China's report pointed to the ability of individuals whose privacy rights have been violated to seek civil liability for damage to reputation (UNCRPD 2010b). The Austrian report cautioned: "In civil society there are doubts about whether people who live or work in homes or institutions are sufficiently protected against the passing on of personal data" (UNCRPD 2010c). Peru

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[23] See Restatement 2nd of Torts. 1977. § 558 (elements of defamation), § 652A (principles for liability for invasions of privacy).

[24] See (Harpur and Bales 2010).

[25] Pub. L. No 110-233 (2008).

[26] Francis and Francis, Privacy (n. 4) p. 12; see (Hoffman 2017, pp. 7–9 of 17).

[27] E.g., (UNCRPD 2011).

noted that it has a national registry of persons with disabilities but that the information is confidential and subject to disclosure only by court order (UNCRPD 2010d).

Independent bodies have also issued reports on CRPD implementation that include Article 22. A draft monitoring report for India from 2013 commented on dissatisfaction with privacy protections for persons with disabilities and recommended that disability and other relevant laws explicitly provide for the right to privacy, specifically for personal, health, and rehabilitation information, and that rehabilitation and medical professionals receive training in privacy rights of persons with disabilities (Gupta et al. 2013, pp. 160–64). A report on Singapore stated that the *Personal Data Protection Act* governed collection, use, and disclosure of personal data, but concluded that it did not cover persons with chronic mental illness who have to report their conditions for medical insurance and was unclear with regard to protections of personal data of people with chronic mental illness (Disabled People's Association Singapore 2015, p. 27).

The European Commission has studied the European Union's implementation of the CRPD. The Commission's Staff Working Document of 2014 commented on a directive and regulation that established a framework for protecting health and other personal data. Under the directive, consent is generally required except when processing the information is necessary to protect the vital interests of the person to whom the information pertains or another person, if the subject of the information is physically or legally not able to provide consent (EC 2014). Further protections were under discussion at the time of the report, and the European Data Protection Supervisor was responding to complaints alleging misuse of information pertaining to individuals with disabilities (EC 2014, pp. 26, 56).

A number of cases alleging violations of Article 22 are pending before the UN's Committee on the Rights of Persons with Disabilities (Office of High Commissioner, UN Human Rights 2017). In an adjudicated case involving the United Kingdom, the Committee, applying Article 2 of the CRPD Optional Protocol, considered the communication of an insulin-dependent service delivery manager for Oracle Corporation who had been laid off (UNCRPD 2012). The government's Employment Tribunal decided against the complainant on his allegation that Oracle failed to make reasonable adjustments and otherwise discriminated against him on the basis of disability. The communication to the Committee alleged that the Employment Tribunal, by finding him not to be a credible witness, attacked his honor and reputation in violation of Article 22 of the CRPD. The Committee found that the dismissal and judicial review took place before the entry into force of the Convention and Optional Protocol in the U.K., so the communication was ruled inadmissible.

6. The Relation of Article 22 to Disability Human Rights Ideas

Professor Degener has recently argued that the CRPD embodies a human rights model of disability, a model that "encompasses the values for disability policy [and] that acknowledges the human dignity of disabled persons." (Degener 2016, p. 3). Privacy and reputation are key aspects of human dignity, so their protection fits neatly into an international treaty based on human dignity principles. The first paragraph of Article 22 is an absolute protection for privacy and reputation rights, couched in language that does not make any comparison with the rights of nondisabled persons. In this respect and using Degener's terms, Article 22 provides for something "more than anti-discrimination." (Degener 2016, p. 4). Professor Kanter has also stressed the departure of the CRPD from anti-discrimination measures that rely on equalizing opportunities to establish a right to substantive equality so that outcomes, not just treatment, will be equal (Kanter 2015, pp. 842–44). The rights set out in the first paragraph of Article 22 are substantive and call for different treatment when the protections society generally affords are not sufficient to guard privacy and reputational interests of those who have disabilities. Like Degener, Kanter contends that the CRPD embodies a human rights approach to disability. Unlike Degener, she sees the human rights approach as fundamentally consistent with a social model of disability, and finds both to be present in the terms of the CRPD (Kanter 2015, pp. 845–48).[28]

In work roughly contemporaneous with the UN General Assembly's consideration and adoption of the CRPD, Professor Stein articulated a human rights model of disability that he found immanent in the draft Convention (Stein 2007). Like Degener, he emphasizes the Convention's focus on the dignity and inherent worth of each person, and the importance of developing the capabilities of all (Stein 2007, pp. 83–85, 106–10). Stein is not the only authority who supports a capabilities approach in understanding and enforcing the rights of persons with disabilities under the Convention (Lang et al. 2011). Following Stein's and others' ideas, guarantees against intrusion and misuse of information would appear central both to dignity and to permitting individuals to achieve basic minimums needed for a meaningful life, as well as to reach toward achieving their full potential free from stereotyping assumptions and discriminatory treatment. Privacy losses are prominent among the negative consequences of disability discrimination that results from institutionalization, fear of contagion, and imposition of stigma.

The privacy provisions of the CRPD are thus consistent with disability rights thinking. Moreover, as a practical matter, quite apart from considerations of theory, privacy protections often safeguard against the most common forms of discrimination and so contribute to the overall goal of the CRPD and disability rights in general. As Professor Roberts notes, "[I]n certain circumstances, discriminators need information to discriminate . . . Restricting potential discriminators' access to information about protected status can significantly reduce the chances of subsequent discrimination" (Roberts 2015, pp. 2099–2100). She cites the example of protecting the confidentiality of genetic information to prevent employment discrimination on that basis (Roberts 2015, pp. 2101, 2132). She further concludes that even at a theoretical level, privacy and anti-discrimination are symbiotic and can advance the same interests and values (Roberts 2015, p. 2121).

It is true that furthering the anti-subordination aims of laws forbidding disability discrimination may require abandoning privacy to some extent and in some situations, as when one requests an accommodation from an employer, or the modification of rules from a public accommodation or government entity (Areheart 2012, p. 714). Disclosure of personal information about disability may also promote solidarity among those with disabling conditions (Areheart 2012, p. 715). There is a loss of privacy involved in coming out as a person with a disability, a step that includes embracing an identity as disabled and joining the community of persons with disabilities. Coming out as disabled has been described as a political matter for precisely that reason (Michalko 2002, pp. 69–70, 78–79). Deciding not to invoke a shield of privacy, whether for strategic, moral, or ideological reasons, ought to be a voluntary decision, however. Legal protections need to be present to prevent unwanted, unwarranted, or abusive intrusion into a person's private sphere.

7. Conclusions

Just what constitutes unwanted, unwarranted, or abusive intrusion into a person's private sphere is an issue that remains to be developed, both in the context of the rights of persons with disabilities and in the context of human rights in general. Authorities have questioned whether typical privacy protection legislation, which relies on notice and consent, can be effective in an era when corporate and government information gathering is pervasive and fully informed consent is rare (Symposium 2013). Because people with disabilities are uniquely at risk of discrimination when privacy protections fail, and because institutional and other settings in which people with disabilities often live are particularly subject to private and public intrusion, people with disabling conditions are canaries in the coal mine for loss of privacy by everyone. The coming years will demonstrate how effectively governments will "protect the privacy of personal, health and rehabilitation information of persons with disabilities on

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[28] For a view consistent with Kanter's, expressed in relation to the views of Professor Stein, see (Weber 2011, pp. 2530–31).

an equal basis with others." (UNGA 2006). Article 22 of the CRPD holds promise for the protection of personal information, dignity, and reputation of individuals with disabilities, but that promise is the beginning of the story, not its end.

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References

Abelson, Reed. 2016. AARP Sues U.S. Over Rules for Wellness Programs. *New York Times*. October 24. Available online: https://www.nytimes.com/2016/10/25/business/employee-wellness-programs-prompt-aarp-lawsuit.html?_r=0 (accessed on 30 March 2017).

Areheart, Bradley A. 2012. GINA, Privacy, and Antisubordination. *Georgia Law Review* 46: 705–18.

Council of Europe. 2010. European Convention on Human Rights. Art. 8 (Right to respect for private and family life). Available online: http://www.echr.coe.int/Documents/Convention_ENG.pdf (accessed on 13 June 2017).

De Paor, Aisling, and Charles O'Mahony. 2016. The Need to Protect Employees with Genetic Predisposition to Mental Illness? The UN Convention on the Rights of Persons with Disabilities and the Case for Regulation. *Industrial Law Journal* 45: 525–55. [CrossRef]

Degener, Theresia. 2016. Disability in a Human Rights Context. *Laws* 5: 35. [CrossRef]

Degener, Theresia, and Andrew Begg. 2017. From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Rights of Persons with Disabilities at the United Nations. In *The United Nations Convention on the Rights of Persons with Disabilities*. Edited by Valentina Della Fina, Rachele Cera and Giuseppe Palmisano. Cham: Springer.

Della Fina, Valentina. 2017. Article 22 (Respect for Privacy). In *The United Nations Convention on the Rights of Persons with Disabilities*. Edited by Valentina Della Fina, Rachele Cera and Giuseppe Palmisano. Cham: Springer.

Disabled People's Association Singapore. 2015. Singapore and the UN CRPD. Available online: http://www.dpa.org.sg/wp-content/uploads/2015/06/Singapore-and-UN-CRPD.pdf (accessed on 1 April 2017).

Dobbs, Dan B. 2000. *The Law of Torts*. St. Paul: West Pub. Co., chap. 29.

European Commission. 2014. Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union. June 5 26 SWD 182. Available online: http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf (accessed on 1 April 2017).

Francis, John G., and Leslie P. Francis. 2014. Privacy, Confidentiality, and Justice. *Journal of Social Philosophy* 45: 408–31. [CrossRef]

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.

Gupta, Shivani, Meenakshi Balasubramaniam, Sudha Ramamoorthy, Rama Chari, and Bhargavi Davar. 2013. Monitoring Report of Civil Society, United Nations Convention on Rights of Persons with Disabilities—India. Available online: http://www.dnis.org/FINAL-MONITORING%20CRPD%20-%20ZERO%20DRAFT%20REPORT.doc (accessed on 1 April 2017).

Harpur, Paul, and Richard A. Bales. 2010. The Positive Impact of the Convention on the Rights of Persons with Disabilities: A Case Study on the South Pacific and Lessons from the U.S. Experience. *Northern Kentucky Law Review* 37: 363–88.

Hoffman, Sharona. 2017. Big Data and the Americans with Disabilities Act. *Hastings Law Journal*. Available online: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=284143 (accessed on 31 March 2017).

Horowitz, Josh. 2016. WhatsApp's encryption could make it a target of the Chinese government. Available online: https://qz.com/655778/whatsapps-encryption-could-make-it-a-target-of-the-chinese-government/ (accessed on 31 March 2017).

Hurley, Deborah. 2015. Taking the Long Way Home: The Human Right of Privacy. In *Privacy in the Modern Age: The Search for Solutions*. Edited by Marc Rotenberg, Julia Horwitz and Jeramie Scott. New York: The New Press, Available online: https://ssrn.com/abstract=2676864 (accessed on 9 June 2017).

International Committee of the Red Cross. n.d. Practice Relating to Rule 105. Respect for Family Life Customary IHL. Available online: https://ihl-databases.icrc.org/customary-ihl/eng/docs/v2_rul_rule105_sectiona (accessed on 31 March 2017).

Kanter, Arlene S. 2015. The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of Persons with Disabilities. *Drake Law Review* 63: 819–83.

Kayess, Rosemary, and Phillip French. 2008. Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 8: 1–34. [CrossRef]

Labman, Shauna. 2004. Genetic Prophecies: The Future of the Canadian Workplace. *Manitoba Law Journal* 30: 227–47.

Lang, Raymond, Maria Kett, Nora Groce, and Jean-Francois Trani. 2011. Implementing the United Nations Convention on the rights of persons with disabilities: Principles, implications, practice and limitations. *ALTER-European Journal of Disability Research* 206: 216–17. [CrossRef]

Martin, Robert, and Klaus Lachwitz. n.d. Some reflections regarding the Preparation of a Comprehensive and Integral Convention on the Promotion and Protection of the Rights and Dignity of Persons with Disabilities. Available online: http://www.un.org/esa/socdev/enable/rights/wgcontrib-EU.htm (accessed on 31 March 2017).

Mégret, Frédéric. 2011. The Disabilities Convention: Toward a Holistic Concept of Rights. *International Journal of Human Rights* 12: 261–78. [CrossRef]

Michalko, Rod. 2002. *The Difference that Disability Makes*. Philadelphia: Temple University Press.

Office of High Commissioner, UN Human Rights. 2017. Committee on the Rights of Persons with Disabilities. Table of Pending Cases. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Tablependingcases.aspx (accessed on 30 March 2017).

Perlin, Michael. 2007. International Human Rights Law and Comparative Mental Disability Law: The Universal Factors. *Syracuse Journal of International Law and Commerce* 34: 333–57.

Perotti, Elena. 2015. The European Ruling on the Right to be Forgotten and its Extra-EU Implementation. Available online: http://dx.doi.org/10.2139/ssrn.2703325 (accessed on 9 June 2017).

Roberts, Jessica L. 2015. Protecting Privacy to Prevent Discrimination. *William & Mary Law Review* 56: 2097–174.

Stein, Michal Ashley. 2007. Disability Human Rights. *California Law Review* 95: 75–121.

Symposium. 2013. Privacy and Technology. *Harvard Law Review* 126: 1880–2041.

The Court (Grand Chamber). 2014. App. No. C-131/12 (Grand Chamber 13 May 2014). Available online: http://curia.europa.eu/juris/document/document.jsf?text=&docid=152065&pageIndex=0&doclang=EN&mode=req&dir=&occ=first&part=1&cid=305802 (accessed on 31 March 2017).

University of Minnesota Human Rights Center (UMHRC). 2012. *Human Rights Yes!: Action and Advocacy on the Rights of Persons with Disabilities*, 2nd ed. Minneapolis: Human Rights Resource Center, chap. 7; Available online: http://hrlibrary.umn.edu/edumat/hreduseries/HR-YES/chap-7.html (accessed on 31 March 2017).

United Nations Committee on the Rights of Persons with Disabilities (UNCRPD). 2010a. Initial Reports submitted by States parties under article 35: Argentina. October 6 CRPD/C/ARG/1. Available online: http://www.un.org/ga/search/view_doc.asp?symbol=CRPD/C/ARG/1 (accessed on 1 April 2017).

United Nations Committee on the Rights of Persons with Disabilities (UNCRPD). 2010b. Initial Reports submitted by States parties under article 35: China. August 30 CRPD/C/CHN/1. Available online: http://www.refworld.org/docid/4efc32622.html (accessed on 1 April 2017).

United Nations Committee on the Rights of Persons with Disabilities (UNCRPD). 2010c. Initial Reports submitted by States parties under article 35: Austria. November 2 CRPD/C/AUT/1. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G11/462/79/PDF/G1146279.pdf?OpenElement (accessed on 1 April 2017).

United Nations Committee on the Rights of Persons with Disabilities (UNCRPD). 2010d. Initial Reports submitted by States parties under article 35: Peru. July 8 CRPD/C/PER/1. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G11/462/79/PDF/G1146279.pdf?OpenElement (accessed 1 April 2017).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). 2011. First New Zealand Report on Implementing the United Nations Convention on the Rights of Persons with Disabilities. Available online: https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/un-reviews-of-nzs-implementation-of-the-convention/first-nz-report-on-implmentation-march-2011/first-new-zealand-report-on-implementing-the-un-convention-on-the-rights-of-persons-with-disabilities/ (accessed on 1 April 2017).

UNCRPD. 2012. McAlpine v United Kingdom of Great Britain and Northern Ireland (13 November 2012) CRPD/C/8/D/6/2011. Available online: http://repository.un.org/bitstream/handle/11176/298831/CRPD_C_8_D_6_2011-EN.pdf?sequence=3&isAllowed=y (accessed on 1 April 2017).

United Nations Committee on the Rights of Persons with Disabilities (UNCRPD). 2014. Concluding observations on the initial report of Denmark. October 30 CRPD/C/DNK/CO/1. Available online: http://repository.un.org/bitstream/handle/11176/310320/CRPD_C_DNK_CO_1-EN.pdf?sequence=1&isAllowed=y (accessed on 1 April 2017).

United Nations General Assembly (UNGA). 1948. Universal Declaration of Human Rights. Available online: http://www.un.org/en/documents/udhr/ (accessed on 9 June 2017).

United Nations General Assembly (UNGA). 1976. International Covenant on Civil and Political Rights. Art. 17. Available online: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx (accessed on 31 March 2017).

United Nations General Assembly (UNGA). 1990a. Convention on the Rights of the Child. Art. 16. Available online: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx (accessed on 31 March 2017).

United Nations General Assembly (UNGA). 1990b. Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. Art. 14. Available online: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CMW.aspx (accessed on 31 March 2017).

United Nations General Assembly (UNGA). 2006. Convention on the Rights of Persons with Disabilities. Available online: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (accessed on 13 June 2017).

United Nations. n.d. Working Group on a Convention. Available online: http://www.un.org/esa/socdev/enable/rights/ahcwgreporta14.htm (accessed on 31 March 2017) (footnotes omitted).

United Nations. 2003. Inclusion International. Available online: http://www.un.org/esa/socdev/enable/rights/wgcontrib-inclintl.htm (accessed on 31 March 2017).

United Nations. 2004. United States Contribution: Disability Rights. Available online: http://www.un.org/esa/socdev/enable/rights/wgcontrib-usa.htm (accessed on 31 March 2017).

United Nations Ad Hoc Committee. 2003a. Issues and Emerging Trends Related to Advancement of Persons with Disabilities. Paper presented at Second Session of Ad Hoc Committee, New York, NY, USA, June 16–27.

United Nations Ad Hoc Committee. 2003b. Bangkok Recommendations on the Elaboration of a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. June 2–4 UN Doc CRPD/A/AC 265/2003/CRP/10. Available online: http://www.un.org/esa/socdev/enable/rights/a_ac265_2003_crp10.htm (accessed on 3 August 2017).

United Nations Ad Hoc Committee. 2004. Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its fourth session. September 14. Available online: https://www.un.org/esa/socdev/enable/rights/ahc4reporte.htm (accessed on 31 March 2017).

United Nations Ad Hoc Committee. 2005. Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its fifth session. February 23. Available online: https://www.un.org/esa/socdev/enable/rights/ahc5reporte.htm (accessed on 31 March 2017).

United Nations Ad Hoc Committee. 2005. Daily summary of discussion at the fifth sessions, UN Convention on the Human Rights of People with Disabilities. February 2. Available online: http://www.un.org/esa/socdev/enable/rights/ahc5sum2feb.htm (accessed on 1 April 2017).

United Nations Ad Hoc Committee. 2006. Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its seventh session. February 13. Available online: https://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7report-e.pdf (accessed on 31 March 2017).

United Nations Ad Hoc Committee. n.d.a References: Article 22: Respect for Privacy. Available online: https://www.un.org/esa/socdev/enable/rights/ahcstata22refinthr.htm (accessed on 31 March 2017).

United Nations Ad Hoc Committee. n.d.b Letter dated 26 May 2003 from the Executive Director of the Danish Institute for Human Rights addressed to the Secretary of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. UN Doc CRPD/A/AC.265/2003/CRP/9. Available online: https://digitallibrary.un.org/record/496630?ln=en (accessed on 31 March 2017).

United Nations Ad Hoc Committee. n.d.c Third Session: Comments, proposals, and amendments submitted electronically. Available online: https://www.un.org/esa/socdev/enable/rights/ahcstata22tscomments.htm (accessed on 31 March 2017).

Wachter, Sandra. 2017. Privacy: Primus Inter Pares: Privacy as a Precondition for Self-Development, Personal Fulfilment and the Free Enjoyment of Fundamental Human Rights. Available online: https://ssrn.com/abstract=2903514 (accessed on 9 June 2017).

Weber, Mark C. 2007. *Disability Harassment*. New York: NYU Press.

Weber, Mark C. 2011. Disability Rights, Welfare Law. *Cardozo Law Review* 32: 2483–531.

World Network of Users and Survivors of Psychiatry (WNUSP). 2003. Submission to the United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. Available online: http://www.un.org/esa/socdev/enable/rights/contrib-wnusp.htm (accessed on 31 March 2017).

2

Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-To-Steady Progress?

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Abstract: Honouring the requirement of the Convention on the Rights of Persons with Disabilities to introduce supported decision-making (SD) has largely been a case of much talk and little real action. As a socio-economic right, actualising support is resource-intensive as well as being fairly uncharted territory in terms of what works, to what degree and for how long benefits last. This paper, drawing lightly on mainly Australian examples, considers unexplored (and sometimes unorthodox) approaches such as the 'needs-based' principle for setting social welfare priorities as possible ways of revitalising SD through progressive realisation, whether through civil society programs or under the law. It argues that pure repeal of proxy decision-making *on its own* is not viable in realpolitik terms so progressive realisation of 'repeal with adequate support' must instead be devised for SD implementation to progress.

Keywords: supported decision-making; socio-economic rights; progressive realisation; program priorities

1. Introduction

Article 12 of the *Convention on the Rights of Persons with Disabilities* (2006)[1] ('CRPD') is widely, but certainly not universally, understood in line with the views of the monitoring Committee as calling for the repeal of substitute decision-making regimes—such as adult guardianship or proxy decision-making for involuntary mental health patients—and for their replacement with supported-decision-making ('SD') which does not transfer *any* decision making away from the person. The repeal arm located in Article 12(1), (2) advances a civil right (elimination of capacity-based denials of legal capacity and autonomy), while the provision of support subject to 'safeguards' arm found in Articles 12(3), (4), arguably is a socio-economic right (and certainly is treated as such in the realpolitik of government). Like the socio-economic right to health (generally Tobin 2012; Magnusson 2017), SD however presently remains a fairly 'empty' right, even in first world economies. While there are many law reform blueprints (e.g., VLRC 2012; ALRC 2014; Law Commission of Ontario 2017), concepts and principles remain in flux (Carney 2014), legislation is scant,[2] and—despite a proliferation of legislative and non-legislative programs and schemes (Then 2013; Boundy and Fleischner 2013; Browning 2010; Power et al. 2013; Van Puymbrouck 2017)—there is no rigorous evidence of

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[1] *Convention on the Rights of Persons with Disabilities* 999 UNTS 3. Australia was an original signatory when the CRPD and its Optional Protocol opened for signature on 30 March 2007, and ratified the CRPD in July 2008 (entering into force on 16 August 2008) followed by the Optional Protocol in 2009.

[2] Australia has been slower to legislate supported decision-making than Canada or Sweden (Gooding 2014; Gordon 2000; Law Commission of Ontario 2014). So far, other than a bit of dabbling in South Australia, Victoria is the only Australian state to legislate new 'support' measures which avoid conferring proxy decision-making power, limited so far to appointments which the person makes for themselves or in health and mental health: *Powers of Attorney Act 2014* (Vic) ss 87–89; *Mental Health Act 2014* (Vic) Part 3, ss 12–27; *Medical Treatment and Planning Act 2016* (Vic) ss 31, 32 [from March 2018]; also see *Advance Care Directives Act 2013* (SA), s 10(d); *Disability Services Act 1993* (SA) as amended, s 3A (Carney 2015a).

effectiveness (Kohn and Blumenthal 2014; Kohn et al. 2013; Carney 2015b; Davidson et al. 2015). Why is this so?

Have we lost sight of the bigger picture (or given it too little attention)? Such as that law has a patchy record at best in securing rights in general and socio-economic rights such as SD in particular; that neoliberal governance reforms and fiscal austerity have increased pressures on accessing scarce public resources (e.g., for the UK: UN Committee on the Rights of Persons with Disabilities 2017; UK Independent Mechanism 2017, pp. 22–27); that we have bold 'capacity-building' visions of how to harness the potential of informal civil society supports, but little understanding of how to operationalise the marshalling of that non-state 'support' (family or otherwise), and even less appreciation of associated 'risks' of hidden paternalism in the absence of appropriate safeguards? Or that there can be unintended consequences[3] and that competition for access to finite resources carries risks of unfair and unequal outcomes, such as favouring the more powerful or more articulate in the absence of a needs principle or other means of ensuring proportional allocation? Alternatively, have we perhaps simply misread what SD realisation entails?

This paper suggests that the answer to such questions is more 'yes' than 'no', and in addressing some of these themes, it sketches some ideas on how SD implementation may begin to be reimagined and the stalled progress rectified. In doing so it characterises the SD arm of Article 12 as a socio-economic right due to its capacity-building personal development and associated significant resourcing implications for supporters, meaning both that progressive realisation (and non-retrogression) tests must be met, and that there is salience to conversations closer to traditional welfare allocation (and priority setting) debates. Due to the tension in the link between the civil rights and socio-economic arms of Article 12 (and a realpolitik unwillingness of government to move on the civil rights front in isolation) it is also argued that the withdrawal or winding back of most proxies is contingent on delivery of *adequate* Article 12(3) support in those settings. In short it is contended that there is a neglected theoretical and operational indivisibility of the two types of rights in Article 12. Channelling Jenny Goldschmidt's CRPD focus on pursuit of transformative equality and justice—engaging principles of equality, accessibility, autonomy, participation and inclusion (Goldschmidt 2017)—this paper takes a broad brush look at new ways of realising CRPD substantive equality rights in the world of realpolitik, lightly engaging some concrete examples from Australia regarding possible priorities to be favoured.

2. Some (Re-)Conceptualisations?

When confronted with challenging issues it is sometimes helpful to strip out the technical detail to isolate the real shape of the underlying concepts. But first, some clarification of what SD involves.

2.1. SD as a 'Relational' Socio-Economic Right to Scarce Resources?

A short but simplistic answer to the question of the meaning of SD as expressed in Article 12(3) of the CRPD that 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity', when read with the rest of Article 12, is that it is provision of any needed 'support' to enable people to exercise legal capacity to make their own authentic decisions. Article 12(3) follows articulation of the rights to 'recognition everywhere as persons before the law' (Art 12(1)) and to 'enjoy legal capacity on an equal basis with others in all aspects of life' (Art 12(2)). As is well known, the General Comment issued by the monitoring Committee for the CRPD reads Article 12 as requiring immediate withdrawal of any 'substitute' decision-making such as adult guardianship, or proxy-decisions such as under involuntary mental health powers (UN Committee on the Rights of Persons with Disabilities 2014;

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[3] Disability history reminds us of egregious unintended consequences of lofty principles such as deinstitutionalisation (Gooding 2016; Wiesel and Bigby 2015).

Arstein-Kerslake and Flynn 2015, pp. 5–6). This is mainly because of the egregious abuses associated with exercise of those powers, but also by implication in reading Article 12 as entirely concerned with civil rights which therefore do not permit progressive realisation.

As now explained, I read SD implementation within Article 12 as a 'package', and a package where civil and socio-economic rights are in some tension. On this reading, any imperative to withdraw substitute decision-making extends beyond proxy decisions made under the law (e.g., adult guardianship and mental health involuntary treatment) to also include any unconsented and 'significant'[4] proxy decision-making occurring in natural relationships in civil society (as with the paternalism associated with say a worryingly subordinated dependent or abusive relationship). And that the withdrawal or winding back of most proxies, especially outside mental health treatment, is contingent on delivery of *adequate* Article 12(3) support in those settings.[5] This is because the right to SD is properly characterised as a socio-economic right (Carney 2015a). Fundamentally, then, SD as conceived in Article 12(3) is about ensuring that everyone has *access to* the necessary resources and assistive relationship(s) to enable full expression of their human agency as a *relational* being (see for example Herring 2016, p. 18; Gooding 2012, p. 435).

Despite the artificiality and deficiencies of taxonomies distinguishing say civil from socio-economic rights (see generally, Marks 2009) or first from so-called second or third generation rights (Tushnet 2016) and conceding the seamless relationships of such rights with each other, there *are* some useful markers. Socio-economic rights, such as to health or education, are often distinguished as imposing 'positive' liberties (claims on the state for expenditure or access to resources) while civil rights can be realised in a 'negative' or protective way, such as in describing civil rights to privacy or autonomy as the 'right to be left alone' (simply guaranteed by the state against interference with enjoyment). Although SD in the CRPD is only about ensuring equal access to agency as legal capacity, most SD programs to date offer a much wider spectrum of supports for greater agency in decision-making, so viewing SD *purely* as a 'civil and political right' (De Bhailís and Flynn 2017, pp. 17–18) is not persuasive. It is not persuasive because even though civil and political rights are not cost-free (protection of say the right to liberty, or freedom from torture all have machinery-of-enforcement costs), the resources to be marshalled to realise SD in *any* form are I contend both central to the right in question and are *very* much more substantial than those associated with civil and political rights. Like the rights to health or to social security, this *quantitative* difference in required resourcing is one of the characteristics that marks them out as socio-economic rights (attracting the correlative principle of progressive realisation). It is also that heavy resourcing implication that engages principles of realpolitik, which likewise presses for progressive realisation. I therefore find it no answer to deflect from engaging with this socio-economic character of SD, or its resource burden, by instead pointing to say the 'myriad ways' in which support can be delivered, or to requirements of personal tailoring of support to individual circumstances; for socio-economic rights share both of those attributes. It is the resourcing attributes, not these latter ones, which are critical in my analysis.

The socio-economic right to support includes among other things any necessary resources associated with reading a person's will and preferences when unable to verbalise choices, and facilitation of choice through provision of information or other assistance required in order to understand and select between options. This in itself can be costly and time-consuming to deliver. But as Jonathan Herring observes, its realisation also entails a radical paradigm shift. Writing about the role of law (but by extension also encompassing any SD program) under this re-conception, the object is explained as not so much to 'emphasize independence, liberty, and autonomy; but

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[4] The qualifying caveats are necessary because everyone tacitly or expressly accepts a degree of paternalist influence by others over what might be termed the minutiae of everyday life and social interaction.

[5] The adequacy of SD too is a subjective question, where reasonable minds will differ. My point is simply that not having any SD, or only having an empty 'opportunity' for SD to emerge within civil society settings such as family and other networks, without asking about the substance of that support, *fails* the test.

rather . . . to *uphold relationships and care*' (Herring 2016, p. 18). For the friendless this necessarily entails establishing or finding equivalents for missing relationships (e.g., recruiting supporters or finding other sources of advice and support), while the correlative 'safeguards' obligation of Article 12(4) calls attention to ensuring an acceptable 'quality' of those relationships, including avoiding the risk of a relationship of dependence or domination (Arstein-Kerslake and Flynn 2017). All of this explains why SD trials have proved to be so resource intensive (Bigby et al. 2017; Purcal et al. 2017), even though their goals and achievements were often quite modest.[6] But of course it also highlights the matrix of socio-economic contributors to overlapping and cumulative barriers and disadvantages encountered by those to be assisted by SD, such as poverty or problematic behaviours compounding reliance on care, and heightening levels of 'control' or surveillance of their lives (for an introduction, (Goggin et al. 2017)). Despite what some may wish, the evidence so far is that SD simply cannot be delivered 'on the cheap', at low cost.

2.2. *Conceptual Language for SD Realisation and the Role of Law*

Metaphorical mapping of conceptual debates and choices arguably highlights some important distinctions between the legal or program outcomes sought or able to be realised for the lived lives of people. These distinctions I suggest are the difference between actual and token or symbolic realisation of SD as a socio-economic right.

Many laws and many debates focus on the *making* of orders or accessing services. These may be thought of as 'gateway' issues, since they are about how easy or difficult it is to pass through the gate, and because little if any attention is paid to what occurs once a person has gained access (e.g., there is little monitoring and few if any safeguards beyond the access point or 'time'). Involuntary civil commitment and adult guardianship laws for instance tend to be weighted towards the gateway issues of the *making* of a sound and procedurally fair order rather than what happens afterwards. Other laws and debates are about finding an access route to a desired legal benefit, service or resource. These may be thought of as 'pathway' issues, because the focus is on the ability (or not) of a person to become *connected* to the social good in question, with little if any attention on whether the good in question is beneficial or not, or for how long any benefit subsists (Community Treatment Orders in mental health exemplify provision of such a pathway—an opportunity to have priority access to community mental health resources, but leaving debatable what is actually provided, or its benefits, if any: (Segal et al. 2017)). Other laws and debates by contrast are about seeking to achieve or guarantee access to a resource for a person. These may be thought of as akin to 'ticket to service' issues, because the focus here is on *requiring* the state or other providers to actually *deliver* the service or resource in question (as exemplified in say a legally enforceable *right* to social security), or at least in showing the service arrived (see Tait et al. 1995).

Of these labels, I suggest that SD as conceived in Article 12(3) is a 'ticket to services' product. But is this ticket to service mainly realised by adopting a treaty or passing a domestic law? What is the power of such laws in delivering on this? The answer I suggest is rather deflating. Making a normative 'ought' statement is one thing; but *operationalising* it so it translates into changes to the lived lives of people is quite another. International treaties like the CPRD certainly are among the most powerful of normative statements. But treaties do not automatically become part of the domestic law of a country, and their normative position may have little traction with the public at large (or what is often termed the 'beltway' of everyday politics). They are not self-actualising and may not even change culture and values, for as Jenny Goldschmidt (2017, pp. 12–13) notes, rights have lost purchase recently; and if actively opposed by ordinary folk they may even result in a backwards step (constituting what would

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[6] Those modest aims—such as increasing understanding of the difference between substitute and supported decision-making or providing 'assistance with decision-making' rather than some theoretical purity of human agency which is beyond us all—are not necessarily objectionable. However, it highlights how difficult it is to define 'success' in realising the aims of SD, and draws attention to another 'cost-benefit' calculus when prioritising allocation of scarce community resources.

be a breach of the 'non-retrogression' test for implementation of socio-economic rights if the product of government action).

Even when normative statements of international law command widespread popular acceptance, as say with the 'right to health', and even when such propositions are incorporated in the 'peak' constitutional documents of nations (as is often the case with the right to health), the operational impact may be negligible or slight. Thus at best it can be argued that a constitutional right to health 'changes the conversation' of the body politic (DeLaet 2015), even though there is, as yet, no empirical evidence of its ability to generate *any* additional resourcing at all (Chilton and Versteeg 2016). This is true also of US jurisprudence, as hopes of substantive change following adoption of a 'right to treatment' in mental health were dashed by experience (Carney et al. 2008). Nothing lasting really came of US and Canadian court jurisprudence laying down minimum criteria for civil commitment (Fischer 2006, p. 158; Appelbaum 1994), the qualified rights of competent patients to refuse treatment, or the limited 'right to treatment' for those detained (see Case Comment 1973; Eisenberg and Yeazell 1980, pp. 468–69; Perlin 2011).

So how does all this conceptual mapping help to understand the policy challenges associated with the limited implementation of SD to date?

3. Some Policy Challenges

One thing that is crystal clear from the Australian pilot programs for SD is that, irrespective of whether they achieve the desired outcomes or not, programs of support piloted so far in Australia are very costly (Bigby et al. 2017; Purcal et al. 2017, pp 32–33, 49). So, in a real-world context, even though not everyone needs support (e.g., some in mental health) and costs will vary with the individual, some priority setting is inevitable: for no government has unlimited resources.

Now these priorities can either be set by default (through inaction or by responding to the most vocal pressure groups) or result from explicit policy choices. Australia's introduction of provision for 'plan nominees' and support in its National Disability Insurance Scheme ('NDIS') is a (crude) legislative and program example of the latter. Appointment of a nominee and/or funding for support are both now seen as potential inclusions in personal plan packages, though the costs of any SD support mean its inclusion is rare and rarely is it fully funded. Further, the NDIS covers only small numbers of people (just 475,000 of the 4.3 million Australians with some form of disability: (Productivity Commission 2017, pp. 5, 16, 70)), and predominantly those with an intellectual disability and autism. This highlights some of the equity and distributional issues entailed when priorities are set in this ad hoc way. People with only marginally lesser needs than NDIS participants (or greater 'complex' needs such as associated criminal justice or poverty issues: (Steele et al. 2016)), simply miss out on either form of support. Skewing of access towards intellectual disability and autism results in inequality of access for otherwise apparently similar support needs of people with acquired brain injuries or mental illness/ psychosocial disabilities,[7] while NDIS design features mean that older citizens with mild dementias miss out entirely due to its age ceiling (other than for people already in the scheme prior to reaching retirement age).

So firstly, what 'does' Article 12 require of governments? Is repeal of proxy powers alone ever acceptable in the absence of support, and would this ever be ethically acceptable to any government? And, secondly, if progressive realisation is either the proper reading of Article 12(3) or is the only realistic pathway ever perceived to be available by governments, are there any insights to be drawn from debates about the merits or otherwise of needs-based allocation of welfare resources? These two questions are dealt with below.

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[7] Mental illness or psychosocial disability is the third most common disability after intellectual disability and autism, but accounts for only 6% of NDIS scheme participants: (Productivity Commission 2017, p. 16).

3.1. Repealing Substitute Decision-Making First/in Isolation?

Whether expressly or by implication, many commentators have accepted that the most immediate priority is giving effect to the CRPD Committee's insistence on eliminating all coercive powers (repealing all involuntary mental health and guardianship laws). This also is not happening, so is it time to 'tell 'em they're dreamin' in the memorable line from the Australian film *The Castle* (Wikipedia 1997), or is the reason for lack of legislative action due to a misreading? I suggest it is a misreading of how Article 12 in general is to be operationalised,[8] or at least that this is so in the world of realpolitik.

I argue that the first reason for such sluggish progress in either repealing laws like adult guardianship, or even adding some SD options to the statute book, lies in the neglected *indivisibility* of the civil and the socio-economic rights contained in Article 12. For legislatures (or indeed for social policy programs in general), winding back or eliminating most instances of substitute decision-making *needs to go hand in glove* with establishment of meaningful SD programs or arrangements. One way of demonstrating this for Australia is to pose the thought experiment of asking how life was for most such people (not involuntary mental health patients who were already under proxy treatment regimes) around half a century ago—*before* substitute decision-making laws were fashioned into something close to current guardianship legislation. This is interesting because in practice for many (or most) people, essentially there were *no laws at all*: the only options were the rarely used costly and cumbersome avenue of the inherent superior court protective jurisdiction; *automatic* property guardianship on becoming an involuntary patient; and—in some states such as Victoria—*administrative* procedures of medical certification of need for management (Carney 1982). This was the situation rectified by reforms introducing accessible least restrictive but substitute decision-making guardianship reforms, as recommended by an enquiry which sat between 1982 and 1984 (an Orwellian date, though not actually enacted until 1986: (Carney 1989)).

Of course, it is always problematic to ignore the cultural, organisational and other differences between historical eras, but since no-one found the then prevailing situation acceptable in the 1980s, it is surely difficult to argue that abolition of say guardianship laws *alone* would now be acceptable (the case for repeal alone is much easier to make in mental health where support may not be required). To the contrary, I contend that this is the whole purpose of the CRPD's inclusion in Article 12 of the *correlative* socio-economic right to support. Absent such support all that results from repeal is that state paternalism for all (under guardianship) is replaced, in the case of too many people for comfort, by civil society paternalism (by family or citizens who are generally well-meaning but unschooled in how properly to realise assistance and avoid paternalism). A paternalism that is less visible and less open to scrutiny, even if delivered by people theoretically likely to hold values closer to those of the person being assisted/subtly coerced, and even if unprotested by (i.e., notionally 'chosen by') the person. That is ethically unacceptable for most (some of course would judge it the lesser of evils). No government is likely to readily go down that path when that risk is judged excessive.

It is of course possible to argue that the remit of Article 12 as a whole is confined to realising rights of legal agency, meaning that the only way situations of domination trigger Article 12 scrutiny at all is where the person subject to paternalism turns to (or 'potentially' turns to) law to escape paternalism's clutches (as nicely argued by (Arstein-Kerslake and Flynn 2017, p. 27)).[9] Only rights such as to independent living under Article 19 would then be accepted as genuine socio-economic rights in the CRPD on this basis. Even if this were to be accepted (contrary to my reading), the language of Art 12(3)

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[8] For analysis questioning the conceptual weaknesses of a strong reading of the CRPD on the basis of 'meshing' of articulated will/preferences and presumed autonomy goals, such as read from prior life history or 'diachronic identity' (Burch 2017, pp. 394–97).

[9] The problem sought to be addressed is that '[i]n the informal sphere of familial relationships and services for daily decision-making . . . many of the decisions made . . . do not appear to have legal consequences or rise to the level of an exertion of legal agency. However, for many people with cognitive disabilities, some of the most damaging decision-making denials occur within these informal spheres' (Arstein-Kerslake and Flynn 2017, p. 24).

at the very least surely still sets provision of SD as a hard, *practical precondition* to any step to realise legal capacity, such as through repeal of guardianship (much perhaps as a right to a fair trial often requires funding for advocacy). Legislators and policy-makers certainly will not take unilateral repeal or other action in the face of the possibility of things being *worse* for affected citizens; so, repeal is not unconditional however we read Article 12.

While repeal of guardianship is easy, realising the correlative socio-economic right to support without incurring an all too common resultant paternalism and undue influence within the civil society settings which remain is not at all easy to address. Since it is rare indeed for people to *actually* ever make an entirely independent autonomous decision without taking into account external views of others (or community 'expectations'), merely removing barriers to autonomous decision-making as an end in itself cannot take us far at all; we need to know to what extent autonomy is *achieved* (Carney 2017c). Rather than such a starry-eyed consequential 'status' of self-actualisation, I would contend that the focus is better placed on a more modest notion such as the *means* by which people can be assisted to more fully and/or more often exercise their 'will' and/or 'preferences' (since the two are not necessarily the same: Szmukler 2017 IALMH paper summarised in (OPA 2017, p. 51)).

Seen in this light, the definition of 'success' in realising this Article 12(3) CRPD right to SD becomes quite debatable. Is it enough simply to 'try' to facilitate SD (a perhaps largely symbolic gain) or as argued below should there be insistence on a showing of progress? If so, how much progress and how durable should progress be? Is it enough that a new culture and language is adopted between the person being 'supported' and those around them (which may yield 'slow-burn' gains over time), or should, as suggested below, attention be on measuring change in the *number* and *type* of decisions *actually* being made? And, if so, can trends of expanded confidence in the number and magnitude of decisions being made be taken at face value without considering any (offsetting?) enhanced 'risk' of any unfortunate outcomes of those decisions? Surely not. Surely nor should the answers to these questions differ between SD schemes that are legislated as against being program or civil society initiatives (the range sketched in (Carney and Beaupert 2013)).

Since SD is something delivered to assist someone other than the supporter to realise their Article 12 rights, I argue that the contribution made by law and policy primarily must surely be on achievement of some minimum level of competence and understanding of SD by supporters, and where this does not exist naturally (as rarely it does) then it turns on the success and durability of capacity-building of SD among supporters. And since Article 12 is about ensuring/promoting optimal achievable equality, regard surely must then be had to the *substantive* as distinct from symbolic achievements of supporters in serving as the instrumental agents for realising optimal decision-making autonomy of those being assisted. This might for the purposes of the present discussion be translated into some crude conceptual labelling of the forms of SD. Labelling which deliberately here is pitched to be inclusive in the sense of catching not only SD under some legal auspice but also the much larger numbers of people receiving it under a formal civil society scheme, or the even larger numbers living and supported 'informally' by family or friends in natural civil society settings.

For simplicity, the 'substance' of such arrangements, on an evaluative spectrum from good to awful, might be badged as SD which is: (i) sensitive/substantive (i.e., SD at its optimal best); (ii) symbolic/empty (i.e., well-intentioned SD, but in name only); and (iii) abusive/oppressive (i.e., SD which is paternalistic substitute decision-making 'in disguise', whether by default or design (or as Matthew Burch evocatively puts it, '[w]hat happens when manipulation dons the mantle of support': (Burch 2017, p. 397)). The latter is of the greatest concern, not only because in practice CRPD autonomy enhancing is being contradicted, but also because in some instances it is the result not of lack of capacity of the supporter to do the right thing, instead involving deliberate abuse and exploitation of the person being supported (Arstein-Kerslake and Flynn 2017). However, the middle category is of concern too, since its symbolic window-dressing deflects public policy attention by conveying a false appearance of CRPD compliance. Only the first category passes CRPD muster, but so far there is no evidence (other than unscientific anecdotal evidence) that *any* law or program *actually* is entitled to the label (though the same could of course be said of proxy decision-making).

So, what is entailed by priority setting and what 'language' maps the conceptual territory of laws and programs associated with that part of the challenge of 'properly' realising SD in the way sketched so far?

3.2. Setting Priorities for Allocating Limited Resources for SD

The second reason for sluggish progress in implementing SD (beyond the indivisibility point discussed in 3.1) I suggest may be due to a failure to address the realpolitik of implementing socio-economic rights in times of real or perceived austerity.[10] Now I recognise that some will regard it as almost heretical to speak about setting 'priorities' for the realisation of human rights. Yet socio-economic rights have always provided for 'progressive realisation' by State Parties (especially in recognition of the challenges of developing states), subject to a correlative 'non-retrogression' obligation (not going backwards);[11] and it is hard to find examples even of wealthy countries not taking a similar progressive (i.e., staged) and/or selective (i.e., needs-based) approach to their realisation. Despite the jurisprudence on the obligation to 'respect, protect and fulfil' (Wills and Warwick 2016; Forman et al. 2016), progressive realisation of universal socio-economic rights does of course risk glacial progress at best or constant postponement to the 'never-never land' at worst, especially in the face of neoliberal fiscal austerity which constrains public funding options even in wealthy first-world economies.

Welfare policy seems particularly well adapted to addressing progressive realisation issues because it constantly engages with the competition and choices arising between the three principles of distributive justice for setting priorities about allocation of necessarily scarce resources: the competing principles of (i) equality (universal provision but at the risk of spreading resources too thinly); (ii) equity (proportionate return on prior contributions); and (iii) 'need' such as by means testing (see Carney 2006, chp. 4; Devereux 2016, pp. 168–78). The realpolitik of governing, especially in the age of neoliberal austerity, is that the needs principle will often be selected (and on its own) unless the case can be made for some selective *supplementary* application of a more costly principle, such as illustrated by Steven Devereux's argument for supplementary provision of universal access to 'essential' services (Devereux 2016, pp. 178–79). In just this vein the right to health has been refined to stipulate a limited number of 'minimum core obligations' (the specification or measurement of which proves problematic: (Forman et al. 2016)), effectively elevating the core ahead of the right generally. Selective provision of a social good such as income or a service (such as by means-testing access or rates, or other forms of rationing) reflects prioritisation of the most pressing or acute need, including any redistributive pursuit of greater equality in access to the social good in question; though over the long history of welfare both 'social investment' (capacity-building initiatives) and needs-based programs are evident (see for example, Smyth and Deeming 2016).

Indulge for a moment engaging with the heretical thought exercise of asking how to isolate a 'minimum core' for SD, or how otherwise to provide a rank order of possible priority targets for early roll out of SD. Possible inclusions on such a 'shopping list' of possible steps towards realising the ultimate goals of the 'support-with-safeguards' principle of Article 12(3) of the CRPD might include:

(a) addressing the most egregious breaches (perhaps people languishing under heavy drug restraints in care homes, though for an argument to cover family settings too, see: (OPA 2017, p. 38));

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[10] Targetting (priority setting allocation such as through means testing) is one of the three fundamental choices/tension in welfare provision (the others being universal provision and provision proportionate to say prior contributions or years of work/citizenship: (Devereux 2016)).

[11] For elaboration of these twin principles in the context of neoliberal shrinking of public resources, see the insightful discussion of the *International Covenant on Economic Social and Cultural Rights*, one of the two main 'parents' of the CRPD (Wills and Warwick 2016, especially pp. 640–46, 653–55).

(b) addressing the most pervasive but more routine support needs (such as for a supporter or nominee/representative payee in social security);
(c) prioritising the needs of the least visible and most vulnerable (such as people lacking friends or relatives, or overly reliant on a very 'protective' carer; or those who are criminalised or labelled with complex needs);
(d) tackling issues where law or policy has the strongest track record in being brought into actual practice (perhaps by operationalisation of advance directives);
(e) concentrating on groups fortunate to be more plentifully resourced (such as Australia's NDIS population); or
(f) picking the issues where the impact is most cost-effective (such as legislation allowing people to authorise someone else to convey information or access records on their behalf)?

I suggest a case can be made for putting almost *any* of the above items first on the list, and for choosing almost any subsequent running order of the remaining items. For instance calls have been made for more attention to be paid to the routine needs of large numbers of ordinary people (i.e., item (b): (Carney 2015a)) and concern expressed about neglect of the needs of people who are socially isolated (item (c)). But adapting Anna Arstein-Kerslake et al.'s observation that NDIS resourcing is already adequate to also properly fund SD, a start could very well be made with that population (noting however the authors difficult to avoid worry that SD may just become 'another service' controlled and delivered by others rather than by those being supported: (Arstein-Kerslake et al. 2017)). Reasonable minds will differ. Others may rightly urge keeping item (a) at the top of the list due to the depth of infringement of liberty and strong presence of actual or de facto coercion (actual in the case of involuntary treatment or restraint; often de facto where people are living in 'total institution' settings and/or feeling beholden to their carers). But there are several ethical and social values and standpoints potentially in play even here: of the just mentioned measure of diminution of individual autonomy; of the alternative measure of empowering or allowing 'others to decide' (the amount of paternalism or disempowerment); or by the measure of how much 'harm' is visited on the person (from consequential harms and risks[12]). So, in varying ways, prioritising any one (or putting others into a rank order for realisation) inevitably reprises the choice between, or weighting of, the just mentioned values of equality, equity and need (whether assessed by measurable variables like severity or more amorphous concepts such as 'vulnerability').

However, the problems are not yet finished. For knowing when Article 12(4) safeguards are called for involves yet another of those tricky 'threshold' questions. Certainly, as already argued, Article 12(3) extends a correlative entitlement to 'support' as the required replacement for some form of substitute decision-maker. In that sense, it provides the answer to the concern that reading Article 12 simply as outlawing substitute decision-making would merely return people to say Victoria's 'pre-1984' situation of having neither an accessible substitute decision-maker (just costly and ultra-paternalistic Supreme court actions) nor any practical support (at least outside institutional or coercive orders). This would involve a return to what I have characterised above as the morally unsupportable position of being 'free' of substituted decision-making but with nothing but a theoretical (and unrealisable in practice) ability to enjoy autonomous decision-making unless blessed with access to 'perfect' natural or civil society supporter(s). But, as Linus Broström (2017) points out, there is a vast literature about the ease with which even the most conscientious and well-intentioned informal supports can rapidly degrade to operate paternalistically, under the thrall of forms of undue influence (Broström 2017). So finding ways to bring about the paradigm shift in values and skills of civil society members to genuinely realise 'support-with-safeguards' free of undue influence in the way envisioned by the CRPD, is a

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[12] Indeed it was this latter lack of adequate safeguard protections against the risk of large social security debts that led me to focus on the 'mass/mundane' issues facing representative payee arrangements (Carney 2017a, pp. 10–13).

major empirical challenge in capacity building of supporters (Carney 2017c). But first there is the thorny question of where any bright line is set for 'undue' influence.

For its part, operationalising such a threshold of undue influence is very challenging. Common law principles of equity on undue influence could in theory make a contribution (Sloan 2012, chp. 7), but they do not readily lend themselves to simple application outside the higher courts. Concepts of vulnerability have been advanced by some in the related context of guardianship reform or elsewhere (Hall 2012 [as basis for guardianship]; Herring 2016, pp. 83–85 [inherent parens patriae], 243–49 [contracts]) . Here the focus on webs of relationships and 'layering' of contributions to vulnerability (Luna 2009; Luna and Vanderpoel 2013) holds the promise of a richer calibration of individual and social-contextual dimensions (such as being socially isolated). However, vulnerability too remains a very woolly concept (Kohn 2014; Smith et al. 2010; Herring 2016, chp. 2, especially pp. 6–11). Vulnerability, then, is no generic standard or test, but one which calls for conceptual clarity between different formulations, along with specification in particular contexts (such as in quarantining special disability trusts: (Carney 2017b)). That specification may in turn be open to the criticism that it is a 'stark binary' capacity test in disguise, unless framed along the lines of Martha Fineman or Amartya Sen's 'universal vulnerability' or 'spatial/environmental' terms (for a detailed review: (Brown et al. 2017; Clough 2017), also the four articles underpinning [and fully republished within] her doctoral thesis: (Clough 2015)).

Turning to the risk of contravention of CRPD autonomy maximising values by civil society actors in ordinary relationship settings, it is again important to take a grounded real-world approach. Arguably all citizens are prone to adapt behaviour and choices to some degree in response to forms of external influence (Herring 2016, chp. 2). So, it is only when influence is judged to be a form of 'undue' influence that it becomes of concern legally, ethically, or socially. But as just shown, there probably is no bright line test which identifies the threshold beyond which concern is properly raised. At best there sometimes may be some assistance to be derived in posing a crude counterfactual, such as by comparing the lived-life autonomy enjoyed by someone under as against a person without guardianship or its companions. For surely it is unacceptable to argue that it is 'better' that a person enjoys *less* autonomy, or is subject to more paternalism in a civil society setting, than would be the case under say guardianship.

Might all of these worries about finding and prioritising resources and resolving design and safeguards issues be contributing to the very slow progress being made towards realising the legislative or program 'package' for SD as I argue is conceived in Article 12 of the CPRD? Does it not help to understand in realpolitik terms if no other, why legislatures such as Victoria have combined some minor 'easing back' of civil committal powers in mental health with the enunciation of rights to nominate supporters (*Mental Health Act 2014* (Vic), s 24)? A measure sure to be criticised by the CRPD Committee for its failure to repeal involuntary treatment but which it seems has already proved rather empty on the supporter side due to low take-up (Brophy 2017), as evidenced by the presence of nominated supporters at just four per cent of committal hearings (MHT 2016, p. 15). How can Victoria be faulted on a 'priority of needs' basis for at least *starting with* an area as rights-sensitive and fraught as mental health (especially if that support is not forthcoming in the way envisaged)? For self-evidently this is a strong candidate for inclusion on any hypothetical 'minimum core' for progressive realisation of the right to SD.

If this analysis has purchase, where does it leave Article 12 'repeal in conjunction with adequate SD' in the longer term? With a de facto status quo and glacial progression for much of the duration? Surely if simple repeal of substitute decision-making without more is not an option on ethical grounds or because it is unattractive to government realpolitik, and only the resource-intensive 'repeal & replace' avenue is open, as argued above, then the answer is 'yes.' Now this undoubtedly is an unsettling conclusion. But it is nothing other than the standard approach regarding implementation of other socioeconomic rights such as the rights to housing, to health, or to social security.

4. Conclusions

This paper was stimulated by the apparently glacial progress made in the decade since the CRPD enunciated the right to support. It has explored—well more accurately perhaps it has 'lightly sketched'—some less orthodox conceptual and distributional frames (such as welfare's 'priority of needs principle') as possible ways of injecting greater momentum into the implementation of SD by looking at it through a different lens than that of what might be termed the 'capacity-analysis' literature.

In doing so I am mindful that some may object that a lot of 'below the radar' support programs and pilot schemes have already been generated internationally (e.g., Power et al. 2013; Van Puymbrouck 2017), or that SD resourcing costs are overstated, so we should remain patient. Others will object that even if progress is inadequate, it would be positively sacrilegious to isolate particular beneficiaries or to contemplate progressive realisation of what was framed as a universal entitlement. Both may be right. And there are no doubt other lenses which could be applied, such as a justice-reinvestment analysis (for an overview Brown et al. 2016) designed to boost resources available for SD by earmarking and reallocating savings from lowering the load on say the already costly adult guardianship and mental health machinery (while remaining alert to avoiding the past failure of deinstitutionalisation to hypothecate similar 'savings' while States congratulated themselves on their purist 'reforms': (Mansell and Ericsson [1996] 2013; Caplan and Ricciardelli 2016, p. 33)). However as I have previously written about the right to health, even John Tobin's optimistic book about actualising the right to health closes by writing that: 'Following Lauterpacht,[13] it can safely be said that if economic and social rights are at the vanishing point of human rights law, as a surprising number of jurists and philosophers still seem to think, then the right to health is at the vanishing point of economic and social rights' (Tobin 2012, p. 371).

The worry tackled in this paper is that the socio-economic right to SD risks dropping below even that vanishing point; hence canvassing of some rather heretical paradigm shifting thought experiments as a way of assessing progress to date and the way forward. Rather than pessimism about Article 12 in general and SD in particular 'running on empty', I suggest that the slow but measured progressive realisation so far is also the course to stay for the future. After all, isn't that the history of pursuit of substantive equality, with its messy needs priority and other principles (Fredman 2016; Goldschmidt 2017)? If so, does it not become even more imperative to know when SD serves to build capacity, for how long benefits subsist and at what economic cost, as a current study is designed to reveal (further, LIDS 2017)?

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References

ALRC. 2014. *Equality, Capacity and Disability in Commonwealth Laws: Final Report*. Sydney: Australian Law Reform Commission.

Appelbaum, Paul S. 1994. *Almost a Revolution: Mental Health Law and the Limits of Change*. Oxford: Oxford University Press.

Arstein-Kerslake, Anna, and Eilionóir Flynn. 2015. The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law. *The International Journal of Human Rights* 20: 1–20. [CrossRef]

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[13] Adapting the wry 1952 comment by Sir Hersch Lauterpacht about the limited normative power of the international law of war ('if international law is the vanishing point of law...the law of war is the vanishing point of international law').

Arstein-Kerslake, Anna, and Eilionóir Flynn. 2017. The Right to Legal Agency: Domination, disability and the protections of Article 12 of the Convention on the Rights of Persons with Disabilities. *International Journal of Law in Context* 13: 22–38. [CrossRef]

Arstein-Kerslake, Anna, Joanne Watson, Michelle Browning, Jonathan Martinis, and Peter Blanck. 2017. Future Directions in Supported Decision-Making. *Disability Studies Quarterly*. [CrossRef]

Bigby, Chris, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Weisel, and Lizzie Smith. 2017. Delivering Decision-making Support to People with Cognitive Disability—What has been learned from pilot programs in Australia from 2010–2015. *Australian Journal of Social Issues* 52: 222–40. [CrossRef]

Boundy, Marcia, and Bob Fleischner. 2013. *Supported Decision Making Instead of Guardianship: An International Overview*. Washington: TASC [Training & Advocacy Support Center], National Disability Rights Network.

Brophy, Lisa. 2017. Nominated supporters in mental health. Paper presented at IALMH Congress Session, Prague, Czech Republic, July 14.

Broström, Linus. 2017. Due and Undue Influence in Supported Decision Making: Mapping the moral landscape. Paper presented at XXXV International Congress of Law and Psychiatry, Charles University, Prague, Czech Republic, July 9–14.

Brown, David, Chris Cunneen, Melanie Schwartz, Julie Stubbs, and Courtney Young. 2016. *Justice Reinvestment: Winding Back Imprisonment*. Basingstoke: Palgrave Macmillan.

Brown, Kate, Kathryn Ecclestone, and Nick Emmel. 2017. The Many Faces of Vulnerability. *Social Policy and Society* 16: 497–510. [CrossRef]

Browning, Michelle. 2010. *Report by Michelle Browning 2010 Churchill Fellow To Investigate New Models of Guardianship and the Emerging Practice of Supported Decision Making*. Canberra: Winston Churchill Memorial Trust.

Burch, Matthew. 2017. Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis. *Journal of Applied Philosophy* 34: 389–402. [CrossRef]

Caplan, Mary, and Lauren Ricciardelli. 2016. Institutionalizing Neoliberalism: 21st-Century Capitalism, Market Sprawl, and Social Policy in the United States. *Poverty & Public Policy* 8: 20–38.

Carney, Terry. 1982. Civil and Social Guardianship for Intellectually Handicapped People. *Monash University Law Review* 8: 199–232.

Carney, Terry. 1989. The Limits and the Social Legacy of Guardianship. *Federal Law Review* 18: 231–66.

Carney, Terry. 2006. *Social Security Law and Policy*. Sydney: Federation Press.

Carney, Terry. 2014. Clarifying, Operationalising and Evaluating Supported Decision Making Models. *Research and Practice in Intellectual and Developmental Disabilities* 1: 46–50. [CrossRef]

Carney, Terry. 2015a. Supported Decision-making for People with Cognitive Impairments: An Australian perspective? *Laws* 4: 37–59. [CrossRef]

Carney, Terry. 2015b. Supporting People with Cognitive Disability with Decision-making: Any Australian law reform contributions? *Research and Practice in Intellectual and Developmental Disabilities* 2: 6–16. [CrossRef]

Carney, Terry. 2017a. Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse? *Journal of Ethics in Mental Health* 10: 1–17. Available online: http://www.jemh.ca/issues/v9/theme3.html (accessed on 11 October 2017).

Carney, Terry. 2017b. Financial Planning Mechanisms (Lasting Power of Attorney, Guardianship, and SNT) for persons with ID in Australia? Paper presented at International Symposium on Special Needs Trusts, Faculty of Law, The University of Hong Kong, Hong Kong, October 13–14.

Carney, Terry. 2017c. Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building? *Law in Context*. forthcoming.

Carney, Terry, and Fleur Beaupert. 2013. Public and Private Bricolage-Challenges balancing law, services & civil society in advancing CRPD supported decision making. *University of New South Wales Law Journal* 36: 175–201.

Carney, Terry, David Tait, and Fleur Beaupert. 2008. Pushing the Boundaries: Realising rights through mental health tribunal processes? *Sydney Law Review* 30: 329–56.

Case Comment. 1973. Wyatt v Stickney and the Right of Civilly Committed Mental Patients to Adequate Treatment. *Harvard Law Review* 73: 1282–306.

Chilton, Adam S., and Mila Versteeg. 2016. *Rights Without Resources: The Impact of Constitutional Social Rights on Social Spending*. Coase-Sandor Working Paper Series in Law and Economics No. 781; Chicago: University of Chicago.

Clough, Beverley. 2015. Exploring the Potential of Relational Approaches to Mental Capacity Law. Ph.D. Thesis, School of Law, University of Manchester, Manchester, UK.

Clough, Beverley. 2017. Disability and Vulnerability: Challenging the Capacity/Incapacity Binary. *Social Policy and Society* 16: 469–81. [CrossRef]

Davidson, Gavin, Berni Kelly, Geraldine Macdonald, Maria Rizzo, Louise Lombard, Oluwaseye Abogunrin, Victoria Clift-Matthews, and Alison Martin. 2015. Supported Decision Making: A review of the international literature. *International Journal of Law and Psychiatry* 38: 61–67. [CrossRef] [PubMed]

De Bhailís, Clíona, and Eilionóir Flynn. 2017. Recognising Legal Capacity: Commentary and analysis of Article 12 CRPD. *International Journal of Law in Context* 13: 6–21. [CrossRef]

DeLaet, Debra L. 2015. What a Wonderful World it Would Be: The Promise and Peril of Relying on International Law as a Mechanism for Promoting a Human Right to Health. *Global Health Governance* 9: 92–113.

Devereux, Stephen. 2016. Is Targeting Ethical? *Global Social Policy* 16: 166–81. [CrossRef]

Eisenberg, Theodore, and Stephen C. Yeazell. 1980. The Ordinary and the Extraordinary in Institutional Litigation. *Harvard Law Review* 93: 465–517. [CrossRef] [PubMed]

Fischer, Jennifer. 2006. A Comparative Look at the Right to Refuse Treatment for Involuntarily Hospitalized Persons with a Mental Illness. *Hastings International and Comparative Law Review* 29: 153–86.

Forman, Lisa, Luljeta Caraoshi, Audrey R. Chapman, and Everaldo Lamprea. 2016. Conceptualising Minimum Core Obligations under the Right to Health: How should we define and implement the 'morality of the depths. *The International Journal of Human Rights* 20: 531–48. [CrossRef]

Fredman, Sandra. 2016. Substantive Equality Revisited. *International Journal of Constitutional Law* 14: 712–38. [CrossRef]

Goggin, Gerard, Linda Steele, and Jessica Robyn Cadwallader. 2017. Normality and disability: Intersections among norms, law, and culture. *Continuum* 31: 337–40. [CrossRef]

Goldschmidt, Jenny E. 2017. New Perspectives on Equality: Towards Transformative Justice through the Disability Convention? *Nordic Journal of Human Rights* 35: 1–14. [CrossRef]

Gooding, Piers. 2012. Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law. *Psychiatry, Psychology and Law* 20: 431–51. [CrossRef]

Gooding, Piers. 2014. Supported Decision-Making: A Disability and Human Rights-Based Concept for Mental Health Law. Ph.D. Thesis, Monash University, Clayton, Australia.

Gooding, Piers. 2016. From Deinstitutionalisation to Consumer Empowerment: Mental health policy, neoliberal restructuring and the closure of the 'Big bins' in Victoria. *Health Sociology Review* 25: 33–47. [CrossRef]

Gordon, Rob. 2000. The Emergence of Assisted (Supported) Decision-making in the Canadian Law of Adult Guardianship and Substitute Decision-Making. *International Journal of Law and Psychiatry* 23: 61–77. [CrossRef]

Hall, Margaret. 2012. Mental Capacity in the (Civil) Law: Capacity, autonomy and vulnerability. *McGill Law Journal* 58: 61–94. [CrossRef]

Herring, Jonathan. 2016. *Vulnerable Adults and the Law*. Oxford: OUP.

Kohn, Nina A. 2014. Vulnerability Theory and the Role of Government. *Yale Journal of Law and Feminism* 26: 1–27.

Kohn, Nina A., and Jeremy A. Blumenthal. 2014. A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities. *Disability and Health Journal* 7: S40–S43. [CrossRef] [PubMed]

Kohn, Nina A., Jeremy A. Blumenthal, and Amy T. Campbell. 2013. Supported Decision-Making: A Viable Alternative to Guardianship? *Penn State Law Review* 117: 1111–57. [CrossRef]

Law Commission of Ontario. 2014. *Legal Capacity, Decision-Making and Guardianship. Discussion Paper May 2014*. Toronto: Law Commission of Ontario.

Law Commission of Ontario. 2017. *Legal Capacity, Decision-Making and Guardianship: Final Report*. Toronto: Law Commission of Ontario.

LIDS. 2017. Effective Decision-Making Support. La Trobe University Living With Disability Research Centre. Available online: http://www.latrobe.edu.au/lids/research/support-for-decision-making/decision-making-support (accessed on 11 September 2017).

Luna, Florencia. 2009. Elucidating the Concept of Vulnerability: Layers not labels. *International Journal of Feminist Approaches to Bioethics* 2: 121–39. [CrossRef]

Luna, Florencia, and Sheryl Vanderpoel. 2013. Not the Usual Suspects: Addressing Layers of Vulnerability. *Bioethics* 27: 352–32. [CrossRef] [PubMed]

Magnusson, Roger. 2017. *Advancing the Right to Health: The Vital Role of Law*. Geneva: World Health Organization.

Mansell, Jim, and Kent Ericsson. 2013. *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*. Dordrecht: Springer, First published 1996.

Marks, Stephen P. 2009. The Past and Future of the Separation of Human Rights into Categories. *Maryland Journal of International Law* 24: 209–43.

MHT. 2016. *Mental Health Tribunal Annual Report 2015–2016*. Melbourne: Mental Health Tribunal.

OPA. 2017. *Designing a Deprivation of Liberty Authorisation and Regulation Framework*. Melbourne: Office of the Public Advocate.

Perlin, Michael L. 2011. The Right to Treatment and the Road Ahead: "Abandoned Love": The Impact of Wyatt v. Stickney on the Intersection Between International Human Rights and Domestic Mental Disability Law. *Law & Psychology Review* 35: 121–239.

Power, Andrew, Janet Lord, and Allison de Franco. 2013. *Active Citizenship and Disability: Implementing the Personalisation of Support, Cambridge Disability Law and Policy Series*. Cambridge: Cambridge University Press.

Productivity Commission. 2017. *National Disability Insurance Scheme (NDIS) Costs*. Canberra: Productivity Commission.

Purcal, Christiane, Trish Hill, Kelly Johnson, and Rosemary Kayess. 2017. *Evaluation of the Supported Decision Making Phase 2 (SDM2) Project: Final Report*. Sydney: Social Policy Research Centre, UNSW.

Segal, Steven P., Stephania L. Hayes, and Lachlan Rimes. 2017. The Utility of Outpatient Commitment: I. A Need for Treatment and a Least Restrictive Alternative to Psychiatric Hospitalization. *Psychiatric Services*. [CrossRef] [PubMed]

Sloan, Brian. 2012. *Informal Carers and Private Law*. Oxford: Hart Publishing.

Smith, Maxwell J., Carrie Bernard, Kate Rossiter, Sachin Sahni, and Diego DSilva. 2010. Vulnerability: A Contentious and Fluid Term. *The Hastings Center Report* 40: 5–6. [CrossRef] [PubMed]

Smyth, Paul, and Christopher Deeming. 2016. The 'Social Investment Perspective' in Social Policy: A Longue Durée Perspective. *Social Policy & Administration* 50: 673–90. [CrossRef]

Steele, Linda, Leanne Dowse, and Julian Trofimovs. 2016. Who is Diverted: Moving beyond Diagnosed Impairment towards a Social and Political Analysis of Diversion. *Sydney Law Review* 38: 179–206.

Tait, David, Terry Carney, and Kirsten Deane. 1995. *Ticket to Services or Transfer of Rights?: Young People and Guardianship*; Canberra: National Youth Affairs Research Scheme.

Then, Shih-Ning. 2013. Evolution and Innovation in Guardianship Laws: Assisted decision-making. *Sydney Law Review* 35: 133–66.

Tobin, John. 2012. *The Right to Health in International Law*. Oxford: Oxford University Press.

Tushnet, Mark. 2016. Notes on Some Aspects of the Taxonomy of 'Generations' of Rights. *Journal of Institutional Studies [Revista Estudos Institucionais]* 2: 475–85. [CrossRef]

UK Independent Mechanism. 2017. Disability Rights in the UK: Submission to inform the CRPD list of issues on the UK. Available online: https://www.equalityhumanrights.com/en/our-human-rights-work/monitoring-and-promoting-un-treaties/un-convention-rights-persons-disabilities (accessed on 3 September 2017).

UN Committee on the Rights of Persons with Disabilities. 2014. *General Comment No. 1 (2014)*. Geneva: UN Committee on the Rights of Persons with Disabilities.

UN Committee on the Rights of Persons with Disabilities. 2017. List of Issues in Relation to the Initial Report of the United Kingdom of Great Britain and Northern Ireland. Available online: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2fQ%2f1&Lang=en (accessed on 3 September 2017).

Van Puymbrouck, Laura. 2017. *Supported Decision Making in the United States: A White Paper by CQL*. Towson: Council on Quality and Leadership.

VLRC. 2012. *Guardianship: Final Report*. Melbourne: Victorian Law Reform Commission.

Wiesel, Ilan, and Christine Bigby. 2015. Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974–2014. *Urban Policy and Research* 33: 178–94. [CrossRef]

Wikipedia. 1997. The Castle. Available online: https://simple.wikipedia.org/wiki/The_Castle_(movie) (accessed on 18 August 2017).

Wills, Joe, and Ben Warwick. 2016. Contesting Austerity: The potential and pitfalls of socioeconomic rights discourse. *Indiana Journal of Global Legal Studies* 23: 629–64. [CrossRef]

3

Drawing the Line: Disability, Genetic Intervention and Bioethics

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Abstract: Meteoric scientific advances in genetic technologies with the potential for human gene editing intervention pose tremendous legal, medical, social, ethical and moral issues for society as a whole. Persons with disabilities in particular have a significant stake in determining how these technologies are governed at the international, domestic and individual levels in the future. However, the law cannot easily keep up with the rate of scientific progression. This paper aims to posit a methodology of reform, based on a core value of human dignity, as the optimal course of action to ensure that the interests of persons with disabilities, other possibly marginalised groups, and the scientific community, are balanced fairly. The paper critically analyses the current law and varying bioethical perspectives to ultimately conclude that a clear principled approach toward open discussion and consensus is of paramount importance to have any chance of devising an effective regulatory regime over human gene editing technology.

Keywords: disability; human rights; genetics; gene editing; bioethics; governance; human dignity; eugenics; germline; Convention on the Rights of Persons with Disabilities

The true good is in the different, not the same (Menand 2004).

1. Introduction

Popular, professional and scholarly interest in genetics and their influence on human variability, behaviour and development has grown exponentially in recent years. In no small part has this interest been bolstered by mainstream media coverage of large-scale collaborative scientific initiatives like the Human Genome Project, which endeavoured to identify and map the human genome and determine the sequence of nucleotide base pairs that make up our DNA. Even over a decade ago, the President's Council on Bioethics asserted that:

> [W]e have entered upon a golden age for biology, medicine, and biotechnology. With the completion of (the DNA sequencing phase of) the Human Genome Project and the emergence of stem cell research, we can look forward to major insights into human development, normal and abnormal, as well as novel and more precisely selected treatments for human disease ... In myriad ways, the discoveries of biologists and the inventions of biotechnologists are steadily increasing our power ever more precisely to intervene into the workings of our bodies and minds and to alter them by rational design (President's Council on Bioethics 2003, pp. 4–5).

Our knowledge and expertise in the realm of genetic engineering and methods through which to alter our genetic makeup have expanded exponentially since that statement. Science continually pushes the contemporary boundaries of what can be done just as much as it does for what we think should or should not be done. In 2017, we now have access to ground-breaking technologies that are becoming more accurate and inexpensive, and therefore more widespread. Human genome editing is one such practice that is rapidly advancing with the potential to outpace legal regulation at the national, international and institutional levels.

Atypical biotechnological advancement and (lack of) regulation poses a vast array of ethical, social, legal and human rights issues for the disability human rights movement. From one perspective, misuse of these technologies could quite quickly develop into a new eugenics movement akin to humanity's sordid and abominable forays into such immoral practices throughout history. From another, it beckons new horizons for the human race and promises of a 'better' human or a 'better' life for those already living with disabilities. This debate touches on notions of normality, discrimination and fundamental values of human dignity, and prompts a number of unsettling questions. Will society's attitudes towards and treatment of persons with disabilities become determinant purely on their genetic makeup? Will such people be further ostracised as a result of potentially not having 'desirable' genetic traits? Will there be active eugenic practices to 'eradicate' genetic disability? Most importantly, will there be a way to stop that from happening?

This paper aims to search for an answer to the last question so as to negate the need to ask the former ones. It contends that genomic technology, its use and development, should be appropriately regulated in the future so as to balance the interests of science with those of people with disabilities. Section 2 briefly elucidates humanity's abhorrent past of eugenic practices in the 20th Century. By tracking technological advancement in the human genetic modification sphere, it draws analogies between the two eras to shed light on the well-founded concern of some disability rights advocates that it risks delving into the realm of a 'neo-eugenics' movement. Section 3 canvasses the opposing bioethical theories that underpin various legal, medical, social, ethical and moral perspectives in this area. Section 4 explores and critically analyses the way in which the international community and individual nation states (particularly Australia) have attempted to effectively protect the interests of those with disabilities in light of these technological advances. Finally, Section 5 will propose a human rights model of reform to remedy flaws and omissions in the current regulatory system, such that disability rights advocates have a powerful and influential voice in shaping a genetic tool that has the capacity to shape how they live their lives.

Ultimately, the greatest obstacle for effective regulation is the undeniable fact that the rapid development of these technologies is unstoppable. However, the way in which they are used can be changed and controlled. With the implementation of appropriate international and domestic regulatory regimes that not only consider the past and present, but also comprise an element of foresight, persons with disabilities are less likely to be adversely affected. That is the rationale for this paper. Developing genetic technologies pose a crucial and eventually universal issue as they become more accessible and less expensive; undoubtedly the quickest way to their abuse.

2. Classical and Neo-Eugenics

Prevailing attitudes towards the 'other' are often influenced by the contemporary and prevailing social, political, cultural and technological developments at any point in human history. This section aims to track eugenics, as one such attitude, from its oldest form through to the current day in order to exemplify the issues that genetic technologies pose for people with disabilities.

2.1. Classical Eugenics: How Far Have We Gone?

Eugenics is not a new concept. The term's classical meaning was originally articulated by Francis Galton as:

> the science of improving stock, which is by no means confined to questions of judicious mating, but [includes] all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had (Galton 1883, p. 17).

Essentially, it constitutes a set of beliefs and practices that advocate for 'improvement' of the human race by the application of genetic laws based on Darwin's theory of evolution and Mendelian laws of inheritance (Somsen 2009). Galton's theories were influential, rapidly spreading to the United States and beyond (Black 2008). They eventually birthed government-sponsored eugenics movements across the world, which aimed to both encourage those considered to have 'good' heritable traits to have more children and discourage or expressly prohibit those thought to be 'unfit' from doing the same (Baruch et al. 2005, p. 34).

Disability rights advocates are troubled by historical eugenics because such policies were almost always directed towards groups that had, or were perceived to have, physical or mental impairments (Amundson and Tresky 2008, p. 113). The starkest and most barbarian example of these practices was the Nazi 'racial hygiene' policy, which actively sought to prevent Germans from reproducing with people considered to be 'biologic threats' given their 'inferior' genes (Bachruch 2004, p. 419). A further offshoot of this policy was the Aktion T4 program. Pursuant to guidelines from the government, the program required German doctors to administer an involuntary 'mercy death' by euthanasia to patients deigned to be 'incurably sick, by critical medical examination' (Proctor 1988, p. 177). People with disabilities, confined to a mental health institution or otherwise impaired were quickly categorised as such (Amundson and Tresky 2008, p. 113), aligning with the program's underlying policy of negative eugenic 'cleansing' (Breggin 1993). Ultimately, historians estimate that between 200,000–250,000 people with physical and intellectual disabilities were murdered under the Aktion T4 program between 1939 and 1945 (Herberer 2002, p. 62; Burleigh 1994).

Francis Fukuyama, a previous member of the President's Council of Bioethics, consequently condemned this chapter of history as 'the last important political movement to explicitly deny the premise of universal human dignity' (Fukuyama 2002, p. 156). The harsh impact of these practices can still be felt today, particularly in communities of those with disabilities. The past highlights the great importance of discouraging the use of genetics, or any other trait or characteristic, as a rationale for discriminating against any person or group (Bachruch 2004, p. 420). If nothing else, the Nazi era should serve as a bleak reminder that there is a slippery slope between a eugenic ideology and a human atrocity. The only thing needed to bridge the gap between them is a 'tool'. What is worrying is that this next tool might be here sooner than expected.

2.2. *Genomic Technology as Neo-Eugenics: How Far Have We Come?*

An impressive number of ground-breaking technological and scientific developments over the last 40 years have drastically developed the scientific community's ability to manipulate genetic material. Baldi believes that these developments signify 'the end of our evolutionary odyssey' (Baldi 2001, p. 163). We can now test embryos for genetic defects, gender and disease even before implantation through in vitro fertilisation procedures, investigate gene function in a plethora of organisms (Dzau and Cicerone 2015, p. 411) and, as emphasised in this paper, may soon have the ability to alter our fundamental genetic makeup, which may in turn be inherited by our offspring (Hoge and Appelbaum 2012, p. 1549). Genome editing is a type of genetic engineering that allows for flexible insertion, deletion or replacement of deoxyribonucleic acid ('DNA') in cellular organisms through the use of engineered nucleases (Ishii 2015, p. 1).

The most recently developed, highly exalted and technologically disruptive gene editing tool is the CRISPR-Cas 9 ('CRISPR') system. Essentially, CRISPR is a family of engineered nucleases based on segments of a bacterial defence mechanism that both identifies and removes foreign viruses from the bacterial genome as an adaptive immune response (Hsu et al. 2014, p. 1264). Small parts of the viral DNA sequences are left scattered between repeated bacteria DNA sequences, known as 'clustered regularly interspaced short palindromic repeats' (or CRISPR), so that the bacteria can more easily protect itself against the same virus in the future.

A key aspect of the adaptive immune response is the protein Cas9, which can seek out, cut and eventually degrade viral DNA (Doudna 2015). Put simply, scientists have determined how to harness Cas9's capabilities into a tool that enables an organism's genome to be 'cut' or spliced at any targeted location specified by 'guide' ribonucleic acid ('RNA') molecules (Dzau and Cicerone 2015, p. 411), whether they be 'as large as an entire gene [or] as small as a single nucleotide' (Altman et al. 2015, p. 25).

What makes CRISPR such an incredible development in genetics is that it allows edits to become significantly more efficient, accurate and cost-effective, whilst being less technically problematic than ever before (Esvelt and Wang 2013, p. 1; Ledford 2015, p. 21). Its usage in the scientific community is growing rapidly as a result. In April 2015, Chinese scientists reported results of an attempt to alter the DNA of non-viable human embryos using CRISPR to correct a heritable blood mutation that causes beta thalassemia (Liang et al. 2015). The experiments resulted in changing only some of the genes, and had off-target effects on other genes. The scientists who conducted the research stated that CRISPR is not yet ready for clinical application in reproductive medicine. Even so, a point was made: if those embryos had been viable, then implanted in a woman and been brought to term, we would have created genetically modified humans (Center for Genetics and Society and Friends of the Earth 2015, p. 22).

Nevertheless, as with any disruptive technology, this unprecedented advance in genetic engineering holds great promise for generational therapeutics, but has sparked a large social and ethical debate. That debate will be further explored through the lens of bioethics and disability human rights in Section 3. Suffice it to say for now that what is especially concerning is that edits can be made not only in adult somatic cells, but also in germline cells, such as those in embryos and gametes. The crucial difference between somatic and germline cells is that the former is idiosyncratic and any effects of an edit are limited to a single individual, whilst genome changes to the latter can be inherited by offspring, thus impacting future individuals' bodies and minds (Ishii 2015, p. 19). To that end, the National Academies of Sciences and Medicine released a consensus statement of the Committee for the International Summit of Gene Editing, which emphasises that the alteration of germline cells is irresponsible and could have far-reaching, unintended, or adverse consequences for human evolution; genetically, culturally and, in terms of disability human rights, socially as well (National Academies of Sciences and Medicine 2015). Furthermore, many scientists, including Jennifer Doudna, one of the inventors of CRISPR, have urged a worldwide moratorium on clinical application of CRISPR to human germline modification until the full implications of the technology 'are discussed among scientific and governmental organisations . . . and interest groups' (Baltimore et al. 2015; Lanphier et al. 2015).

To take a step back and examine what such developments might mean for persons with disabilities is a difficult and controversial task. In October 2015, the UN International Bioethics Committee stated that the ethical problems of human genetic engineering should not be confused with the ethical problems of 20th Century eugenics movements; however, it is still problematic because it challenges the idea of human equality and opens up new forms of discrimination and stigmatisation for those with disabilities. It is true that the ethos of the current technological phenomenon contrasts with that of classical eugenics, given that to some extent it has been accepted that 'it makes no evolutionary sense to drive our species through a man-made bottleneck of genetic uniformity' (Brosius and Kreitman 2000, p. 253).

Nevertheless, there are strong parallels to be drawn between the eugenics era and the growing role of human genetic modification following the Human Genome Project. As already noted, classical eugenics was concerned with selecting certain *people* through forced sterilisation, restrictive reproduction laws and secret killings (Fischer 2012, p. 1097). The growing concern is that a neo-eugenics movement may be instead focused on the selection of certain *genes* (King 2001, pp. 171–72). There are fears that the allure of the doctrine of social advancement that the Council for Responsible Genetics has termed 'biological perfectibility' will result in organised neo-eugenics programs that slowly but surely aim to eradicate genes that cause disability, whilst inserting inheritable 'better' genes (Council for Responsible Genetics 2005). Though, at least in Australia, the idea of such government-sanctioned programs appears too remote a possibility, in the past legitimate concerns have been expressed by the President of the American Association of People with Disabilities:

> One would hope that reactions to the Holocaust and the advent of the disability rights and independent living movements in the U.S. and around the world would have put an end to the eugenic efforts to eliminate disabled people . . . Unfortunately, if we examine the rhetoric of some influential modern scientists and ethicists, we can see the emergence of a new eugenics tied to the rapid advances in scientific understanding of the human genome (Imparato 2004).

Similar statements have been echoed by Disabled Peoples International (DPI), which highlights that:

> Human genetics poses a threat to us because while cures and palliatives are promised, what is actually being offered are genetic tests for characteristics perceived as undesirable . . . These technologies are, therefore, opening the door to a new eugenics which directly threatens our human rights ((Disabled Peoples International DPI, p. 3)).

These techniques may be aimed to eliminate disabling traits that are deemed 'abnormal', 'defective' or even 'cruel'. If disabling features in a foetus were to be seen as features that would render its life not worth living, then the same view would likely be taken for existing people already living with those same conditions (Jones 2011b, p. 103). Misapplication of genetic practice under such a pretence could quite clearly amount to eugenics. Notwithstanding that genetic disability does not account for all types of disability, such as those that are acquired through accident, injury and armed conflict, initiatives like the Human Genome Project could contribute to the creation of the notion of disability as deviance and people with disabilities, whether living or embryonic, as a different species whose lives are intrinsically less valuable than others (Turmusani 2004). If so, neo-eugenics would not be a retrospective regulation of living people, but rather a pre-emptive strike on unborn future generations (Witzany 2016, p. 281).

Furthermore, there are fears that human germline genetic modification will adversely affect human dignity and wider societal attitudes towards those living with disabilities, casting people as 'problems' that could have been avoided, and putting pressure on families to have genetically 'perfect' children (Baruch et al. 2005, p. 7). It is argued by Pollack that the negative end game of human germline modification is that those who have not had their genes modified, or who acquire disabilities or otherwise inherit them, will be born into a world 'with a complexity of genome different from what . . . technology will be able to define as "normal' (Pollack 2015, p. 871). Neo-eugenics may therefore reduce persons with disabilities merely to their genetic makeup or origins, rather than as people of equal standing (Jones 2011b, p. 103; Iles 1996, p. 47). In a world where people with disabilities may already be considered by some as 'lesser', such a development would only serve to widen the gap that disability rights advocates must bridge. That sentiment is echoed by Baruch et al., who assert that the normalisation of genetic enhancement might 'decrease society's tolerance for and willingness to support and treat those living with disabilities'(Baruch et al. 2005, pp. 7, 27). Lander similarly highlighted the 'moral grayness' and eugenic practices that are inherent in genetic modification of human life (Lander 2015, p. 7). Ultimately, they conclude that CRISPR practice on human germlines can only proceed if there is a strong ethical argument to do so, or if necessity dictates it so. Otherwise, clinical practice should be banned.

In any case, the potential implications of human germline genetic modification for those with disabilities ultimately turn on the way in which tools such as CRISPR are utilised in the future. Will society be coerced (whether overtly or impliedly) into its widespread use, or will there be sufficiently effective and adaptable regulation that considers and protects disability human rights?

3. Disability, Bioethics and Human Rights: Clash or Cooperate?

How we conceptualise disability human rights and genetic technologies like human germline engineering and CRISPR tools frames the regulatory measures we believe are appropriate. To properly appreciate the current relevant law, and to ultimately point toward an appropriate model that balances human and scientific interests, we must first understand the human rights and bioethical principles that underpin various sides of this controversial debate. The discipline of bioethics is centred on the critical assessment of ethical and legal controversies that arise from emerging situations and possibilities brought about by advances in biological medicine (Smith 2012, p. 2). Therefore, it is pertinent to examine the three competing schools of thought on disability through an overarching bioethical lens:

(1) The traditional utilitarian medical model of disability;
(2) The pro-disability rights perspective of the social model;
(3) The human rights model of disability, a more recently emerging trend amongst disability rights scholarship.

As will become apparent in the following passages, one's bioethical perspectives and corresponding views on disability rights may affect their fundamental normative position on the issue of how technologies like CRISPR should or should not be used and regulated, and for what purpose. Generally, proponents of the medical model would be more open to the use of a less regulated CRISPR for curative purposes. In the same way, those who propound the social and dignitarian models may be more inclined to its opposition and greater regulation, in the former case on grounds of possible further systemic disadvantage to persons with disabilities, and in the latter case due to the threat of harm to their human dignity.

This paper asserts that it is a regulatory framework founded on the human rights model, or at the very least, a combination of the social model and human rights model, that best protects the rights and interests of people with disabilities in the face of rapid genetic technology advancement.

3.1. The Medical Model and Beneficence

Throughout history, people with disabilities have unfortunately been treated by some as tragic burdens and objects of pity by society (Kayess and French 2008, p. 5). This perspective stems from the medical model of disability, which focuses on an individual's limitations by viewing disability as a deficiency or deviation from the norm that requires cure, treatment, care and protection to alter the person so as to conform them to the existing social structures, processes and environments in which they live. This is an attempt to allow them to live a 'normal' life. Little emphasis is placed on the role the world and environment play in disabling people with impairments, thus well and truly earning the moniker 'the politics of disablement' (Oliver 1990). The medical model has existed at least since the advent of the Industrial Revolution (Oliver 1996) and sadly 'has guided and dominated clinical practice with the resulting assumption that both problems and solutions lie within disabled people rather than within society' (French 1994). As such, over the years the model has served to perpetuate negative and unhelpful attitudes and discriminatory practices that further oppress, ostracise and disable people with impairments (Finkelstein and Stuart 1996, pp. 175–76).

In a similar vein to 'curing' or 'eliminating' the harm of disability from the world are bioethical perspectives that strongly align with the medical model. A central tenet of bioethical study is the principle of beneficence, which comprises aims to achieve the two distinct, but related, goals of preventing harm and producing good (Smith 2012, p. 22). Of course, any application of this principle requires an advance assessment of three ethical dilemmas (Walters 1978, p. 50):

(1) what constitutes 'harm';
(2) what constitutes 'good';
(3) what are the possible negative social consequences that might come from new biomedical technologies in order to protect groups of individuals from that harm.

To the lay person, these propositions might appear to have subjective answers. The lay person would be right. However, utilitarian advocates of the medical model would hold that the best moral action in such a case is the one that maximises overall utility or benefit for the greatest number of people. To that end, Savulescu takes this basic bioethical creed a step further into the realm of disability and reproductive rights in claiming that a moral utilitarian principle of procreative beneficence exists (Savulescu et al. 2015). In summary, the principle requires that:

> couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information (Savulescu et al. 2015, p. 415).

The position is that through available technologies like CRISPR, parents should aim to remove 'disease genes', which cause a genetic disorder or predispose the person to the development of a disease. This perspective, essentially a form of eugenic practice disguised as mere biological reductionism, argues that it is irrational to choose an embryo that will not have the 'best life'. It further cloaks itself as a morally persuasive, rather than coercive, principle. Its final and most chilling formation is seen in the views of philosophers like Peter Singer, who believe that 'the killing of a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all' (Singer 1993, p. 191).

As this paper will soon show, in reality disabilities are generally not experienced as 'pain and suffering', nor are persons with disabilities 'harmed' by their impairment (Jones 2011b, p. 102). In actual fact, most of the suffering occurs as a 'result of not enough human caring, acceptance and respect' as a human being like others without a disability (Saxton 1988, p. 222). Even so, this crucial misconception underpinning the medical model and principle of procreative beneficence grounds a utilitarian argument that, in the same way it is morally wrong to harm another human, it is morally wrong to bring a person with a disability into the world on the basis of the pain and suffering it would bring onto the newborn (Harris 1990). The conclusion reached by Harris is that it is kinder to prevent the birth of a person with a disability (Harris 1998, p. 118; Marzano-Parisoli 2001). Any argument that such a world is morally preferable must rest on the assumption that 'a life with even moderate disabilities or impairments is a life with less moral value than other lives' (Bennett 2009, p. 271). Therefore, utilitarian individualism perceives people with disabilities as:

> commodities to be 'serviced' and . . . as an economic burden on society; their defects are emphasised and their worth is judged by their contribution to society. Being objects of charity, they are patronised and, at worst, they are perceived as dehumanised 'others' (Parmenter 2005, p. 53).

This paper disagrees with the proposition that whether a person will live a 'good' or 'best life' is wholly dictated merely by a genetic sequence or trait that forms part of who they are (Asch 2000; Shakespeare 1995). In that respect, there can be no effective regulation of genetic technology to safeguard human rights under these principles because, at a fundamental level, they do not conceive of a person with a disability as a 'full-value human'.

3.2. The Social Model

Whereas the medical model locates the problem in the impairment of the individual, the contrasting social model views disability as a social construct of discrimination and oppression that denies or limits personhood, beyond the individual's condition (Kayess and French 2008, p. 5; Degener 2014, p. 4). At the heart of the social model is the notion of 'systemic disadvantage', which is highlighted in the structural, social and exclusory barriers purposely or inadvertently erected by society (Oliver 1990, p. 47). Furthermore, the social model is based on a series of dichotomies, between impairment and disability, social and medical models, and persons with and without disabilities (Shakespeare 2013, p. 216). In relation to the distinction between the terms 'impairment' and 'disability, the former relates to the individual on a private level, whilst the latter relates to society on a structural level. Impairment refers to 'a characteristic, feature or attribute within an individual which is long term and may . . . be the result of disease, genetics or injury' (Thomas et al. 1997, p. 2), and may affect appearance, function of mind or body and/or cause pain and fatigue. These physical, sensory, intellectual or psychological variations do not have to lead to disability unless society fails to accommodate and include people with those differences. Article 1 of the Convention on the Rights of Persons with Disabilities ('CRPD') provides an open definition of disability, such that it includes, but is not limited to 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations 2007). In other words, disability is imposed over impairment by excluding individuals from being able to fully participate in society (Oliver 1996, p. 22). It is with these definitions in mind that we assess the relative merits and shortcomings of each conception of disability.

However, the social model has been criticised almost as much as the medical model (Shakespeare 2002). Whilst it has been instrumental in launching the disability movement, promulgating positive disability identity and encouraging barrier removal and rights legislation, it is ultimately a 'blunt instrument for explaining and combating the social exclusion that disabled people face, and the complexity of [their] needs' (Shakespeare 2013, p. 220). Its simplicity is its major flaw. In the context of human genetic engineering (or, in reality, any disruptive technology that affects the barriers people with disabilities might face) and CRISPR, utilisation of the social model, which lacks nuance, to underwrite any policy or regulatory rights protection regime is more difficult than it at first appears. Though the social model is indeed a useful tool for identifying systemic causes of disadvantage, it falls short in determining what action should be taken in response (Samaha 2007, p. 27). There is a disconnect between causation of the disability and policy, which produces an issue where the social model's account of causation forms the sole reason for social change (Samaha 2007, p. 37). The consequent issue then is that the resulting policy to remedy the issue is reactive. In a rapidly evolving technological landscape, to adequately protect the rights of persons with disabilities and other interest groups is not to retrospectively attempt to fix problems caused by scientific advancement, but rather to proactively create a global system of substantive and normative human rights.

Therefore, whilst a competent heuristic approach, the social model is imperfect (Degener 2014, p. 5). In light of the swift scientific advances made each week, if not each day, its utility is limited. Disability is an already complex issue made even more complex by the ethical and legal debate of genetic engineering. As such, we might be best served by a governance model underpinned by an alternative that more effectively allows for differing levels of analysis and policy.

3.3. Human Rights and Dignitarianism: A Way Forward

The third and final tenet of the bioethical and disability rights triad in the human genetic engineering debate is that of the emerging human rights model of disability and the complementary dignitarian ideology (Brownsword 2009, p. 25). This model builds upon the foundations of the social model and small aspects of the medical model, but goes further to enforce and protect the human rights of people with disabilities (Degener 2014, p. 29). First, it is contended that the anchor at the heart of modern human rights is the concept of human dignity (Degener and Quinn 2002, p. 30): a moral value attributable to each person by virtue of his or her humanity (Grant 2007) and independent of social status, gender, genetic makeup, physical or mental ability or any other characteristic (Basser 2011, pp. 19–20; Fukuyama 2002, pp. 14, 149). Human dignity is valuable especially for those who have traditionally been denied an equal place in society, because it reinforces the idea that all people are equal rights-bearers (Basser 2011, p. 21). Essentially, 'valuing human dignity means acknowledging the inherent worth of human beings; therefore violating dignity involves conveying the message that some are of less worth than others' (Reaume 2002–2003, p. 672).

In saying that, human dignity is a complex principle. It also involves a positive interpretation of 'humaneness' (Jones 2011a, p. 36). Basser elucidates four elements necessary for a person to be treated with dignity:

> First is the absolutely crucial requirement that a person's physical integrity is respected . . . Secondly, human dignity means that every person has the inherent right to be treated as an individual with a personality . . . Thirdly, human dignity means that a person must be

> given voice about any issues which affect their lives and must have the ability wherever possible to exercise choice. Finally, inherent dignity of any individual requires that he or she has access to a fair share of the goods of society (Basser 2011, p. 19).

The human rights model centres on these principles of inherent human dignity by focusing on a person's medical characteristics only if absolutely necessary. It states that the 'problem' is extrinsic to the person and grants autonomy to the individual in relation to decisions or circumstances affecting him or her (Quinn and Degener 2002, p. 14). The human rights model differs from the social model in many respects, but most importantly, it explains why enforceable and inalienable human rights do not require an absence of impairment (Degener 2014, p. 6), includes a broader set of rights available to persons with disabilities, and values impairment as part of human diversity and variation.

As opposed to the views of Savulescu and Harris, the human rights model's fundamental critique of human genomic technologies is that their eventual widespread availability, use and probable misuse ultimately undermines, devalues and disempowers persons with disabilities unless rights safeguards are developed (Jones 2011b, p. 41). These threats have not gone unnoticed by the disability community. Such techniques are often seen to have the capacity to both threaten and to safeguard human dignity (McLean and Williamson 2007, p. 41). On the one hand, they may be viewed as supporting dignity of human life by improving health and alleviating suffering, such as by minimising the number of infants born with impairments and genetic disease or by respecting the reproductive liberty of those already born. On the other hand, eliminating or seeking to minimise the existence of people with genetic impairment may be perceived as offending human dignity, and thus human rights. From the latter perspective, DPI has posited the ethical and moral problems of more widely available genetic technology rather poignantly:

> How can we live with dignity in societies that spend millions on genetic research to eradicate disease and impairment, but refuse to meet our needs to live dignified and independent lives? We cannot. We will not. The genetic threat to us is a threat to everyone. The value of life must not be reduced to a matter of genetic inheritance ((Disabled Peoples International DPI, p. 4)).

That being said, this paper does not posit that parents with children diagnosed with genetic disabilities and cognisant of their carrier status of the relevant genes are, in making reproductive decisions about the possibility of future offspring also being diagnosed with a genetic disability (such as prenatal diagnosis followed by pregnancy termination, or preimplantation genetic diagnosis), making judgments about the human dignity of their children already affected by the genetic condition. It is clear that any application of principles of human dignity to assess decisions made in relation to persons with genetic disabilities and their treatment must be more nuanced to avoid any such misconceptions.

This begs the question as to what role human dignity and the human rights model should play in ethically governing genetic development whilst protecting the rights and interests of persons with disabilities. Two conceptions of human dignity are relevant. The first conception is as a form of 'empowerment' by supporting individual autonomy (Brownsword 2009, p. 26). This is best exemplified in both the Universal Declaration of Human Rights ('UDHR'), which provides that 'all human beings are born free and equal in dignity and rights', and the CRPD, which aims to 'promote respect for [persons with disabilities'] inherent dignity' under Articles 1 and 3. The second conception is as a form of 'constraint' on the autonomy of scientists acting in ways that might infringe human rights (Brownsword 2009, p. 28). As will be discussed in Section 4, human dignity as constraint is axiomatic in the three UNESCO Declarations on bioethics and genetics, as well as the Council of Europe's Oviedo Convention. The centrality and prevalence of these concepts is the strongest support for the human rights model of disability and is therefore the best place to begin an analysis of the current legal system.

4. How Do We Regulate?

The legal and ethical implications of manipulating the human genome depict a nebulous future. The globalisation of technological advances like CRISPR has exposed the absolute inadequacy of the development of nation-based bioethics for effectively addressing the threats raised by genomic technology (Lenzerini 2006, p. 292). Vast cross-jurisdictional inconsistency of legal genetic regulation may permit practices of uncertain morality and legality, such as human germline engineering, to develop in countries unwilling to enact such regulations. Ultimately, this paper emphasises the fact that, at present, the existing framework of human rights is likely systemically inadequate to address all threats to human dignity caused by rapid developments in biogenetics (Lenzerini 2006, p. 447; Iles 1996, p. 41).

4.1. International Law

As already noted, international law instruments such as the UDHR and UNESCO Declarations provide for human dignity both as an operational principle and moral precept (McCrudden 2008, pp. 668–71). For the purposes of genetics, this section will focus on two international law schemes: the CRPD and the UNESCO Declarations.

4.1.1. CRPD

The first point of reference for any discussion of disability human rights instruments in the common day must be the CRPD. The CRPD was the first UN human rights treaty adopted in the 21st Century and was reportedly the most rapidly negotiated ever (UN Secretary General 2006). It has been touted as a 'great landmark in the struggle to reframe the needs and concerns of persons with disabilities in terms of human rights' (Kayess and French 2008, p. 2). In regards to many issues that face persons with disabilities, it succeeds in protecting their rights. Articles 1 and 3(a) both emphasise the CRPD's agenda to codify the inalienable human rights of persons with disabilities by virtue of their human dignity, equal in scope and force with people without disabilities (Degener 2014, p. 7). A plethora of other articles comprehensively elucidate the many rights that others take for granted. On this, it should be commended.

However, from the particular perspective of human genome modification, the CRPD falls far short of effectively limiting potential abuses of CRISPR tools in the future. According to Wolbring and Diep (2016, p. 10) the CRPD could apply to gene editing in two ways:

(1) regulating the actual use of gene editing technologies like CRISPR; and
(2) in the aftermath of gene editing becoming more readily used, minimising the negative social consequences for persons with disabilities.

For a number of reasons, the potential application and substantive effectiveness of the CRPD in governing actual use of gene editing technologies is unclear.

First, the CRPD does not conceive of the potential impact of genetic technologies. Terms such as 'genetics', 'bioethics' or 'eugenics' do not feature once in the document. These glaring omissions highlight a fundamental lack of foresight as to the future threat genetic technologies and their misuse may pose to the disability human rights cause.

Second, though it is arguable that the anti-discrimination protections provided under Article 5 could validly critique pre or post-birth gene editing interventions aimed at 'fixing' impairment, the CRPD would be of little utility if gene editing interventions of any and all genes were permitted (Wolbring and Diep 2016, p. 12). This is again an example of how the purposes for which CRISPR and other gene editing technologies are used is crucial to their effective governance.

Third, a person's inherent right to life and its enjoyment on an equal basis with others under Article 10 remains starkly silent on 'genetic science aimed at the elimination of impairment-related human diversity and pre-birth negative selection of foeti with identified or imputed impairment' (Kayess and French 2008, p. 29). The further omission of such eugenic practices is a significant flaw.

Fourth, Article 17, which states that 'every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others', is the most limited of the substantive rights. 'Physical integrity' clearly points towards internal physicalities of DNA makeup. A more robust right might have been useful in the context of human somatic and germline modification, but the statement is essentially confined to a principle with no specific application towards the human rights violations it purports to address. Therefore, the potential use of 'coercive State power for the purpose of 'treatment' remains without any specific regulation' (Kayess and French 2008, p. 30). It should be further noted that although Article 17 could draw attention to the involuntary treatments of a 'competent' adult. Even so, the right to physical and mental integrity is unlikely to apply if parents have genetic interventions performed on their children or embryos, or where adults with disabilities agree to genetic intervention (Wolbring and Diep 2016, p. 12).

Fifth, the general principle of 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity' articulated in Article 3 similarly expresses a principle with no application to particular situations. In this case, noting the role of eugenics or biological reductionism as grounds for failure to respect that difference would greatly improve the persuasive and moral force of the instrument.

Sixth, even if the above protections were more substantial, the definition of 'disabled people' under Article 1, whilst inclusive, appears to imply that embryos that have their somatic or germline cells modified and are adversely affected as a result (so as then to have a disability), would not have had any rights infringed as at the time of the modification because they did not have any human dignity upon which to infringe. This paper notes that whilst this regulatory 'gap' appears to exist, human dignity is arguably less effective in regulating the application of technologies like CRISPR to embryos. The conceptualisation of the moral and legal status of the embryo 'as a human' is an issue subject to a plethora of ethical, legal and religious complications that differ widely across and within countries. As such, this paper merely notes the wording of the CRPD to highlight that it might be less problematic for nation states to legislate with regard to these embryos instead, as will be discussed below in Section 4.2.

In contrast, the CPRD's role in preventing the deterioration of the lived experience of persons with disabilities following the rise of gene editing is slightly more promising. CRISPR may one day be used in genetic enhancement. 'Disability' under the CRPD is arguably a changing concept that includes future disability. Wolbring and Diep assert that the CRPD may be applicable to people who are currently considered non-disabled, but will be classified as disabled as ability expectations rise due to the prevalence of genetic and technological enhancement of human (Wolbring and Diep 2016, p. 14). Only time will tell whether, in mitigating these negative consequences, the CRPD will be used to demand access to particular genetic products and procedures or to restrict their use and, further, how robust such approaches will be.

Even so, the CRPD falls short, on balance, to adequately protect the rights of current and future persons with disabilities in respect of human genome engineering.

4.1.2. UNESCO Declarations: Is Soft Law Tough Enough?

Whilst not as recently endorsed as the CPRD, the UNESCO Declarations exist as a framework of non-binding international soft law that has specifically aimed to regulate bioethics at a universal level. The scheme comprises:

(1) The Universal Declaration on the Human Genome and Human Rights ('UDHGHR');
(2) The Universal Declaration on Bioethics and Human Rights ('UDBHR'); and
(3) The International Declaration on Human Genetic Data ('IDHGD').

Of the trio, the UDHGHR and UDBHR are the most relevant for present purposes. As such, the IDHGD will not be further discussed in this paper. The norms articulated in the UDHGHR and UDBHR, including the central tenets of human dignity and human rights, enjoy a wide consensus at the international level (El-Zein 2008, p. 318). In fact, they have become a legal and ethical reference point in the drafting of national laws and regulations around the world (Ida 2003, p. 368); a 'slow burn' influence. Nevertheless, it should be kept in mind that these Declarations are general in scope, and avoid dealing in specific detail with particular issues in biotechnology or bioethics. This was a deliberate choice by the UNESCO General Conference to proceed gradually and prudently (El-Zein 2008, p. 319). Even so, the provisions show a level of prescience as to the dangers the human race and persons with disabilities might face as human gene editing technology develops.

The UDHGHR aims to delineate and promulgate a universal ethical standard-setting framework that member States can and should utilise in determining and implementing their own bioethical policies. The Preamble takes as its starting point a cognisance of the potential advantages and dangers of human genomic research and applications, emphasising that 'such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics'. It goes on to state a fundamental ethical principle of human rights and dignitarianism in Article 1:

> The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

The reference to the genome as 'the heritage of humanity' is of particular relevance to the utility and moral viability of human germline gene modification. 'Heritage' has strong connotations with heritability. It therefore appears that, given the genome underpins our inherent human dignity and inclusive diversity, Article 1 attempts to discourage the artificial alteration of inheritable human germline cells. Following this definition, it is also recognised that there is a global responsibility on the international community as a whole to protect the disadvantaged, beyond single States and governments (International Bioethics Committee 2015, p. 27).

Clearly, the UDHGHR does not specifically denounce eugenic ideals. However, Lenzerini (2006, p. 318) asserts that Article 6 does provide a general prohibition against a range of conduct that would encompass discriminatory neo-eugenic practices through genetic experimentation in stating that:

> No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

Article 2 entrenches an individual's right to respect for their human dignity and diversity, rather than their value being reduced to a sum of their genetic characteristics. Article 3 further emphasises that the human genome is not static: it evolves over time. As such, the countless variations and mutations in our DNA and their potentialities are expressed and viewed differently depending on the individual's natural and social environment. When Articles 2, 3 and 6 are read in conjunction, the UDHGHR conveys a persuasive narrative of the importance of values like dignity, respect, uniqueness and diversity.

In turn, a cumulative reading of Articles 1, 2 and 6 highlights the overarching need to balance the possible positive and negative consequences associated with the growing prevalence of genetic technology. Most important for the purposes of safeguarding disability human rights are Articles 10 and 11. The former establishes the paramountcy of respect of human rights, freedoms and dignity of individuals of groups over research or research applications relating to the human genome. The latter forbids practices that are contrary to human dignity outright. This suggests that whilst knowledge is important for the advancement of the human race, it is the way in which that knowledge is utilised that determines whether human rights are violated by a subversion of human dignity (McLean and Williamson 2007, pp. 41–42).

Finally, Article 24 explicitly notes germline interventions as potentially contrary to human dignity. Though Article 24 is not a substantive protective right in itself, it does direct the International Bioethics Committee to make recommendations in relation to the identification, and arguably regulation, of such practices. By way of comparison, though Article 13 of the Oviedo Convention permits genome intervention for 'preventive, diagnostic or therapeutic purposes' (a point on which the UDHGHR is non-specific), it is pointedly made clear that this is so 'only if its aim is *not to introduce any modification in the genome of any descendants*' (emphasis added).

The relatively more modern UDBHR sheds further light on the proposed balance between individual rights and science referenced in the UDHGHR. Article 3 provides that human dignity, rights and fundamental freedoms are to be fully respected and, most importantly, 'the interests and welfare of the individual should have priority over the sole interest of science or society'. The content of such a provision is clear: the sanctity of human dignity and equality prevails over both the general interest to research and scientific progress and any other societal interest as a whole (Lenzerini 2006, p. 336).

These underlying principles militate against scholars like Savulescu, Singer and Harris interpreting provisions of the UDBHR in a manner consistent with utilitarian ideals of procreative beneficence, which arguably infringe human dignity. Article 4, for example, provides that:

> In applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants and other affected individuals should be maximised and any possible harm to such individuals should be minimised.

Whilst proponents of procreative beneficence would argue that the direct and indirect benefits to persons with disabilities lie in their 'release' from or 'cure' of impairment, with little actual 'harm', it cannot be properly considered to be the object to which the UDBHR is put.

Moreover, Article 8 provides a marked improvement over Article 17 of the CRPD in that it provides a more specific application of the principle of personal integrity:

> In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

The provision undoubtedly recognises that particular groups, like persons with disabilities, are especially susceptible to the adverse effects of misused genetic technologies. Researchers too must recognise, evaluate and re-evaluate the potentially far-reaching effects of their work at every stage, as required by Article 20. This continual cycle of risk assessment and management is imperative as a form of both self and peer-based regulation.

Finally, the UDBHR must necessarily defend the potential victims of discrimination. To that end, Article 11 mirrors Article 6 of the UDHGHR in that 'no individual or group should be discriminated against or stigmatised on any grounds, in violation of human dignity, human rights and fundamental freedoms.' Further, Article 14(2)(d) aims to direct the objectives of science and technology to the elimination of the marginalisation and the exclusion of persons on any grounds. Whether the whole of the scientific community will adhere to such broad dignity-based statements is unclear.

Despite its breadth, the applicability of the UDBHR may be restricted by the concession in Article 27 that these principles may be limited by state law in the interests of, among others, the protection of public health and the protection of the rights and freedoms of others. Again, it is unclear how a disability rights approach would contend with possibly competing notions of an 'obligation to let oneself be fixed' in the interests of public health frameworks, or the protection of the rights and freedoms of caregivers and others present in the lives of persons with disabilities (Wolbring and Diep 2016, p. 15). Further, a recurrent and seemingly endemic issue in instruments like the UNESCO Declarations in relation to human genetic engineering, is that an embryo cannot be seen to have human dignity so as to invoke the corresponding human rights (El-Zein 2008, p. 322).

In any case, the UNESCO universal soft law regime constitutes arguably the most comprehensive and solid foundation for the future international regulation of human genetic technology for both the interests of persons with disabilities and the broader human race. However, they are but a first step in such a difficult pursuit (El-Zein 2008, p. 318).

4.2. State Domestic Law

Despite the broad persuasive scope of such international instruments, they do not have any real binding force within each signatory nation state until domestic legislation to that effect is enacted. However, national policy frameworks governing human genome editing, both somatic and germline:

> extend across a continuum that distinguishes between degrees of permissiveness, that is, between legally binding legislation and regulatory and/or professional guidance or research versus clinical applications (Isasi et al. 2016, p. 337).

As such, many of these national regimes aim to imitate international law's emphasis on human dignity and diversity by leaning towards taking a more prohibitive stance, at least in relation to human germline gene modification (Basser 2011, p. 36). Many countries ban human germline engineering (Araki and Ishii 2014, p. 116). However, the regulatory landscape suggests that it is not totally prohibited worldwide. The arrival of CRISPR has, and will continue to, disrupt medical, legal and ethical consensus even further.

Where legislation imposes a prohibition or restriction on germline interventions, it is generally paired with severe criminal sanctions that range from long imprisonment terms to significant fines (Isasi et al. 2016, p. 337; Center for Genetics and Society 2015). For example, the Australian position is quite severely prohibitive. Section 15(1) of the relevant Commonwealth law (Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006) and Section 11(1) of the identical Victorian law (Prohibition of Human Cloning for Reproduction Act 2008) provides that a person commits an offence and may be imprisoned for up to 15 years if:

(1) the person alters the genome of a human cell in such a way that the alteration is heritable by descendants of the human whose cell was altered; and
(2) in altering the genome, the person intended the alteration to be heritable by descendants of the human whose cell was altered (emphasis added).

Furthermore, Sections 20(3) and 16(3) of each respective statute also criminalise the intentional placement of such an altered cell into the body of a woman. Both provisions require an element of mens rea, which gives rise to some uncertainty as to their potential enforceability. Nevertheless, the dual rationale for such provisions in preventing alteration of the 'heritage of humanity' is clear. First, there is an evolutionary imperative to refrain from making germline changes, the implications of which are currently unknown. Second, doing so fundamentally violates the principle of human dignity entrenched in the UNESCO Declarations. Relevantly, if either practice were to become widespread or commodified, that violation would be even more greatly focused on the dignity and value of persons with disabilities (Isasi et al. 2016, p. 337).

At the opposite end of the spectrum are countries with permissive approaches that aim to promote scientific progress because of its perceived benefit to humanity. Under policies adopted in China and the United Kingdom, research conducted for reproductive purposes is permitted under strict regulation and clinical applications are not expressly criminalised (Isasi et al. 2016, p. 337). Of the plethora of approaches worldwide, not one is necessarily completely right or wrong. However, global inconsistency may be eroded over time as one country's procedure eventually becomes the scientific and ethical standard (International Bioethics Committee 2015, p. 27). Given the rate that science is progressing and technologies like CRISPR are becoming more accurate, it is likely that the permissive approach will gain traction. Therefore, in the case of that eventuality, it is necessary to assess a regulatory model that will protect persons with disabilities in a pro-genetic era.

5. How Should We Regulate?

In light of these shortfalls at both the international and national levels, this paper will attempt to posit a solution to the seemingly intractable issue of human gene editing research that has the greatest chance of a beneficial outcome for the disability and science communities alike. Two 'disclaimers' must be made at this juncture. First, this paper does not purport to propose a complete regulatory model per se, but rather a methodology to balance the interests of both the scientific and disability communities. Second, there is a general problem of inefficacy in legally regulating fast moving technologies like CRISPR. This paper contends that the most practical and ideal genetic research governance model is one grounded in human rights and dignity. It should involve a global discussion and consensus (insofar as is possible) including all relevant interest groups, especially those most likely to be disadvantaged by the use of gene editing technologies.

5.1. Why a Human-Rights Based Regulatory Framework?

There exist four potential oversight approaches to human germline editing technologies:

(1) a complete international ban;
(2) a temporary moratorium on research until ethical and scientific issues have been resolved;
(3) principled international and domestic regulation; or
(4) a laissez-faire approach (Bosley et al. 2015, pp. 383–85).

Given the heterogeneity of national ethical and legislative codes and the accessible cost of CRISPR, a complete ban or temporary moratorium will be virtually impossible to enforce worldwide (Altman et al. 2015, p. 26). Furthermore, a laissez-faire approach arguably creates the inevitable risk, especially in less stringently restricted countries, that research will be conducted before ethical due diligence. This could also lead to a patenting war, with all the likely unethical shortcuts that may entail, the winner of which will be granted enormous control over the development, scope and uses of CRISPR technology (Parthasarathy 2016). This leaves one option: regulation. Luckily, the institutional framework for regulation already exists in the UNESCO framework, national law and research guidelines. Nevertheless, an integrated and universal regulatory model must be actualised.

It is unclear exactly which form the regulatory model should take in order to remain effective and flexible whilst also instilling confidence in the people whose interests are to be protected. The broad literature on regulation yields many viable avenues. Whilst theories of decentralised or polycentric regulation (Black 2002, p. 4) often appear more applicable to the transnational context, they have had their legitimacy and accountability heavily criticised at that level. One promising framework that may be of great assistance in framing further debate on an appropriate and applicable model is Jonathan Kolieb's 'regulatory diamond' (Kolieb 2015), which builds on the seminal work of Ian Ayers and John Braithwaite in 'responsive regulation' theory (Ayres and Braithwaite 1992). The crux of responsive regulation is that regulatory instruments must adapt to the actions of the people or entities they aim to regulate. This determines the level of intervention required, and whether escalations or de-escalations are necessary over time.

However, a key shortcoming of the original Braithwaitian model was its sole focus on compliance with certain standards (Kolieb 2015, p. 143) and its corresponding omission in seeking improvement on the behaviour of those being regulated. The Koliebian model goes further in not only incorporating 'compliance regulation' (the regulatory mechanisms that encourage adherence to particular behavioural standards) but also 'aspirational regulation' (the regulatory mechanisms that encourage those regulated to improve their behaviour beyond minimal adherence to the minimum standards). The regulatory diamond points out that achieving compliance with legal requirements is only half of the solution to the problem being addressed. In this case, that problem is the growing viability and impact of genetic technologies. There is a powerful aspirational regulatory potential that has been untouched at this point. As Kolieb notes, from the perspective of a regulator:

> Their view of the regulated entity is no longer dominated by negative conceptions of an entity that needs to be curtailed and compelled to comply with minimum legal standards. With the diamond, the conception that pervaded responsive regulation theory is moderated by the understanding that regulated entities can also exceed such standards, and positively contribute to addressing the societal problem in question (Kolieb 2015, p. 161).

As CRISPR and other similarly disruptive technologies become more widespread, the inherent limitations of the law as a regulatory instrument mean that it should also be paired with other aspirational regulation instruments to drive researchers and private companies providing these services to act beyond the baseline legal requirements to secure the interests of persons with disabilities and other minorities as members of our society who might be adversely affected by the technologies. What such aspirational instruments might include will first depend on the minimum standard expected.

Then, putting aside aspirational regulation, why a model based on adherence to standards of human rights and dignity? There are multiple reasons for submitting CRISPR and other genetic technologies to regulation under the meta-norms of human rights and dignity:

(1) As highlighted in Section 4 of this article, the entirety of the UNESCO bioethical and human genome soft law framework is based on those foundational concepts. By mirroring those principles in a regulatory framework, it connects the legitimacy of UNESCO policy to the evolving international scientific and ethical practice (Somsen 2009, p. 114). Whilst there is no univocal ethic espoused in the Declarations, by and large the prevailing values are dignitarian and well suited to the current issue.

(2) An underlying ethic that focuses on the concept of human dignity as a constraint on autonomy is 'not only the most suitable for a liberal deliberative democracy' as in today's globalised society (Somsen 2009, p. 114), but is also the only possible answer to the reality of the disability community's disadvantaged position vis-à-vis continuous and rapid scientific advances like CRISPR (Fukuyama 1992; Brownsword 2004). The human rights model of disability is strongly complemented by, and shares largely the same objectives as, the idea of inherent human dignity. If the two ideas work in tandem, persons with disabilities will have the best chance at enacting beneficial reform at both international and national levels.

(3) A system of human rights and dignity has the potential to be flexible and adaptive to future technological change through the articulation of new international human rights principles specific to gene editing. The common acceptance of its underlying principles would also assist in its quick adoption by national regulatory agencies and parliaments (Mathews et al. 2015, p. 160). Whilst there is a considerable challenge in ensuring that such a regime is articulated clearly enough to be meaningful whilst not so broadly as to be arbitrary (Somsen 2009, p. 115), it is arguably the best theoretical framework at this point in time.

With these points in mind, we may conceptualise how best to formulate such a regime.

5.2. The Way There

Science is a global endeavour. As such, it is vital that nation-states and governments accept the principle of a shared global responsibility in relation to the editing of the human genome (International Bioethics Committee 2015, p. 27). An effective governance approach must be simple in operation, anticipatory and adaptive, and, most importantly in cases of disruptive technology, grounded in social acceptability after considering the views of all stakeholders (Reiss, p. 2). On social, ethical and evolutionary questions of this magnitude and nature, arguably the only way to achieve each of those objectives is through genuine collective discussion (Wolbring 2015, p. 446; Baker 2016, p. 273; Sarewitz 2015, p. 414; Araki and Ishii 2014, p. 18).

There are countless issues with universal governance of ethically polarising technologies, not the least of which are broad spectrum of secular, cultural and religious views of individuals, the public and government. Public policies on human gene editing range from prohibitionist, to regulated, to permissive. As such, it is likely unwise to set out, at least at this early stage, a comprehensive set of governance rules protecting human interests in the vain hope that they will be communicated, understood, implemented, obeyed and enforced overnight. Such thoughts are fanciful and of little assistance in resolving the ethical dilemma. On this point, Susan Peschin, the President and CEO of the Alliance for Ageing Research, stated that:

> Principles generally serve to motivate people to do the things that seem good and right, but without the constraints and external pressure of specific rules. Introduce specific regulations on the safety and efficacy of gene editing and that starts to infringe on people's ethical limits, which traditional medical product regulation is not designed to address (Peschin 2017).

This paper agrees. We must first reach a normative consensus to effectively frame the broad international law, regulations and customs to eventually, and ideally, 'trickle down' into entrenched and more easily enforceable national laws. Though they will likely differ to various extents, the overarching principles will guide legislative bodies to an ethical governance model predicated on the protection of human dignity for all, including people with disabilities (Reiss, p. 5).

The 'Res-AGo-rA'[1] research project, released in April 2016, offers a comprehensive governance framework for responsible research and innovation that ties in with the overarching human rights and dignity model. Essentially, it states that the first step in attaining some form of 'consensus' is for national ethical bodies and interest groups to come together to take responsibility for innovative advances and their societal consequences and draft agreed upon guidelines for research into gene editing (Lindner et al. 2016, p. 10). Richard Hayes, former Executive Director of the Centre for Genetics and Society, has expressed similar sentiments:

> A productive next step might be to have a high-level task force representing the full range of constituencies with major stakes in these issues undertake a comprehensive review and assessment of options for global oversight and regulation (Hayes, p. 8).

Therefore, regulators and scientists must listen to public, community and civil society organisations and many others, who in turn must each listen to each other (Center for Genetics and Society and Friends of the Earth 2015, p. 39). Of course, numerous scholars have highlighted the importance of the disability justice refrain, 'Nothing About Us, Without Us', in having any legitimate discussion about the regulation of gene editing technologies (Shakespeare 2015, p. 446; Wolbring 2015; Benjamin 2016, p. 51; Thompson, p. 46; Knoppers 2016, p. 272). The voices of those from the disability community must be heard. Ultimately, any discussion and eventual consensus relating to human germline modification research and clinical use must adhere to the principles of human dignity outlined above and exemplified in the UNESCO Declarations.

Recently, a Committee composed of members of the National Academy of Science ('NAS') and the National Academy of Medicine ('NAM') embarked on the gargantuan task of addressing how we should regulate gene editing technologies like CRISPR. The Committee ultimately advocated a strong public participation model in developing any governance frameworks. In its deliberations, it focused in particular on:

(1) safeguarding and promoting individual health and wellbeing;
(2) cautiously approaching novel technologies in response to consistently changing information;
(3) respecting individual rights;
(4) warding against undesirable social consequences; and

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[1] Responsible Research and Innovation in a Distributed Anticipatory Governance Frame. A Constructive Socionormative Approach.

(5) equally and equitably distributing information, burdens and benefits (National Academies of Sciences and Medicine 2017, p. 23).

Crucially, it established seven key principles foundational to the governance of human gene editing, even across national and cultural borders (National Academies of Sciences and Medicine 2017, p. 24):

(1) Promoting wellbeing: this principle aims to prevent harm by applying genome editing technologies to increase health and wellbeing whilst ensuring a reasonable balance of risk and benefit for any such application;
(2) Transparency: this principle encourages the free flow of information between stakeholders, including full, frank and timely disclosure and meaningful public input and debate in all aspects of policymaking for CRISPR and related technologies;
(3) Due care: this principle requires careful and deliberate conduct by researchers in relation to their patients, including appropriate supervision and consistent reassessment of risks, advances in technology and medicine, and cultural opinions;
(4) Responsible science: this principle serves to set and maintain high research standards in compliance with the norms of international society and the profession. This includes quality research design, review and evaluation, transparency, and the correction of false or misleading data or analysis;
(5) Respect for persons: this principle necessitates cognisance of the inherent human dignity of all people and the freedom of and respect for personal choice. Genetic characteristics are not indicative of any greater or lesser moral value. Further, respect for persons embodies active commitments to prevent neo-eugenics movements akin to the past, and to destigmatise disability;
(6) Fairness: this principle obliges us to treat all equally, including in distributing risks and benefits of research and enabling the equitable access to resulting clinical applications of human gene editing;
(7) Transnational cooperation: this principle highlights the immense need for collaboration in both research and regulation, whilst accommodating for different cultural perspectives. Adherence requires, where possible, coordination of international regulatory standards and processes, and data sharing between scientific communities and regulatory authorities.

This paper cannot find evident faults with these principles. They are neither too broad and meaningless, nor narrow and overly restrictive, in that they allow space for nations to comply in their own ways, but with common and consistent objectives. There appears to be no set hierarchy or priority to any one value over the other, though this paper notes that the principles relating to respect to persons and fairness are obviously vital for the preservation of the interests of persons with disabilities.

As to what the content of any policy instruments that arise out of discussions, this paper cannot say in any great detail. A number of such instruments have been proposed in the past, including:

- A 2002 proposal, which called for a ‘Convention on the Preservation of the Human Species’, aimed to prohibit human reproductive cloning and human germline genetic modification, and establish national oversight systems that ensured that use of gametes or embryos met consent, safety and ethical standards (Annas et al. 2002).
- A 2007 proposal, which asserted that the concept of a complete ban on human reproductive cloning had essentially attained the status of customary international law, to codify this into an international instrument under the UNESCO framework (Kuppuswamy et al. 2007).
- A 2008 proposal, which posited a ‘Genetic Heritage Safeguard Treaty’ based on the 1970 Nuclear Nonproliferation Treaty, to serve the dual function of both encouraging responsible applications of human genetic research as well as delineating limits on those applications deemed ‘undesirable’ (Metzl 2008).

Whatever the future may hold, this paper hopes for a respectful and coherent debate and an influential international instrument (or at the very least, a series of regionalised instruments) that prioritises respect for and protection of human dignity of people with disabilities and other possibly marginalised groups over more scientific and neo-eugenic agendas in human genome editing.

6. Conclusions

The unprecedented speed of technological development in human genome editing in recent years is testament to the globalised scientific community's unyielding passion for knowledge. Yet, even with such a (hopefully) noble motivation, innovations such as CRISPR have the potential to be utilised as tools of neo-eugenics. If they were so used, especially in germline intervention, the potential ramifications on the rights and ways of life of members of the disability community are numerous and far-reaching. Through an analysis of bioethical principles and traditional and modern conceptions of disability, this paper suggests that human dignity is the core moral precept and value on which modern international and domestic law frameworks operate in this ethically problematic sphere. Furthermore, there are significant flaws, gaps and uncertainties in the existing regulatory system. This is not the place to suggest a new set of international bioethical guidelines to govern human genome editing whilst preserving the human rights of persons with disabilities; that is an issue for wide deliberation and consensus. Instead, this paper proposes a mechanism by which a new human-rights-based regulatory instrument may be conceived to benefit both the disability and science communities. A set of clearly articulated principles will set the necessary debate and discussion on the right course. Nevertheless, the time for action is now. As increasingly accurate genome editing technology proliferates across national borders, a coherent and cohesive international stance on the issue is more urgently needed than ever. Time waits for no human right.

References

Altman, Russ B., Shamik Mascharak, and Niklaus Evitt. 2015. Human Germline Crispr-Cas Modification: Toward a Regulatory Framework. *American Journal of Bioethics* 15: 25–29.

Amundson, Ron, and Shari Tresky. 2008. Bioethics and Disability Rights: Conflicting Values and Perspectives. *Bioethical Inquiry* 5: 111–23. [CrossRef]

Annas, George J., Lori B. Andrews, and Rosario M. Isasi. 2002. Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations. *American Journal of Law & Medicine* 28: 151–78.

Araki, Motoko, and Tetsuya Ishii. 2014. International Regulatory Landscape and Integration of Corrective Genome Editing into in Vitro Fertilization. *Reproductive Biology and Endocrinology* 12: 108. [CrossRef] [PubMed]

Asch, Adrienne. 2000. *Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements*. Prenatal Testing and Disability Rights. Edited by Erik Parens and Adrienne Asch. Washington: Georgetown University Press.

Ayres, Ian, and John Braithwaite. 1992. *Responsive Regulation: Transcending the Deregulation Debate*. Oxford: Oxford University Press.

Bachruch, Susan. 2004. In the Name of Public Health—Nazi Racial Hygeine. *New England Journal of Medicine* 351: 417–20. [CrossRef] [PubMed]

Baker, Beth. 2016. The Ethics of Changing the Human Genome. *BioScience* 66: 267–73. [CrossRef]

Baldi, Pierre. 2001. *The Shattered Self: The End of Natural Evolution*. Cambridge: MIT Press.

Baltimore, David, Paul Berg, Michael Botchan, Dana Carroll, R. Alta Charo, George Church, Jacob E. Corn, George Q. Daley, Jennifer A. Doudna, Marsha Fenner, and et al. 2015. A Prudent Path Forward for Genomic Engineering and Germline Gene Modification. *Science* 348: 36–38. [CrossRef] [PubMed]

Baruch, Susannah, Audrey Huang, Daryl Pritchard, Andrea Kalfoglou, Gail Javitt, Rick Borchelt, Joan Scott, and Kathy Hudson. 2005. *Human Germline Genetic Modification: Issues and Options for Policymakers*. Baltimore: Genetics and Public Policy Center, Johns Hopkins University Berman Institute of Bioethics.

Basser, Lee Ann. 2011. Human Dignity. In *Critical Perspectives on Human Rights and Disability Law*. Edited by Marcia H. Rioux, Lee Ann Basser and Melinda Jones. Leiden: Martinus Nijhoff Publishers, pp. 17–36.

Benjamin, Ruha. 2016. Interrogating Equity: A Disability Justice Approach to Genetic Engineering. *Issues in Science & Technology* 32: 50–54.

Bennett, Rebecca. 2009. The Fallacy of the Principle of Procreative Beneficence. *Bioethics* 23: 265–73. [CrossRef] [PubMed]

Black, Edwin. 2008. *War against the Weak: Eugenics and America's Campaign to Create a Master Race*. New York: Dialog Press.

Black, Julia. 2002. Critical Reflections on Regulation. *Australian Journal of Legal Philosophy* 27: 1–46.

Bosley, Katrine S., Michael Botchan, Annelien L. Bredenoord, Dana Carroll, R. Alta Charo, Emmanuelle Charpentier, Ron Cohen, Jacob Corn, Jennifer Doudna, Guoping Feng, and et al. 2015. Crispr Germline Engineering—The Community Speaks. *Nature Biotechnology* 33: 478–86. [CrossRef] [PubMed]

Breggin, Peter. 1993. Psychiatry's Role in the Holocaust. *International Journal of Risk & Safety in Medicine* 4: 133–48.

Brosius, Jurgen, and Martin Kreitman. 2000. Eugenics—Evolutionary Nonsense? *Nature Genetics* 25: 253. [CrossRef] [PubMed]

Brownsword, Roger. 2004. What the World Needs Now: Techno-Regulation, Human Rights and Human Dignity. In *Global Governance and the Quest for Justice*. Edited by Roger Brownsword. Oxford: Hart Publishing, p. 203.

Brownsword, Roger. 2009. Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies. In *New Technologies and Human Rights*. Edited by Thérèse Murphy. New York: Oxford University Press, pp. 19–84.

Burleigh, Michael. 1994. *Death and Deliverance: 'Euthanasia' in Germany, C.1900 to 1945*. Cambridge: Cambridge University Press.

Center for Genetics and Society. 2015. *Human Germline Modification: Summary of National and International Policies*. Berkeley: Centre for Genetics and Society.

Center for Genetics and Society and Friends of the Earth. 2015. *Extreme Genetic Engineering and the Human Future: Reclaiming Emerging Biotechnologies for the Common Good*. Berkeley: Center for Genetics and Society.

Council for Responsible Genetics. 2005. *Position Paper on Human Germline Manipulation*. Cambridge: Council for Responsible Genetics.

Degener, Theresia. 2014. A Human Rights Model of Disability. Available online: http://www.academia.edu/18181994/A_human_rights_model_of_disability (accessed on 10 June 2016).

Degener, Theresia, and Gerard Quinn. 2002. Survey of International, Comparative and Regional Disability Law Reform. In *Disability Rights Law and Policy: International and National Perspectives*. Edited by Silvia Yee and Mary Lou Breslin. Leiden: Martinus Nijhoff.

Disabled Peoples International (DPI). 2000. *Disabled People Speak on the New Genetics: DPI Europe Position Statement on Bioethics and Human Rights*. London: DPI Europe.

Doudna, Jennifer A. 2015. *How Crispr Lets Us Edit Our DNA*. London: TEDGlobal, Transcript.

Dzau, Victor J., and Ralph J. Cicerone. 2015. Responsible Use of Human Gene-Editing Technologies. *Human Gene Therapy* 26: 411–12. [CrossRef] [PubMed]

El-Zein, Souheil. 2008. International Regulation of Human Genetics. In *Genetic Engineering and the World Trade System*. Edited by Daniel Wuger and Thomas Cottier. New York: Cambridge University Press, p. 315.

Esvelt, Kevin M., and Harris H. Wang. 2013. Genome-Scale Engineering for Systems and Synthetic Biology. *Molecular Systems Biology* 9: 641. [CrossRef] [PubMed]

Finkelstein, Vic, and Ossie Stuart. 1996. Developing New Services. In *Beyond Disability: Towards an Enabling Society*. Edited by Gerard Hales. London: SAGE Publications.

Fischer, Bernard A. 2012. Maltreatment of People with Serious Mental Illness in the Early 20th Century: A Focus on Nazi Germany and Eugenics in America. *Journal of Nervous and Mental Disease* 200: 1096–100. [CrossRef] [PubMed]

French, Phillip. 1994. What Is Disability? In *On Equal Terms—Working with Disabled People*. Edited by Phillip French. Oxford: Butterworth-Heinemann.

Fukuyama, Francis. 1992. *The End of History and the Last Man*. New York: Free Press.

Fukuyama, Francis. 2002. *Our Posthuman Future: Consequences of the Biotechnology Revolution*. New York: Farrar, Strauss and Giroux.

Galton, Francis. 1883. *Inquiries into Human Faculty and Development*. London: Macmillan.

Grant, Evadné. 2007. Dignity and Equality. *Human Rights Law Review* 7: 299–329. [CrossRef]

Harris, John. 1990. The Wrong of Wrongful Life. *Journal of Law & Society* 17: 90–105.

Harris, John. 1998. *Clones, Genes and Immortality: Ethics and the Genetic Revolution*. Oxford: Oxford University Press.

Hayes, Richard. 2008. Is There an Emerging International Consensus on the Proper Uses of the New Human Genetic Technologies? Paper presented at the US House of Representatives Foreign Affairs Committee Subcommittee on Terrorism, Nonproliferation and Trade Hearing on Genetics and Other Human Modification Technologies: Sensible International Regulations or a New Kind of Arms Race? Los Angeles, CA, USA, June 19.

Herberer, Patricia. 2002. Targeting the "Unfit" and Radical Public Health Strategies in Nazi Germany. In *Deaf People in Hitler's Europe*. Edited by Donna F. Ryan and John S. Schuchmann. Washinton: Gallaudet University Press.

Hoge, Stephen K., and Paul S. Appelbaum. 2012. Ethics and Neuropsychiatric Genetics: A Review of Major Issues. *International Journal of Neuropsychopharmacology* 15: 1547–57. [CrossRef] [PubMed]

Hsu, Patrick D., Eric S. Lander, and Fenc Zhang. 2014. Development and Applications of Crispr-Cas9 for Genome Engineering. *Cell* 157: 1262–78. [CrossRef] [PubMed]

Ida, Ryuichi. 2003. Bioethics and International Law. In *Ordine Internazionale E Valori Etici*. Edited by Nerina Boschiero. Verona: Societa Italiana di Diritto Internazionale, p. 365.

Iles, Alastair T. 1996. The Human Genome Project: A Challenge to the Human Rights Framework. *Harvard Human Rights Journal* 9: 27–60. [PubMed]

Imparato, Andrew J. 2004. *Testimony: Senate Hearing on Prenatal Genetic Testing Technology*. Washington: United States Congress, Committee on Commerce, Science, and Transportation, Subcommittee on Science, Technology, and Space.

International Bioethics Committee. 2015. *Report of the Ibc on Updating Its Reflection on the Human Genome and Human Rights*. Paris: UNESCO.

Isasi, Rosario, Erika Kleiderman, and Bartha Maria Knoppers. 2016. Editing Policy to Fit the Genome? *Science* 351: 337–39. [CrossRef] [PubMed]

Ishii, Tetsuya. 2015. Germ Line Genome Editing in Clinics: The Approaches, Objectives and Global Society. *Briefings in Functional Genomics*. Available online: http://bfg.oxfordjournals.org/content/early/2015/11/27/bfgp.elv053.full (accessed on 14 June 2016).

Jones, Melinda. 2011a. Introduction: Dignity. In *Critical Perspectives on Human Rights and Disability Law*. Edited by Marcia H. Rioux, Lee Ann Basser and Melinda Jones. Leiden: Martinus Nijhoff Publishers, pp. 85–86.

Jones, Melinda. 2011b. Valuing All Lives—Even "Wrongful" Ones. In *Critical Perspectives on Human Rights and Disability Law*. Edited by Marcia H. Rioux, Lee Ann Basser and Melinda Jones. Leiden: Martinus Nijhoff Publishers, pp. 87–116.

Kayess, Rosemary, and Phillip French. 2008. Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 8: 1–34. [CrossRef]

King, David. 2001. Eugenic Tendencies in Modern Genetics. In *Redesigning Life? The Worldwide Challenge to Genetic Engineering*. Edited by Brian Tokar. London: Zed Books, pp. 171–81.

Knoppers, Bartha Maria. 2016. Human Gene Editing: Principles & Precedents. Available online: http://nationalacademies.org/cs/groups/genesite/documents/webpage/gene_172445.pdf (accessed on 3 May 2017).

Kolieb, Jonathan. 2015. When to Punish, When to Persuade and When to Reward: Strengthening Responsive Regulation with the Regulatory Diamond. *Monash University Law Review* 41: 136–63.

Kuppuswamy, Chamundeeswari, Darryl Macer, Mihaela Serbulea, and Brendan Tobin. 2007. *Is Human Reproductive Cloning Inevitable: Future Options for UN Governance*. Tokyo: United Nations University Press.

Lander, Eric S. 2015. Brave New Genome. *New England Journal of Medicine* 373: 5–8. [CrossRef] [PubMed]

Lanphier, Edward, Fyodor Urnov, Sarah Ehlen Haecker, and Michael Werner. 2015. Don't Edit the Human Germ Line. *Nature* 519: 410–11. [CrossRef] [PubMed]

Ledford, Heidi. 2015. Crispr, the Disruptor. *Nature* 522: 20–24. [CrossRef] [PubMed]

Lenzerini, Federico. 2006. Biotechnology, Human Dignity and the Human Genome. In *Biotechnology and International Law*. Edited by Francesco Francioni and Tullio Scovazzi. Portland: Hart Publishing, pp. 285–340.

Liang, Puping, Yanwen Xu, Xiya Zhang, Chenhui Ding, Rui Huang, Zhen Zhang, Jie Lv, Xiaowei Xie, Yuxi Chen, Yujing Li, and et al. 2015. Crispr/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes. *Protein & Cell* 6: 363–72.

Lindner, Ralf, Stefan Kuhlmann, Sally Randles, and Bjørn Bedsted. 2016. *Navigating towards Shared Responsibility*. Brussels: ResAGora.

Marzano-Parisoli, Maria Michela. 2001. Disability, Wrongful-Life Lawsuits, and the Human Difference: An Exercise in Ethical Perplexity. *Social Theory and Practice* 27: 637–59. [CrossRef]

Mathews, Debra J. H., Sarah Chan, Peter J. Donovan, Thomas Douglas, Christopher Gyngell, John Harris, Alan Regenberg, and Robin Lovell-Badge. 2015. Crispr: A Path through the Thicket. *Nature* 527: 159–61. [CrossRef] [PubMed]

McCrudden, Christopher. 2008. Human Dignity and Judicial Interpretation of Human Rights. *European Journal of International Law* 19: 655–724. [CrossRef]

McLean, Sheila, and Laura Williamson. 2007. *Impairment and Disability: Law and Ethics at the Beginning and End of Life*. London: Routledge.

Menand, Louis. 2004. The Science of Human Nature and the Human Nature of Science. In *Genetics, Disability, and Deafness*. Edited by John Vickrey Van Cleve. Washington: Gallaudet University Press, pp. 5–22.

Metzl, Jamie. 2008. Brave New World War. Center for Genetics and Society. Available online: http://www.geneticsandsociety.org/article.php?id=3985 (accessed on 1 June 2016).

National Academies of Sciences and Medicine. 2015. *On Human Gene Editing: International Summit Statement*. Washington: National Academies of Sciences and Medicine.

National Academies of Sciences and Medicine. 2017. *Human Genome Editing: Science, Ethics, and Governance*. Washington: National Academies Press.

Oliver, Michael. 1990. *The Politics of Disablement*. Basingstoke: Palgrave Macmillan.

Oliver, Michael. 1996. *Understanding Disability: From Theory to Practice*. New York: St. Martin's Press.

Parmenter, Trevor R. 2005. Are We Engineering Ourselves out of Existence? *Journal of Intellectual and Developmental Disability* 30: 53–56. [CrossRef]

Parthasarathy, Shobita. 2016. Crispr Dispute Raises Bigger Patent Issues That We're Not Talking about. *The Conversation*. April 4. Available online: https://theconversation.com/crispr-dispute-raises-bigger-patent-issues-that-were-not-talking-about-56715 (accessed on 13 June 2016).

Peschin, Susan. 2017. How Should We Regulate Genome Editing? *World Economic Forum*. Available online: https://www.weforum.org/agenda/2017/05/how-should-we-regulate-genome-editing/ (accessed on 2 June 2017).

Pollack, Robert. 2015. Eugenics Lurk in the Shadow of CRISPR. *Science* 348: 871. [CrossRef] [PubMed]

President's Council on Bioethics. 2003. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*. Washington: President's Council on Bioethics.

Proctor, Robert N. 1988. *Racial Hygeine: Medicine under the Nazis*. Cambridge: Harvard University Press.

Quinn, Gerard, and Theresia Degener. 2002. *The Current Use and Future Potential Use of United Nations Human Rights Instruments in the Context of Disability*. New York and Geneva: Office of the United Nations High Commissioner for Human Rights.

Reaume, Denise G. 2002–2003. Discrimination and Dignity. *Louisiana Law Review* 63: 645–96.

Reiss, Thomas. 2015. Governance Approaches for Human Gene Editing Based on Responsible Research and Innovation. Paper presented at the National Academies of Sciences and Medicine's International Summit on Human Gene Editing, Washington, DC, USA, December 1–3.

Samaha, Adam. 2007. What Good Is the Social Model of Disability? *The University of Chicago Law Review* 74: 166. [CrossRef]

Sarewitz, Daniel. 2015. Crispr. Science Can't Solve It. *Nature* 522: 413–14. [CrossRef] [PubMed]

Savulescu, Julian, Jonathan Pugh, Thomas Douglas, and Christopher Gyngell. 2015. The Moral Imperative to Continue Gene Editing Research on Human Embryos. *Protein & Cell* 6: 476–79.

Saxton, Marsha. 1988. Prenatal Screening and Discriminatory Attitudes About Disability. *Women and Health* 13: 217–24. [CrossRef]

Shakespeare, Tom. 1995. Back to the Future? New Genetics and Disabled People. *Critical Social Policy* 44: 22–35. [CrossRef]

Shakespeare, Tom. 2002. The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability* 2: 9–28.

Shakespeare, Tom. 2013. The Social Model of Disability. In *The Disability Studies Reader*. Edited by Lennard J. Davis. Abingdon: Routledge.

Shakespeare, Tom. 2015. Gene Editing: Heed Disability Views. *Nature* 527: 446. [CrossRef] [PubMed]

Singer, Peter. 1993. *Practical Ethics*, 2nd ed. Cambridge: Cambridge University Press.

Smith, George P., II. 2012. *Law and Bioethics: Intersections Along the Mortal Coil*. Abingdon: Routledge.

Somsen, Han. 2009. Regulating Human Genetics in a Neo-Genetic Era. In *New Technologies and Human Rights*. Edited by Thérèse Murphy. New York: Oxford University Press, pp. 85–127.

Thomas, Pam, Lorraine Gradwell, and Natalie Markham. 1997. Defining Impairment within the Social Model of Disability. *Greater Manchester Coalition of Disabled People*. Available online: http://disability-studies.leeds.ac.uk/files/library/thomas-pam-Defining-Impairment-within-the-Social-Model-of-Disability.pdf (accessed on 29 May 2016).

Thompson, Charis. 2015. Governance, Regulation, and Control: Of Which People, by Which People, for Which People? Paper presented at the National Academies of Sciences and Medicine's International Summit on Human Gene Editing, Washington, DC, USA, December 1–3.

Turmusani, Majid. 2004. Genetic Technology and the UN Disability Convention. *Disability World*. Available online: http://www.disabilityworld.org/12-02_05/news/genetictech.shtml (accessed on 3 June 2016).

UN Secretary General. 2006. Secretary-General Hails Adoption of Landmark Convention on Rights of People with Disabilities. SG/SM/10797-HR/4911-L/T/4400. December 3. Available online: http://www.un.org/press/en/2006/sgsm10797.doc.htm (accessed on 8 June 2016).

United Nations. 2007. UN Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

Walters, LeRoy. 1978. Bioethics as Field of Ethics. In *Contemporary Issues in Bioethics*. Edited by Tom L. Beauchamp and LeRoy Walters. Los Angeles: Calif Dickenson, p. 49.

Witzany, Guenther. 2016. No Time to Waste on the Road to a Liberal Eugenics? *EMBO Reports* 17: 281. [CrossRef] [PubMed]

Wolbring, Gregor. 2015. Gene Editing: Govern Ability Expectations. *Nature* 527: 446. [CrossRef] [PubMed]

Wolbring, Gregor, and Lucy Diep. 2016. The Discussions around Precision Genetic Engineering: Role of and Impact on Disabled People. *Laws* 5: 37. [CrossRef]

4

Unveiling the Challenges in the Implementation of Article 24 CRPD on the Right to Inclusive Education. A Case-Study from Italy

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Abstract: Since the 1970s, Italy has undertaken a process of inclusion of children with disabilities in mainstream schools, has implemented an anti-discriminatory educational policy, and abandoned segregated educational practices. In September 2014, the Italian Government initiated a process of "modernization" of the whole educational system, and attempted to fully align domestic legislation with the wide-ranging obligations enshrined in Article 24 CRPD. Law No. 107/2015 on the reform of the educational system empowered the Government to adopt legislative decrees to promote *inter alia* an effective and inclusive education for persons with disabilities. After a long and somewhat troubled process, a legislative decree on inclusive education was finally adopted in April 2017. This article, building upon previous research, critically discusses the innovations brought by this recent reform, situating them in the broader Italian legislative framework on the rights of people with disabilities. By focusing on Italy as a case-study, this article aims to reflect on the challenges surrounding the creation of an inclusionary educational system that goes beyond a mere integration in mainstream schools and ensures full and effective participation of all learners, meeting the standards imposed by Article 24 CRPD.

Keywords: UN Convention on the Rights of Persons with Disabilities; inclusive education; support teacher; Law No 104/1992; Law No 107/2015; legislative decree No 66/2017

1. Introduction

Italy has long implemented an anti-discriminatory educational policy, and abandoned segregated practices in education, by advancing a policy known as "school integration" (*integrazione scolastica*) since the 1970s (Caldin 2013). As noted elsewhere (Ferri 2017), even before the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), in 2009,[1] the Italian legislative and policy framework was characterised by a relatively high standard of protection of the right to education of pupils with disabilities (Rossi et al. 2016; Addis 2015; Troilo 2012, 2016; Busatta 2016; Penasa 2014). Despite a progressive legal framework, however, numerous shortfalls have slowly emerged in the Italian school system. In the last few years, several complaints have been brought to court by parents of pupils with disabilities seeking to enforce the right to education, to combat alleged discrimination of disabled pupils at school, and ultimately to challenge the lack of implementation or the incorrect implementation of the legislation in place. The UN Committee on the Rights of Persons with Disabilities (CRPD Committee), in its Concluding Observations (COs) to the Italian Initial Report on the implementation of the Convention (CRPD Committee 2016a), while commending Italy for

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[1] Law of 3 March 2009 No 18 '*Ratifica ed esecuzione della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità, con Protocollo opzionale, fatta a New York il 13 dicembre 2006 e istituzione dell'Osservatorio nazionale sulla condizione delle persone con disabilità*' in *Gazzetta Ufficiale* (OJ) of 14 March 2009 No 6.

the long-standing commitment in realizing inclusive education for persons with disabilities, has also identified legislative gaps and practical challenges to be addressed in order to fully implement Article 24 CRPD.

In 2014, a new[2] reorganisation of the Italian educational system was triggered under the government led by Prime Minister Matteo Renzi. The Law No. 107/2015,[3] so called "*LaBuonaScuola*" (TheGoodSchool) has commenced a process of reform of various aspects of the educational provision in order to improve its efficiency, to enhance autonomy of schools (Cocconi 2015a, 2015b), and to boost the overall quality of education. It has set forth the criteria and principles that the Government must follow when adopting legislative decrees that regulate specific aspects of the educational system. Law No. 107/2015 also has *inter alia* engaged with many aspects related to the education of students with disabilities, empowering the Government to adopt a legislative decree on inclusive education. This Decree (No 66/2017)[4] on inclusive education was finally adopted in April 2017, after a relatively long and somewhat troubled process. Against this background, this article, building upon previous research (Ferri 2017, 2018a), aims to discuss the innovations brought by the Law No 107/2015 and its implementing Legislative Decree No. 66/2017, situating them in the broader Italian legislative framework. By focusing on Italy as a case-study, it endevours to provide a timely reflection on the challenges surrounding the creation of an inclusionary educational system that goes beyond a mere integration in mainstream schools and ensures full and effective participation of all learners as envisaged by Article 24 CRPD. After this introduction, the remainder of this article is divided into five sections. Building on the broad array of literature on the topic (Arnardóttir 2011; Broderick 2014; De Beco 2014; Shaw 2014; Cera 2015; Della Fina 2017), Section 2 begins with a short account of the obligations laid down in Article 24 CRPD, and examines the normative meaning of the concept of "inclusive education" purported by this provision. Section 3 briefly presents the Italian legal framework on the right to education of persons with disabilities. Section 4 discusses the most salient features of educational policy for persons with disabilities, and critically analyses its practical implementation in light of domestic case law. Section 5 examines the most recent developments: the new Law No. 107/2015 and the Legislative Decree No. 66/2017. This section does not discuss the new reform in its entirety. Rather it focuses on those provisions that purport innovations in respect to the inclusion of pupils with disabilities in schools. Taking into account the extreme complexity and intricacy of the Italian system, the section does not delve into the technicalities of the Decree, but aims to highlight in a general fashion some of the most notable provisions, assessing them vis a vis Article 24 CRPD. Section 6 concludes by reflecting on the challenges in the implementation of an inclusive and rights-based educational system encountered in Italy and by highlighting the extent to which the new Italian legislation might provide an example of good practice to other States Parties.

2. The Right to Inclusive Education in the UN Convention on the Rights of Persons with Disabilities

2.1. Inclusive Education in Article 24 CRPD

The CRPD recasts disability as a social construction and "brings a human rights dimension to disability issues" (De Beco 2014, p. 269). It embraces the view that disability stems primarily from the failure of the social environment to meet the needs and aspirations of people with disabilities, and is underpinned by the principles of non-discrimination and equality, which encompass the right to reasonable accommodation (Seatzu 2008; Kayess and French 2008). Its innovative character arises from its elaboration of existing human rights within the disability context. The CRPD does not simply

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[2] The Renzi reform is the latest (and probably the most ambitious) of a series of reforms of the educational system that have been launched since the late '1990s. An account of these reforms until 2011 has been traced by Grimaldi and Serpieri (2012).

[3] In OJ of 15 July 2015 No 162.

[4] In OJ of 16 May 2017 No. 122.

prohibit discrimination on the grounds of disability, but covers the whole spectrum of civil, political, economic, cultural and social rights. The CRPD specifically proclaims the right of persons with disabilities to education in Article 24. This provision is very wide and must not be interpreted in isolation. Rather, it must be read in conjunction with other rights provided in the text and in light of the general principles of the Convention, enunciated in Article 3.[5] The overall obligation Article 24 purports is the realization of an inclusive education system at all levels.

Article 24 CRPD, which is the first international legally binding instrument to contain a reference to the concept of quality inclusive education (Broderick 2014), builds on established soft law, such as the Jomtien World Declaration on Education for All (1990), the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993), and the Salamanca Declaration and Framework for Action (1994). However, Article 24 CRPD does not give a normative definition of inclusive education. The CRPD Committee has tried to fill this *lacuna*. It seems to have embraced the view of inclusion as "a dynamic approach of responding positively to pupil diversity and of seeing individual differences not as problems, but as opportunities for enriching learning", already advanced by the UNESCO (UNESCO 2005, p. 12), and has conceptualised inclusive education (CRPD Committee 2016b, para. 10) as

(a) A fundamental human right of all learners. Notably, education is the right of the individual learner and not, in the case of children, the right of a parent or caregiver. Parental responsibilities in this regard are subordinate to the rights of the child;
(b) A principle that values the well-being of all students, respects their inherent dignity and autonomy, and acknowledges individuals' requirements and their ability to effectively be included in and contribute to society;
(c) A means of realizing other human rights. It is the primary means by which persons with disabilities can lift themselves out of poverty, obtain the means to participate fully in their communities and be safeguarded from exploitation. It is also the primary means of achieving inclusive societies;
(d) The result of a process of continuing and proactive commitment to eliminating barriers impeding the right to education, together with changes to culture, policy and practice of regular schools to accommodate and effectively include all students.

In its General Comment No 4, the CRPD Committee has also sought to trace the boundaries among the concepts of exclusion, segregation, integration and inclusion in education, and clarified which actions are needed to ensure that children with disabilities participate within the mainstream education system and to fully fulfil the obligation included in Article 24 (CRPD Committee 2016b, para. 11). According to the Committee, exclusion "occurs when students are directly or indirectly prevented from or denied access to education in any form", while segregated education is "provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities". The Committee also contrasted integration as a "process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardized requirements of such institutions", with inclusion. The latter "involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences". The Committee also made it clear that placing students with disabilities within mainstream schools, without accompanying support

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[5] Article 3 enunciates the Convention's general principles, which include: respect for individual dignity, autonomy, and independence; respect for difference and acceptance of disability as human diversity; non-discrimination; equal opportunity; complete and meaningful participation; accessibility; gender equality; and respect for children's rights and support for their evolving capabilities.

and structural changes to the curriculum and teaching and learning strategies, does not accomplish the obligations laid down in Article 24 CRPD.

As highlighted by De Beco (2014, p. 287) Article 24 CRPD closely follows the social model of disability, since it requires Parties to achieve a truly inclusive non-discriminatory educational system by removing all the barriers to participation. In other words, in order to achieve an inclusive educational system States Parties must ensure that persons with disabilities can access an inclusive, quality and free primary and secondary education on an equal basis with others.

2.2. Overview of the Obligations of States Parties under Article 24 CRPD

Article 24(1) CRPD requires States Parties to guarantee inclusive education for all persons with disabilities at all levels and to ensure inclusive lifelong learning opportunities. Article 24(2) lists a series of measures that States Parties are required to adopt to create an inclusive educational system. As noted in a study of the Office of the High Commissioner for Human Rights (OHCHR 2013), these measures are not to be read separately one another, rather must be interpreted jointly, and in light of other provisions of the Convention. Without providing a detailed discussion (for further details see: (Della Fina 2017; Broderick 2014)), we limit ourselves to highlight that Article 24(2)(b) CRPD, read in conjunction with the general principle of accessibility, prescribes that the entire education system is accessible, "including buildings, information and communication, comprising ambient or frequency modulation assistive systems, curriculum, education materials, teaching methods, assessment and language and support services". An inclusive system should reflect "Universal Design", which is recognised by the CRPD, and should be accessible to all students, to the greatest extent possible, without the need for specific adaptation. However, reasonable accommodation must be provided to students with disabilities when needed (Article 24(2)(c) CRPD), together with "effective individualized support measures . . . in environments that maximize academic and social development, consistent with the goal of full inclusion" (Article 24(2)(e) CRPD). Reasonable accommodation is designed to meet the specific needs of a person with a disability in a particular case, and concerned with the removal of the specific disadvantage to which a disabled student would otherwise be subjected by standard educational practices or systems. The CRPD Committee has clarified that accommodations include "changing the location of a class, providing different forms of in-class communication, enlarging print, materials and/or subjects in sign, or providing all handouts in an alternative format, providing students with a note-taker, or a language interpreter or allowing students to use assistive technology in learning and assessment situations" or "allowing a student more time, reducing levels of background noise" (CRPD Committee 2016b, para. 30). Support measures appear to be methods that "supplement the reasonable accommodations and add a human rights dimension to the right to education of persons with disabilities" (De Beco 2014). Examples of the latter according to the Committee are "the provision of sufficient trained and supported teaching staff, school counsellors, psychologists, and other relevant health and social service professionals, as well as access to scholarships and financial resources" (CRPD Committee 2016b, para. 32).

Article 24(3) CRPD requires State Parties to "enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education", including Braille and sign-language, and to "train professionals and staff who work at all levels of education". Notably, this provision places a specific emphasis on the promotion of the linguistic identity of Deaf people, which is also mentioned in Article 30(4) CRPD[6]. According to Della Fina (2017, p. 455), the purpose of Article 24(3) is to guarantee that people with sensory impairments are not excluded from the

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[6] Article 30 CRPD, which provides the right of persons with disabilities to participate in cultural life, requires Parties to the Convention to take all appropriate measures to ensure that persons with disabilities have access to cultural materials, television programmes, films, theatre and other cultural activities, but also to places for cultural performances or services, monuments and sites. This Article provides for recognition and support of specific cultural and linguistic identity of persons with disabilities, including sign languages and deaf culture (for further discussion see (Ferri 2014)).

mainstream education system and receive instruction in the appropriate languages, modes, and means of communication in environments that maximize their development. This provision sets forth the only exception to inclusive education, allowing the education of blind, deaf, and deafblind children in special schools (Della Fina 2017; De Beco 2014; Broderick 2014). As discussed by Arnardóttir (2011), Article 24 CRPD confers the right to *choose* an inclusive education, thus attempting to strike a balance between the goal of full inclusion and the need, in very limited cases, of special education to meet specific needs of learners with disabilities.

Article 24(4) CRPD requires States Parties to take appropriate measures to employ qualified teachers having skills to teach in an inclusive environment. The CRPD Committee has stated that to fully implement this particular obligation, "States parties must ensure that all teachers are trained in inclusive education and that that training is based on the human rights model of disability" (CRPD Committee 2016b, para. 36). It has also affirmed that

> States parties must invest in and support the recruitment and continuous education of teachers with disabilities. This includes removing any legislative or policy barriers requiring candidates to fulfil specific medical eligibility criteria and the provision of reasonable accommodations for their participation as teachers. Their presence will serve to promote equal rights for persons with disabilities to enter the teaching profession, bring unique expertise and skills into learning environments, contribute to breaking down barriers and serve as important role models. (CRPD Committee 2016b, para. 37)

Lastly, Article 24(5) CRPD reaffirms the right of persons with disabilities to access to general tertiary education, vocational training, adult education and lifelong learning, on an equal basis with others.

All in all, Article 24 CRPD adopts a holistic approach (Palmer 2013). It places on State Parties various obligations, which require them to value the diversity of students with disabilities and to support different abilities in mainstream schools. While being subject to progressive realization within the maximum available resources, as stated by Article 4(2) CRPD, the implementation of the right to education must in fact be assured through the effective allocation of adequate financial and human resources, and the establishment of monitoring mechanisms (Broderick 2014).

3. The Right to Education of Persons with Disabilities in Italy: Overview of the Legal Framework

3.1. The Constitutional Framework

The general principle of protection and promotion of the rights of persons with disabilities, and in particular of their right to education, is anchored to Article 2 of the Italian Constitution (IC), which recognizes and guarantees "the inviolable rights of the person, both as an individual and in the social groups where human personality is expressed".[7] It is also informed by Article 3(1) IC, that provides for the principle of non-discrimination on the grounds of sex, race, language, religion, political opinion, and personal and social conditions, and by Article 3(2) IC, which establishes the principle of substantive equality. According to the latter provision, the State is called to remove the social and economic obstacles that limit the freedom and equality of the citizens and prevent the full development of the human being.

The right to education of persons with disabilities stems from different constitutional provisions, which must be read in combination, in light of the constitutional principles laid out in Articles 2 and 3 IC. Article 33 IC obliges the State to provide a State-school system accessible to all children and affirms the freedom for organisations and individuals to set up private schools with no cost for the

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[7] The English translation of the Italian Constitution is published by the Parliamentary Information, Archives and Publications Office of the Senate Service for Official Reports and Communication and can be found at http://www.senato.it/documenti/repository/istituzione/costituzione_inglese.pdf (accessed on 1 September 2017).

State. Article 34 IC establishes in general terms that "[s]chools are open to everyone", and that primary education, offered for at least eight years, is compulsory and free of tuition fees. Article 38(3) IC affirms that "disabled and handicapped persons are entitled to receive education and vocational training". A wide interpretation of the latter provision in combination with Articles 2 and 3 IC, has led the Italian Constitutional Court to shift from a paternalistic-charitable model of care to a social model oriented view of disability around the mid-eighties, and to spell out a wide-ranging right to inclusive education for people with disabilities (Colapietro 2011).

Since Italy is a regional State, besides the abovementioned provisions concerning the right to education, the IC sets forth the division of competence over educational matters between the State and the Regions. Art 117(1)(n) IC confers on the State the exclusive power to lay down "general provisions on education".[8] The Constitutional Court has established that these "general provisions on education" are concerned with the "basic characteristics" of the educational system,[9] and comprise: the general organisation of the system, the protection and promotion of the autonomy of each educational institution (Cocconi 2015b), the freedom to open private schools and parity between public and private (non-governmental) schools, minimum numbers of school hours per year, the teacher/student ratio, State financial resources, and also the inclusion of people with disabilities (Troilo 2012). When legislating on the basic characteristics of the school system, the State also addresses (and manages through the Ministry of Education, University and Research), two core components: teachers' qualifications and recruitment, as well as salaries.[10]

3.2. The Right to Education of Students with Disabilities in National Legislation

Within this constitutional framework, and long before the approval of the CRPD, when the global scene was still dominated by segregation policies, Italy represented an exceptional example of non-discriminatory educational legislation. The first provisions laying down the conditions and instruments necessary to ensure school integration of pupils with disabilities date back to the 70s. In particular Art. 28 of Law No. 118/71,[11] as interpreted by the Italian Constitutional Court in its decision No. 215/1987, and Law No. 517/77[12] (Addis 2015). The latter piece of legislation has been deemed to purport a change in society by stimulating acceptance of disability as part of human diversity (OECD 2007).

Law No. 104/1992 ("Framework Law for Care, Social Integration and Rights of Persons with Disabilities"),[13] which aims to remove obstacles, improve access and make it possible for disabled people to enjoy mainstream services and facilities (Siclari 2015), re-affirms the right to education and pursues "*integrazione scolastica*" in order to develop the abilities of person with disabilities. This piece of legislation also requires individualized plans for students with disabilities (*Piano educativo individualizzato—PEI*)[14] and the supply of didactic tools and assistive technology to schools, as well as

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[8] This Article must be read in conjunction with Article 33(3) IC that affirms that '[t]he Republic lays down general rules for education'.

[9] Italian Constitutional Court, Judgment No 200/2009.

[10] In addition, Art 117(1)(m) IC empowers the State to determine 'the basic level of benefits relating to civil and social entitlements to be guaranteed throughout the national territory'. The latter competence is aimed at ensuring equality of treatment among users who benefit from the educational services (and more generally social services) across the national territory. Such a cross-cutting national competence implies that whenever a regional law provides for benefits related to social rights (including the right to education), it must be subordinated to the national law that establishes the minimum standards with regard to those rights.

[11] Law of 30 March 1971 No. 118, 'Conversione in legge del D.L. 30 gennaio 1971 n. 5 e nuove norme in favore dei mutilati ed invalidi civili' in OJ 2 April 1971 No 82.

[12] Law of 4 August 1977 No 517 *'Norme sulla valutazione degli alunni e sull'abolizione degli esami di riparazione nonché altre norme di modifica dell'ordinamento scolastico'* in OJ 18 August 1977 No 224.

[13] Law of 5 February 1992 No 104, *'Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate'* in OJ 17 February 1992 No 39.

[14] This article will use the Italian acronym *PEI* in subsequent sections, as the acronym is commonly used in Italian scholarship on the topic.

other forms of technical assistance, when needed. Inclusion is, in practice, ensured by support teachers who provide additional individual instruction and educational support in order to meet the needs of each student with a disability.[15] As national courts have affirmed in different occasions, the support teacher's role is complementary to that of the classroom teacher (Manca 2010, pp. 337–38). Law No. 104/1992 also recognizes homeschooling for those who are temporarily unable to attend school.

In 2010, Law No. 170/2010[16] was passed in order to ensure the right to education to children with "specific learning difficulties" (*Difficoltà Specifiche di Apprendimento*—DSA), i.e., children with difficulties in reading (Dyslexia), writing (Graphic Dyslogia and Dysorthography), or in computing (Discalculia or numeracy problems). The general objective of this act is to give these children equal educational opportunities to successful and efficient education in accordance with their needs and abilities in mainstream schools, implementing teachers' preparation, ensuring a collaboration among teachers, parents and experts of the health services, envisaging targeted flexible educational plans. This law affirms the need for specialized training for teachers in supporting learners with these disabilities, recognizing that it is one of the major challenges to the full and effective inclusion of persons with disabilities in the education system.

Since its inception, no major changes to this framework have been introduced. The main previous reform of the education system (Law No 53/2003[17]) did not include any specific provision on the education of people with disabilities, and limited itself to making explicit reference to Law No 104/1992. In 2008, the Budget Law 2008,[18] as part of general austerity measures and budget cuts, fixed a maximum number of support teachers for children with disabilities who attend classes in public schools, and abolished the possibility (provided for in Article 40(l) of Law No 104/1992) of hiring additional support teachers under fixed-term contracts, who would provide specific educational assistance to children with severe disabilities. However, these provisos were referred to the Italian Constitutional Court (ICC) upon the request of the Sicilian Administrative Council. In its judgment, No 80/2010, the ICC declared them unconstitutional and affirmed that they infringed the fundamental right of education of children with disabilities, set forth in Art 38(3)(4) IC, and violated the principle of equality. Interestingly, the ICC in defining the 'content' of the fundamental right to education for persons with disabilities referred to Article 24 CRPD, in support of its reasoning. Overall, the Court argued that the core minimum guarantees to make the right to education of students with disabilities effective cannot be subject to financial conditions. The ICC pointed out that it is for the legislature to provide appropriate tools to implement the right to education, but underlined that legislative provisions cannot undermine the realisation of a fundamental right by making it conditional on the availability of financial resources (Ferri 2014, 2018b; Ferrari 2012). A recent case, which was decided by the ICC, reaffirmed that the right to education of people with disabilities must be effectively ensured, and that financial constraints cannot undermine the enjoyment of this fundamental right for people with disabilities.[19] In essence, the ICC reiterated that a formal recognition of the right by the legislation is not sufficient if the right is not guaranteed in practice (Blando 2017). The case concerned the transport of students with disabilities to school and their assistance. The Abruzzo regional law provided for a grant to be given to local authorities so that they could ensure transport and assistance to students with disabilities only "within the limits of available funds determined by the annual budget law". In doing so, the law made the regional contribution aimed at implementing the right of students with disabilities to transport services conditional and subject to budget constraints. The ICC, in line with its decision No. 80/2010, held

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[15] Support teachers are qualified teachers who must also obtain further specialized postgraduate training, the requirements of which are established in various bylaws, mainly ministerial decrees.

[16] Law of 8 October 2010 No 170 '*Nuove norme in materia di disturbi specifici di apprendimento in ambito scolastico*' in OJ 18 October 2010 No 244.

[17] Law of 28 March 2003 No 53 '*Delega al Governo per la definizione delle norme generali sull'istruzione e dei livelli essenziali delle prestazioni in materia di istruzione e di formazione professionale*' in OJ 2 April 2003 No 77.

[18] Namely Art 2 paras 413 and 414 of the Law 24 December 2007 No 244 in OJ 28 December 2007 No 285.

[19] Italian Constitutional Court, Judgment No 275/2016.

the regional provision to be unconstitutional. In particular, the Court believed that transportation services for students with disabilities are necessary to guarantee the right to inclusion for persons with disabilities and are an essential element in ensuring the participation of these pupils within the educational process.

4. Italian Educational Policies in a Nutshell and Their (Challenging) Implementation

In spite of the progressive legislative framework, highlighted above, and despite the role played by the ICC in safeguarding the full enjoyment of the right to education for students with disabilities, territorial divides (ISTAT 2016) and flaws have emerged in educational provision and in the actual implementation of Law No. 104/1992.

Territorial differences and mixed practices are partially due to the fact that Italian educational policy system is highly decentralised, and informed by the principle of subsidiarity and the principle of autonomy of schools and educational institutions.[20] The Ministry of Education, University and Research (*MIUR*) is generally responsible for educational policy at a national level. Regional School Offices—RSOs, local authorities and schools play a substantive role in the actual provision of educational services. Schools, in particular, are ultimately responsible for the practical implementation of inclusive education. They define curricula and educational offerings, organise teaching, assign support teachers, allocate hours of support and lay down the individualized education plan (*PEI*). Empirical research has shown that the autonomy of schools has *de facto* led to inclusive practices to be extremely heterogeneous across the territory (Anastasiou et al. 2015). In 2009, after the ratification of the CRPD, the Ministry adopted new "Guidelines on School Inclusion of Pupils with disabilities",[21] which collate a set of recommendations to improve the inclusion of children with disabilities (inspired by the CRPD), and to orient the action of both RSOs, and schools. Despite these guidelines and the MIUR's attempt to centrally orient the action of schools, Dovigo (2016) affirms that inclusion too often depends on the single educational setting, on "local customs". This author also claims that inclusive education is essentially "shaped" by individual school managers and teachers, and the interpretation of what constitutes an inclusive setting "differs widely among schools, and sometimes even among classes in the same school".

Statistic data have shown that there are gaps in educational provision and a lack of continuity in the support provided by teachers in schools (ISTAT 2016; Ferri 2018a). Lack of continuity in the support offered by support teachers is also due to the fact roughly 30% of support teachers ask for redeployment as main classroom teachers five years after obtaining their qualification (Devecchi et al. 2012). The reasons behind requests of redeployment are various, but educational research highlights that working conditions of support teachers are often draining and relationship with children, families, other teachers, and other professionals is, in several cases, problematic (Devecchi et al. 2012; Ianes et al. 2014).

Limited gaps in the legislation have emerged mainly in regards to accessibility of information and communication and accessibility of educational content, and in respect to the lack of legal recognition of alternatives modes of communication (CSS 2016), and Italian Sign language (*Lingua Italiana dei Segni—LIS*). The CRPD Committee, in its COs to the Italian Initial Report on the implementation of the Convention (CRPD Committee 2016a), also highlighted the lack of availability with regard to accessible learning materials and the lack of assistive technology. In addition, the Committee acknowledged that deaf children are not provided with *LIS* interpreters in school, and recommended Italy "desist from recommending general communication assistants as an exclusive alternative".

The most serious flaws concern the lack of provision of adequate support to students and are due to the failure to properly implement the legislation in place. This has been highlighted by the shadow

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[20] These principles are established in the Italian Constitution. The principle of autonomy of schools is implemented by means of the Decree of the President of the Republic No 275 of 8 March 1999 in OJ 10 August 1999 No 186 providing schools with didactic, organisational and research autonomy.

[21] *Ministero dell'Istruzione*, Prot.n 4274.

report on the implementation of the CRPD of the Italian Disability Forum to the CRPD Committee (IDF 2016a, 2016b). The Italian National Observatory on the Situation of Persons with Disabilities[22] also underlined need to improve the operation of the existing system, and to make sure that the right to inclusive education is fully enjoyed by people with disabilities in practice in their everyday life.[23] Gaps have emerged through a series of court cases, mostly initiated by parents of children with learning or intellectual disabilities, in which the parents challenged the appropriateness of existing provision for their children. The National Statistic Office (ISTAT) detected that approximately 8% of families of primary school pupils and 5% of those in the secondary school level have appealed to the District Court or the Regional Administrative Court to obtain an increase in support hours. In almost all the cases that ended up in Italian administrative courts, the applicants asked for the annulment of the individual educational plan (*PEI*) adopted by the public educational institution limiting the number of support teacher hours available to the relevant student (Lottini 2011). Usually, the applicants claimed their right to benefit from the support teacher either for a greater amount of time or for the entire time of school attendance. In some cases, the applicant alleged *inter alia* the violation of the CRPD as ratified by Law No 18/2009.[24] In the majority of cases, administrative courts have annulled the contested measures and held that the '*quantum*' of the teaching support essential to enjoying that right has to be determined exclusively in relation to the need of the student with disabilities, and no other interests can be taken into consideration, not even in case of understaffed administrations.[25] In general, the ordinary district courts were asked to decide cases in which the applicants had filed a complaint outlining discrimination on the grounds of disability. Primarily, the applicants challenged decisions made by public schools to reduce the employment contract of a support teacher to a limited number of hours due to budgetary concerns, and maintained that these constituted an unlawful discrimination and infringements of the fundamental right to education. So far, Italian courts have held that the constitutional and legislative framework in place, read in conjunction or in light of the CRPD, effectively guarantees disabled students the support measures necessary to substantially enjoy the right to education, but make evident a failure to properly implement the legislation in force (Ferri 2017, 2018a, 2018b).

5. The Reform of the Educational System and Inclusive Education: A Step Change?

5.1. Law No. 107/2015 and Inclusive Education

As mentioned above in the Introduction, in September 2014, the Italian Government initiated a process of modernization of the whole Italian educational system and put on the table an additional funding of €3 billion to recruit school teachers and additional staff, but also to innovate facilities and introduce high-speed internet and Wi-Fi in all schools. Law No. 107/2015 (*Riforma del sistema nazionale di istruzione e formazione e delega per il riordino delle disposizioni legislative vigenti)*, so called

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[22] The Italian National Observatory on the Situation of Persons with Disabilities (*Osservatorio Nazionale sulla condizione delle persone con disabilità*) was created in order to implement Article 33(2) CRPD. It was meant to constitute the independent mechanism, but is organisationally placed within the Ministry of Labour and Social Policies, which finances it, and is chaired by the Ministry. It includes representatives of various ministries, including the MIUR, local authorities, Social Security Institutions, the National Statistics Institute, social partners (trade unions and industry organisations), as well as independent experts and DPOs. While it has monitoring tasks, the National Observatory is also a consultative body in charge of technical support for the elaboration and supervision of national disability policies. It promotes the implementation of the Convention, and prepares cross-cutting biannual action plans for promoting the rights of persons with disabilities across the whole range of policies, with a view to achieving the objectives established by the CRPD and by the European Disability Strategy. The First Bi-annual Action Plan on Disability was adopted by the National Observatory in 2013 (Decree of the President of the Republic of 4 October 2013 '*Programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilita*' OJ 28 December 2013 No 303).

[23] Decree of the President of the Republic of 4 October 2013 '*Programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilita'* OJ 28 December 2013 No 303.

[24] E.g., TAR Lombardia, Sez. 3, No 1895/2014.

[25] E.g., TAR Calabria, Sez. 3, No 831/2011.

"*LaBuonaScuola*" (TheGoodSchool) has started an overall reform of Italian schools touching upon different aspects of the educational provision, including that of inclusive education (Cocconi 2015a). Being a delegation law,[26] Law No. 107/2015 provides for general principles and benchmarks that the Government must respect and follow when adopting legislative decrees (which have the same rank as ordinary laws) laying down detailed provisions.

Law No. 107/2015, along the lines traced by Law No. 104/1992, and similarly to its predecessors, aims to ensure that persons with disabilities are not excluded from the mainstream education system on the basis of disability, but included into regular schools and provided with adequate support for their inclusion. It is evident that this reform Law situates itself in continuity with precedent legislation on education and must be read in light and in combination with Law No. 104/1992.[27] Under Law No. 107/2015, schools remains responsible for defining educational offerings, organising teaching, assigning support teachers, allocating hours of support and laying down the *PEI* for each student with a disability. Article 1(14) of Law No 107/2015 requires schools to take into account the number of students with disabilities when indicating the overall number of support teachers needed and when organizing teaching activities. School directors have the power to reduce the number of students per class "in order to improve the teaching quality, also in relation to the needs of pupils with disabilities" (Art. 1(84)). These provisions are clearly aimed to ensure an effective education for students with disabilities. They seem, as envisaged by the CRPD Committee,[28] to require schools to fully respect the well-being of all students and to adequately assess the individuals' requirements and needs.

Article 1(24) of the Law explicitly states that teaching provided to students with disabilities will be ensured through the recognition of different modes of communication. Law No 104/1992 refers, in Article 13(1)(a), to assistive and technical devices to ensure the right to education, and, in Article 13(3) includes a generic reference to the duty of schools to provide "assistance for the autonomy and personal communication of pupils with physical or sensory handicaps". However, it does not mention augmentative and alternative forms of communication. Hence, Article 1(24) seems to fill a legal vacuum and appears to be innovative. It seems also to implement (at least partially) the obligation included in Article 24(3) CRPD. This provision could also be seen as a gateway to ensure *LIS* interpreters in schools, which had been so far neglected, as noted by the CRPD Committee (CRPD Committee 2016a).[29] This provision will soon be complemented by the law on the formal recognition of LIS and of Deaf people as a linguistic community, currently under discussion in the Italian parliament.[30] Once approved, this law will further guarantee the teaching of the sign language in primary and secondary primary schools, as well as the use of the *LIS* interpreters in high schools and universities. Regrettably, Article 1(24) makes it clear that the implementation of different communication modes must occur "without new or increased burdens on public finance". Interestingly, this formulation is very similar to the one adopted in respect to reasonable accommodations in public employment contexts. It is worth recalling that reasonable accommodation duties were included in anti-discrimination legislation only in 2013 (Ferri and Lawson 2016),[31] following the ruling of the CJEU in *Commission v Italy*.[32] The new provision

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[26] Article 76 of the Italian Constitution allows the Government to exercise legislative functions only when delegated by Parliament for a limited time and for specified purposes. The Parliament delegates to the Government the exercise of legislative functions through a delegation law that establishes the principles and criteria that the Government must follow and comply with when exercising the legislative function. The delegation law empowers the Government to adopt one or more legislative decrees, which are deliberated upon by the Council of Ministers.

[27] It is important to note that the La 104/1992 remains the cornerstone of Italian disability law and policy, and the point of reference for any legislative reform which touches upon the rights of persons with disabilities.

[28] See *supra* Section 2.

[29] See above Section 4.

[30] The bill was approved on the 3rd of October 2017 by the Italian Senate, is now under the examination of the Chamber of Deputies.

[31] Law decree 28 June 2013 No. 76, OJ No 150 of 28 June 2013, then converted into Law 9 August 2013, No. 99, G.U. of 22 August 2013, No. 196, concerning 'Preliminary Urgent Measures for the promotion of employment, in particular of youngsters, of social cohesion and on and other Urgent financial measures'.

[32] Commission v Italy, Case C-312/11, 4 July 2013, not yet published.

requires employers to adopt reasonable accommodations, however public employers must implement the duty "without new or increased burdens on public finance and human resources, financial and available under current legislation". This latter provision and Article 1(24) of Law No 107/2015 are clearly dictated by the very same need to contain public expenditures, in a time of harsh economic crisis. However, it is doubtful that such prescriptions comply with the CRPD.[33]

As mentioned above, Law No 107/2015 has empowered the Government to adopt a detailed legislative decree to promote the inclusion of students with disabilities in schools. Article 1(181) gives the mandate to the Government to adopt specific norms on inclusive education and reiterates the commitment towards the realization of a truly inclusive educational system within the legislative framework laid down in Law No 104/1992. It also restates the role of support teachers as the cornerstone of the Italian inclusive educational system. However, it calls the Government to redefine the role of the support teacher and of teaching staff to foster inclusion of students with disabilities, and to reform training and qualification systems for teachers. Article 1(181) also requires the Government to set forth specific provisions to ensure that curricular teachers, schools principals, and administrative staff undertake training on inclusion, thus recognizing that often one of the most obvious barriers to inclusive education are the lack of awareness and adequate training of school staff. Law No 107/2015 also takes stock the systemic flaws emerged in practice, such as the lack of continuity in the support offered by support teachers, and Article 1(181) requires the Government to make sure that pupils to enjoy the same support teacher across the course of their studies. Finally, Law No 107/2015 recognizes the dearth of data on inclusion and Article 1(181) calls the Government on elaborating specific indicators to evaluate the level of school inclusion. This latter aspect could help overcome the criticism expressed by the CRPD Committee in its COs (CRPD Committee 2016a) in relation to the lack of reliable data on the quality of education and the inclusion of students with disabilities. All in all, Article 1(181) of Law 107/2015 has given the Government a clear mandate to innovate the way in which the educational provision is administered, and to improve the way in which inclusive education is realized.

5.2. Legislative Decree No. 66/2017 on the Promotion of School Inclusion for Students with Disabilities: Lights and Shadows

Legislative Decree No. 66/2017 on school inclusion for students with disabilities (Norme per la promozione dell'inclusione scolastica degli studenti con disabilita', a norma dell'articolo 1, commi 180 e 181, lettera c), della legge 13 luglio 2015, n. 107) was approved on the 7th April 2017 and entered into force in May 2017. The process of approval was relatively short, but not smooth. The initial draft decree released by the Government on the 14th January 2017 was severely criticised by DPOs, which also questioned their lack of involvement in the process of elaboration of the text (Ferri 2018a), and encountered fierce opposition outside parliament from trade unions. In February 2017, the newly appointed Minster for Education declared that the text of the draft was to be modified in order to take into account the criticism raised, and claimed that inclusion remains a priority for the government (Ufficio Stampa MIUR 2017). On 16th March 2017, the Parliamentary Commissions in charge of the examination of the draft decree released a positive opinion on it, suggesting additional few modifications. The final text, composed by 20 articles preceded by a Preamble, along the lines traced by the Law No 107/2015, regulates the performance and quality of school inclusion indicators; certification procedures for school inclusion; school organisation, resource allocation; planning and design inclusion; and initial training of teachers for educational support. It attempts to implement the obligations laid down in the CRPD, which is mentioned in the Preamble, just after the relevant provisions of the Italian Constitution. Some provisions of the Decree have a limited innovative character, being more aimed to clarify and put order in what was already provided in various and scattered existing pieces

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[33] It also doubtful that Article 1(24) could survive a constitutional review if a case is brought, as the ICC has so far been quite clear in stating that financial constraints cannot be used as an excuse to undermine the enjoyment of the fundamental right to education.

of legislation. This is for instance the case of Article 3, which better defines the role of local and regional entities in the provision of inclusive educational settings. The Decree however, presents undoubtedly, a number of positive innovative features, which nevertheless bring limited changes to the current system.

Article 1 of the Decree laying down the aims of the decree, attempts to define "inclusive education" and affirms that it "concerns all pupils and students, meets the different educational needs and is accomplished through educational and teaching strategies aimed at developing the potential of each individual" (Article 1(1)(a)). Significantly, the Decree uses only and quite consistently the term "inclusion", and defines it in manner that can be considered compliant to the CRPD. In this respect, the Decree makes a clear attempt, on the one hand, to avoid the use of the word "school integration" (*integrazione scolastica*) used in former legislation, and, on the other hand, to fully align the terminology used by Italian law with the wording of the CRPD. The CRPD Committee has contrasted integration, as a process of placing persons with disabilities in existing mainstream educational institutions without adjustments, with inclusion (CRPD Committee 2016b). Arguably, the Decree aims to put an end at the blurring and interchangeable use of those different terms in Italian laws and policies (*inter alia* D'Alessio 2011, 2013), and to place Italian educational policies in line with the CRPD, by recalling the role of accommodating different educational needs. The wording of Article 1 evokes Article 24(2)(e) CRPD, and the obligation to provide students with disability with access to "effective individualized support measures [. . .] in environments that maximize academic and social development, consistent with the goal of full inclusion". The Decree, in Article 1(1)(c), also affirms that inclusive education is a "fundamental commitment" for all those who participate in the educational settings. This alinea somewhat matches the words of the CRPD Committee that defined inclusive education as "the result of a process of continuing and proactive commitment to eliminating barriers impeding the right to education" (CRPD Committee 2016a).[34]

Article 2(2) states that inclusion is realised through the definition of the *PEI*. In this respect, unsurprisingly, Decree No 66/2017 locates itself in continuity with Law No. 104/1992, which already prescribed the adoption of the *PEI* as inclusion tool. The rationale behind the *PEI* is that of tailoring educational strategies and tools on the need of the student with disability, and to offer students an effective education, as prescribed by Article 24 CRPD. The Decree, however, clarifies that the number of hours of support enjoyed by the student will be decided by the school director only after the *PEI* is laid down and adopted in collaboration with the family. The number of hours, hence, will not anymore be included in the *PEI* itself, which will only highlight in general terms the support needed to adequately foster the potential of the student. This innovation seems clearly aimed to limit the complaints to courts and to put an end to the avalanche of judicial cases seeking the annulment of *PEI* in front of administrative courts because of the insufficient number of hours assigned to the student. This innovation leaves to the school greater autonomy, but also greater discretion in deciding the amount of hours of support after the *PEI* is adopted. This discretion is likely to escape the limit of judicial review of administrative courts.

In addition, by virtue of Article 7(2)(h) of the Decree, the *PEI* must be subject to "to periodic reviews during the year in order to ascertain the achievement of objectives and make any changes" which may prove necessary. The *PEI* has now become integral part of the broader "Individual Project" for the person with a disability, which is elaborated by the (territorially competent) local authority and is meant to tailor health and social services to the specific needs of the person. The Decree, hence, explicitly locates inclusive education within a broader individual strategy to ensure social inclusion and independent living for people with disabilities. The "Individual Project" was already prescribed by Article 14 of the Framework Law No 328/2000[35] concerning social services addressed to individuals

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[34] See above Section 2.

[35] Law of 8 November 2000 No 328 *'Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali'* in G.U. of 13 November 2000 No 265.

and household, with a view to ensure " . . . full integration of disabled people in family and social life, as well as in educational and vocational education and training". It is now mentioned Article 1(1)(b), which clarifies the important role of schools in the elaboration of the overall individual project, in collaboration with families, DPOs, and local authorities.[36]

Interestingly, Article 1(1) also mentions reasonable accommodation as an essential component of inclusive education. The wording of this provision is explicitly inspired by the CRPD, and highly innovative. In fact, although forms of reasonable accommodation were not unknown in the school system (Ferri 2018b), previous Italian legislation on education did not mention neither define this concept.

Another significant novelty is that the number of pupils with disabilities and their gender will be considered when establishing the number of non-teaching staff for each school (Article 3(2)(b) and (c)). According to Cocconi (2017), this means that the needs of students with disabilities must be seriously and effectively taken into account when allocating administrative and teaching staff to each school institution. The reference to gender seems quite notable as it is clearly meant to tackle intersectional disadvantage, in compliance with Article 6 CRPD.[37] In addition, this provision confirms that education provision cannot be governed just on the basis of efficiency and financial viability, but must respond to the needs of students, especially those with disabilities. It limits the discretion of State in identifying the necessary organizational, financial and personal resources.

Notably, school inclusion will now form integral part of the overall evaluation process of the quality of school institutions. In other words, the level of inclusiveness of the school will become one of the parameter to assess the overall quality of the same school. This is a positive development which must be welcomed as it might potentially nudge schools to pay more attention to the way in which, in practice, they realize inclusive settings.

The Decree, however, presents a few weaknesses. Although the Decree requires all the teachers (curricular teachers) to receive training on inclusive education, their role in enhancing inclusive education remains *de facto* marginal, being that mostly ensured by the support teacher. It is also unclear what training curricular teachers are in fact expected to undertake. Article 12 lays down rules for access to the teaching career for educational support in the kindergarten and primary school, and new requirements for support teachers in secondary schools. It requires support teachers to acquire a more solid grounding in social inclusion, after the achievement of the qualifying degree in education as a basic requirement for the teaching function. This should significantly contribute to improve the quality and inclusiveness of the educational system, but, in reality, the Decree has introduced a distinction between teaching qualifications for primary and secondary schools, whose rationale remains unclear. In addition, the Decree attempts to put an end to the turnover of support teachers that endangers the learning experience of students with disabilities and has long been criticised by parents of students with disabilities. However, Article 14 limits itself to provide a generic obligation to guarantee continuous and stable support to students with disabilities. The main novelty included in Article 14 is that fix-term contracts of fully qualified support teachers can be renewed by the school upon the request of the family of the disabled student. No systemic solutions have been adopted.[38]

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[36] In this respect, Decree No 66/2017 has also intervened to amend Article 14, which, in its revised formulation, establishes that the "Individual Project" includes the care and rehabilitation services provided by the National Health Service, the Individual Education Plan provided by the school institutions, the personal services provided by the local municipality, as well as the economic allowances designed to overcome situations poverty, marginalization and social exclusion. See also Article 6 of Decree No. 66/2017.

[37] Article 6 "Women with disabilities" reads as follows: "1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention".

[38] The draft text originally included an obligation on support teachers to remain within the role for ten years. The provision raised harsh criticism because, *ex littera lege,* the provision obliged teachers to stay in the support role, but not to remain in the same school or institution, thus being unuseful to ensure continuity of education and unduly forcing teachers to remain in a role. The final text removed this provision.

The most remarkable limit of the Decree (and probably of the whole reform) is, however, that the funding, which has been assigned to concretely implement the provisions included in the Decree, remains limited. The CRPD Committee has identified among the main barriers to the implementation of Article 24 CRPD "inappropriate and inadequate funding mechanisms to provide incentives and reasonable accommodations for the inclusion of students with disabilities" (CRPD Committee 2016b). In a country where education has been traditionally poorly funded, the lack of funding seems to be an obstacle to the full implementation of the CRPD. In this context, the ambitious definition of inclusive education laid down in Article 1 of the Decree runs the risk to remain a paper tiger, and the practical problems encountered so far are likely to remain unsolved.

6. Concluding Remarks

The CRPD Committee, in its General Comment No. 4 (CRPD Committee 2016b), acknowledged that, for many persons with disabilities around the world education is still available only in segregated settings, where they are isolated from their peers and where the education they receive is of an inferior quality. In this respect, it is undeniable that Italy has provided and still provides an important example of non-discriminatory educational system to be looked at (Kanter et al. 2014). Children with disabilities in Italy have the right to access free primary education and secondary education on an equal basis with others, in the communities in which they live. The legislation, as interpreted by the Constitutional Court, ensures to persons with disabilities the effective enjoyment of the right to education. Italian courts have so far acted as watchdogs, and have played a seminal role in unveiling the inefficiencies in the implementation of the legislation. They have provided an important example of the role judicial institutions can play in the realization of more equitable and accessible educational settings, and in ensuring that a progressive legislation is actually implemented.

Despite the important role of courts, as noted by Dovigo (2016), the evolution of the Italian school system shows that the abolition of special schools does not automatically lead to the full, meaningful inclusion of all pupils in mainstream education. The persistent gaps in actually providing an inclusive education emerged in the last few years have thus prompted a legislative reform of the education system. The ratification of the CRPD has also made evident the need to fully align Italian educational policies with Article 24 CRPD. Italy has shown a political commitment to ensure inclusive education, and this cannot go unnoticed. However, the new Law No. 107/2015 and the recent Legislative Decree No. 66/2017 merely attempt, without questioning the system itself, to improve its functionality. In compliance with the principles set forth in Law No 107/2015, Decree No. 66/2017 updates, reorganizes and rationalizes the legal framework in relation to the education of people with disabilities. It introduces some notable changes, but these appear mostly "cosmetic", even though they take into account Article 24 CRPD. The Decree undoubtedly endeavours to meet (some of) the recommendations of the CRPD Committee, and to solve some of the problems that emerged in case law and that were highlighted by DPOs, especially in relation to the practical support ensured to students with disabilities by support teachers. The text presents also weaknesses, especially when it comes to ensuring training for all teachers. Overall, it remains to be seen whether the changes will be sufficient to meet overall goal of creating a truly inclusive system, and how effective the changes introduced will be. In August 2017, the Ministry has clarified that the most innovative provisions (such as those on the *PEI*) will enter into force in 2019. This delay will allow schools to become familiar with the renewed system, and to put in place all the necessary procedural changes. However, it will, once again, postpone the full realization of a truly inclusive system.

All in all, the Italian case-study shows that inclusive education requires continuous efforts. Law No. 107/2015 and its correlated legislative decree will not (most likely) conclude a process of reform of inclusive education, rather offer additional impetus to continue on the reform and ultimately achieve the objectives of the CRPD. It also highlights that progressive legislation is never sufficient alone, but must be followed by the concrete development of inclusive educational practices.

References

Addis, Paolo. 2015. Il diritto all'istruzione delle persone con disabilità: Profili sostanziali e giurisprudenziali. In *I Diritti Sociali Nella Pluralità Degli Ordinamenti*. Edited by Elisabetta Catelani and Rolando Tarchi. Napoli: Editoriale Scientifica, pp. 150–76.

Anastasiou, Dimitris, James M. Kauffman, and Santo Di Nuovo. 2015. Inclusive education in Italy: Description and reflections on full inclusion. *European Journal of Special Needs Education* 30: 429–43. [CrossRef]

Arnardóttir, Oddný Mjöll. 2011. The Right to Inclusive Education for Children with Disabilities—Innovations in the CRPD. In *Making Peoples Heard: Essays on Human Rights in Honour of Gudmundur Alfredsson*. Edited by Eide Asbjørn, Jakob Th Möller and Ineta Ziemele. Leiden-Boston: Martinus Nijhoff, pp. 197–228.

Blando, Felice. 2017. Soggetti Disabilie Istruzione: La Lotta per il Diritto. Federalismi.it, 10/2017. Available online: http://www.federalismi.it/ApplOpenFilePDF.cfm?artid=34010&dpath=document&dfile=15052017132236.pdf&content=Soggetti+disabili+e+istruzione+-+stato+-+dottrina+-+ (accessed on 30 September 2017).

Broderick, Andrea. 2014. The Right to Inclusive Education: Article 24 of the UN Convention on the Rights of Persons with Disabilities and the Irish Experience. In *The Irish Yearbook of International Law*. London: Bloomsbury Publishing, pp. 25–60.

Busatta, Lucia. 2016. L'universo delle disabilità: Per una definizione unitaria di un diritto diseguale. In *Le Definizioni nel Diritto. Atti Delle Giornate di Studio 30–31 Ottobre 2015*. Edited by Fulvio Cortese and Marta Tomasi. Napoli: Editoriale Scientifica, pp. 335–64.

Caldin, Roberta. 2013. Current Pedagogic Issues in Inclusive Education for the Disabled. *Pedagogia Oggi* 2: 11–25.

Cera, Rachele. 2015. National Legislations on Inclusive Education and Special Educational Needs of People with Autism in the Perspective of Article 24 of the CRPD. In *Protecting the Rights of People with Autism in the Fields of Education and Employment: International, European and National Perspectives*. Edited by Della Fina Valentina and Rachele Cera. Cham, Heidelberg, New York, Dordrecht and London: Springer, pp. 79–108.

Cocconi, Monica. 2015a. La sfida decisiva dell'autonomia scolastica. *Giornale di Diritto Amministrativo* 4: 661.

Cocconi, Monica. 2015b. Gli ingredienti necessari per la ricetta di una «buona» autonomia scolastica. *Istituzioni del Federalismo* 3: 647.

Cocconi, Monica. 2017. Il Compimento del Cantiere Della C.D. Buona Scuola—Il Commento. *Giornale di Diritto Amministrativo* 4: 461.

Colapietro, Carlo. 2011. *Diritti dei Disabili e Costituzione*. Napoli: Editorile Scientifica.

CRPD Committee. 2016a. Concluding Observations on the Initial Report of Italy. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx (accessed on 20 October 2017).

CRPD Committee. 2016b. General Comment No 4 Article 24: Right to Inclusive Education (Adopted 26 August 2016). Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx (accessed on 20 September 2017).

CSS. 2016. Coordinamento Nazionale Famiglie di Disabili Gravi e Gravissimi. Shadow Report on Italy. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx (accessed on 20 September 2017).

D'Alessio, Simona. 2011. *Inclusive Education in Italy*. Rotterdam: Sense.

D'Alessio, Simona. 2013. Inclusive education in Italy: A reply to Giangreco, Doyle and Suter 2012. *Life Span and Disability* 16: 95–120.

De Beco, Gauthier. 2014. The right to inclusive education according to article 24 of the un convention on the rights of persons with disabilities: Background, requirements and (remaining) questions. *Netherlands Quarterly of Human Rights* 32: 263–87. [CrossRef]

Della Fina, Valentin. 2017. Article 24. In *The United Nations Convention on Human Rights: A Commentary*. Edited by Della Fina Valentina, Cera Rachele and Palmisano Giuseppe. Cham: Springer.

Devecchi, Cristina, Filippo Dettori, Mary Doveston, Paul Sedgwick, and Johnston Jament. 2012. Inclusive Classrooms in Italy and England: The Role of Support Teachers and Teaching Assistants. *European Journal of Special Needs Education* 27: 171–84. [CrossRef]

Dovigo, Fabio. 2016. *None Excluded. Transforming Schools and Learning to Develop Inclusive Education, Conference Proceedings*. Bergamo: University of Bergamo, p. 18.

Ferrari, Giulia. 2012. Insegnanti di sostegno per gli alunni portatori di handicap. *Giornale di Diritto Amministrativo* 12: 1248.

Ferri, Delia. 2014. Legal Scholarship and Disability in Italy. Recent Developments and New Perspectives. In *European Yearbook of Disability Law*. Edited by Lisa Waddington, Eilionoir Flynn and Gerard Quinn. Cambridge: Intersentia.

Ferri, Delia. 2017. Inclusive Education in Italy: A Legal Appraisal 10 Year after the Signature of the UN Convention on the Rights of Persons with Disabilities. *Ricerche di Pedagogia e Didattica—Journal of Theories and Research in Education* 12: 1–22.

Ferri, Delia. 2018a. The Past, Present and Future of the Right to Inclusive Education in Italy. In *The Right to Education of People with Disabilities CUP*. Edited by Shivaun Quinlivan, Gauthier De Beco and Janet Lord. Cambridge: Cambridge University Press, Forthcoming.

Ferri, Delia. 2018b. *The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts, OUP*. Edited by Lisa Waddington and Anna Lawson. Oxford: Oxford University Press, Forthcoming.

Ferri, Delia, and Anna Lawson. 2016. Reasonable Accommodation for Disabled People in Employment Contexts. Available online: http://ec.europa.eu/justice/discrimination/files/reasonable_accommodation_in_employment_final2_en.pdf (accessed on 30 September 2017).

Grimaldi, Emiliano, and Roberto Serpieri. 2012. The transformation of the Education State in Italy: A critical policy historiography from 1944 to 2011. *Italian Journal of Sociology of Education* 4: 146–80.

Ianes, Dario, Heidrun Demo, and Francesco Zambotti. 2014. Integration in Italian schools: Teachers' perceptions regarding day-to-day practice and its effectiveness. *International Journal of Inclusive Education* 18: 626–53. [CrossRef]

IDF. 2016a. First Alternative Report to the UN Committee on the Rights of Persons with Disabilities. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx (accessed on 20 September 2017).

IDF. 2016b. Italian Disability Forum's submission for the list of issues on Italy's State Report to the UN Committee on the Rights of Persons with Disabilities. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx (accessed on 20 September 2017).

Istituto Nazionale di Statistica (ISTAT). 2016. L'integrazione Degli Alunni con Disabilità Nelle Scuole Primarie e Secondarie di Primo Grado: Anno Scolastico 2015–2016 (ISTAT, 21 December 2016). Available online: www.istat.it/it/archivio/194622 (accessed on 20 September 2017).

Kanter, Arlene S., Michelle L. Damiani, and Beth A. Ferri. 2014. The Right to Inclusive Education under International Law: Following Italy's Lead. *Journal of International Special Needs Education* 17: 21–32. [CrossRef]

Kayess, Rosemary, and Phillip French. 2008. Out of darkness into light? Introducing the convention on the rights of persons with disabilities. *Human Rights Law Review* 8: 1–34. [CrossRef]

Lottini, Micaela. 2011. Scuola e disabilità. I riflessi della sentenza 80 del 2010 della Corte costituzionale sulla giurisprudenza del giudice amministrativo. *Il Foro Amministrativo Tar* 10: 2403–9.

Manca, Luigi. 2010. Articolo 24. In *La Convenzione ONU sui Diritti Delle Persone con Disabilità*. Edited by Sergio Marchisio, Rachele Cera and Valentina Della Fina. Roma: Aracne, pp. 329–42.

OECD (Organisation for Economic Co-operation and Development). 2007. *Students with Disabilities, Learning Difficulties and Disadvantages: Policies, Statistics and Indicators*. Paris: OECD.

OHCHR. 2013. Thematic Study on the Right of Persons with Disabilities to Education. Available online: http://www.ohchr.org/EN/Issues/Disability/Pages/ThematicStudies.aspx (accessed on 20 September 2017).

Palmer, Jason. 2013. The Convention on the Rights of Persons with Disabilities: Will Ratification Lead to a Holistic Approach to Postsecondary Education for Persons with Disabilities? Available online: https://ssrn.com/abstract=2243137 (accessed on 20 September 2017).

Penasa, Simone. 2014. La persona e la funzione promozionale della scuola: La realizzazione del disegno costituzionale e il necessario ruolo dei poteri pubblici. I casi dell'istruzione delle persone disabili e degli alunni stranieri. In *Tra Amministrazione e Scuola. Snodi e Crocevia del Diritto Scolastico Italiano*. Edited by Fulvio Cortese. Napoli: Edizionio Scientifiche Italiane.

Rossi, Emanuele, Addis Paolo, and Biondi Dal Monte Francesca. 2016. La Libertà di Insegnamento e il Diritto All'istruzione nella Costituzione Italiana. Rivista AIC. April 18. Available online: http://www.osservatorioaic.it/la-libert-di-insegnamento-e-il-diritto-all-istruzione-nella-costituzione-italiana.html (accessed on 20 September 2017).

Seatzu, Francesco. 2008. La Convenzione delle Nazioni unite sui diritti delle persone disabili: I principi fondamentali. *Diritti Umani e Diritto Internazionale* 3: 535–59.

Shaw, Belinda. 2014. Inclusion or choice? Securing the right to inclusive education for all. In *Human Rights and Disability Advocacy*. Edited by Maia Sabatello and Marianne Schulze. Philadelphia: University of Pennsylvania Press, pp. 60–68.

Siclari, Domenico. 2015. Riflessioni sullo statuto giuridico della disabilità nell’ordinamento italiano. *Il Diritto Dell’economia* 28: 553–73.

Troilo, Silvio. 2012. Tutti per uno o uno contro tutti? Il diritto all’istruzione e all’integrazione scolastica della persona disabile di fronte alla molteplicità dei soggetti obbligati (ed alla scarsità delle risorse disponibili). In *Scritti in Memoria di Alessandra Concaro*. Edited by Giuseppe D’Elia, Giulia Tiberi and Maria Paola Viviani Schlein. Milano: Giuffrè, pp. 753–80.

Troilo, Silvio. 2016. I ‘nuovi’ diritti sociali: La parabola dell’integrazione scolastica dei disabili tra principi e realtà. In *La Democrazia Costituzionale tra Nuovi Diritti e Deriva Mediale*. Edited by Giampietro Ferri. Napoli: Edizioni Scientifiche Italiane, pp. 57–81.

Ufficio Stampa MIUR. 2017. Miglioreremo Decreto su Inclusione Scolastica. Studentesse e Studenti con Disabilità Devono Avere pari Opportunità Formative (Ministero dell’Istruzione, Dell’Università e Della Ricerca, 9 February 2017). Available online: http://hubmiur.pubblica.istruzione.it/web/ministero/cs090217quater (accessed on 20 October 2017).

UNESCO. 2005. Guidelines for Inclusion: Ensuring Access to Education for All. Available online: http://unesdoc.unesco.org/images/0014/001402/140224e.pdf (accessed on 20 October 2017).

5

Victims of Violence: The Forced Sterilisation of Women and Girls with Disabilities in Australia

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Abstract: This paper considers the issue of forced sterilisation of women and girls with disabilities in the Australian context. It examines the history and ideological underpinning of this practice, the current Australian regime and the present rationales for court or tribunal authorisation of a sterilising procedure. It is by no means an exhaustive coverage, but aims to critically analyse the current system and make recommendations for reform of Australian law and policy. This paper ultimately concludes that the practice of forced sterilisation in Australia should be criminalised, save for exceptional circumstances.

Keywords: disability; human rights; sterilisation; violence; medical procedures; legal capacity; consent; women; girls; Convention on the Rights of Persons with Disabilities

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1. Introduction

In recent years, the forced sterilisation of people with disabilities in Australia has been a topic of considerable focus and debate, both nationwide and internationally. Despite a barrage of recommendations from people with disabilities, their allies and international bodies to criminalise forced sterilisation, this practice is still legal and sanctioned in Australia. This paper will focus on the forced sterilisation of girls and women as they are disproportionately affected by this procedure (Frohmader 2013). It is an intersectional issue and a gendered practice, the 'result of both gender and disability-based discrimination' (Australian Human Rights Commission 2013, p. 3).

The current legislative and policy framework in Australia permits gross violations of human rights and dignity to occur on a regular basis. Furthermore, consistently authorising this form of violence puts Australia in breach of its international human rights obligations. As such, this paper contends that the involuntary sterilisation of women and girls with disabilities in Australia should be criminalised in all circumstances, save for exceptional situations in which an individual is completely unable to make a decision or, for minors, where there is a serious risk to an individual's health or life. The inadequacy of the current system necessitates a new regime that aligns more closely with the social model of disability: rather than viewing the individual as the problem, attention should be paid to reducing the societal or environmental barriers that lead to the factors that underpin the justifications for the sterilisation of women and girls with disabilities (Shakespeare 2002).

Section 2 of this paper provides an overview of forced sterilisation in Australia, including its recent history and socio-political basis. Section 3 details Australia's human rights obligations under international law, and examines how specific provisions under the *Convention on the Rights of Persons with Disabilities* (Convention on the Rights of Persons with Disabilities 2008a) (CRPD) relate to the practice of forced sterilisation. Sections 4 and 5 outline the current Australian legislative framework in which applications for forced sterilisation of women and girls can be authorised by a court or tribunal and the rationales for authorising forced sterilisation. This background paves the way for a critical analysis of the current Australian system, which is provided in Section 6. This section addresses the ultimate question: should the forced sterilisation of women and girls with disabilities be made illegal in Australia? After asserting that it should, Section 7 details the author's recommendations for legislative and policy reform in Australia.

The forced sterilisation of women and girls with disabilities in Australia must be put to an end. It is time for the Australian Government to jettison their callous indifference towards the life-long impact on individuals that are affected by this practice and bring Australia in line with its human rights obligations.

2. Overview of Forced Sterilisation in Australia

Women with Disabilities Australia (WWDA) have defined forced sterilisation as the 'performance of a procedure which results in sterilisation in the absence of the free and informed consent of the individual who undergoes the procedure' (Frohmader 2013, p. 22). This definition is inclusive of situations in which sterilisation has been authorised by a third party such as a parent, legal guardian, court, tribunal or judge (Frohmader 2013). The CRPD defines persons with disabilities as those who have 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (Convention on the Rights of Persons with Disabilities 2008a, article 1).

It is broadly recognized that sterilisation is a 'process or act that renders a person unable to produce children' (Senate Community Affairs References Committee 2013, p. 6). Various kinds of procedures constitute a sterilising practice. These include permanent or irreversible sterilising procedures, such as a hysterectomy (removal of the uterus and sometimes the cervix, fallopian tubes, ovaries or part of the vagina), tubal litigation (blocking or closing of the fallopian tubes) and endometrial ablation (laser technology used to destroy the uterine lining for purposes of stopping menstruation). This definition also includes non-permanent contraceptive measures such as oral contraceptives, diaphragms, intrauterine devices and long acting reversible contraceptives such as injections (Depo Provera) and implants (Implanon) (Senate Community Affairs References Committee 2013).

For over 20 years, disability advocates have been demanding the Australian Government undertake comprehensive reforms to stop the involuntary and coerced sterilisation of women and girls with disabilities, and develop policies and programs that allow women and girls with disabilities to be afforded respect of their human rights on an equal basis with others (Frohmader 2013). There have been numerous studies undertaken and reports published recommending reform in the sterilisation sphere in Australia. In 1994, the Family Law Council (Family Law Council 1994) concluded that a uniform and consistent approach was needed for all children regardless of their geographical location within Australia. The Council also stated that sterilisation of a child should only be authorised if it is necessary to save the child's life or prevent serious damage to their health (Family Law Council 1994). The Australian Human Rights Commission published reports in 1997 and 2001 propounding that the number of sterilisations being performed on children and women with disabilities in Australia was greater than those that had been authorised by a court or tribunal and that it was clear that the law was failing to protect individuals from involuntary sterilisation (Brady and Grover 1997; Brady et al. 2001). These reports did trigger some minor changes, such as Medicare amending their policies to require that claims for sterilisation of children be accompanied by a court order or medical details of the need for the procedure (Brady et al. 2001). However, there have been no substantial changes made to legislation or policy regarding the forced sterilisation of women and children with disabilities.

The Australian Government has spent a considerable amount of time investigating the issue of forced sterilisation of women and girls with disabilities. The main concern of public policy in this area has focused on "piecemeal development of mechanisms, protocols and guidelines in an attempt to 'minimise the risk of unauthorised sterilisations occurring'" (Standing Committee of Attorneys-General 2004 as cited in Frohmader 2013, p. 26). In December 2000, the Government tabled in the Senate the report '*Sterilisation of women and young girls with an intellectual disability*' which, on the basis of data from the Australian Institute of Health and Welfare, submitted that, between 1993 and 1999, there were few sterilisations of girls with disabilities in Australia (Senate Community Affairs References Committee 2013). In reality, there has been a substantial dearth of quantitative research undertaken in regards to forced sterilisation. Brady et al. (2001) reported in 2001 that 28 authorisations occurred between 1992 and 1998, with eight rejections. In contrast, Brady and Grover (Brady and Grover 1997) adduced Health Insurance Commission data to claim that at least 1045 women and girls had been sterilised during the same period, and noted that there would be others who were treated in public hospitals without attracting Medicare benefits. This lack of concrete data has led to considerable uncertainty around the exact frequency of the practice of forced sterilisation in Australia, a concern that has not been addressed by the Australian Government. In August 2003, Australian Governments, through the then *Standing Committee of Attorneys-General* (SCAG) agreed that a nationally uniform framework for the authorisation of the sterilisation of children was required (Frohmader 2013). From 2003 to 2007, notwithstanding strong resistance from human rights and disability advocates, the SCAG developed proposed legislation that aimed to regulate the authorisation of sterilisation of children with a 'decision-making disability', rather than make the practice of sterilisation of children illegal (Frohmader 2013). In November 2006, the SCAG released a draft bill that set out procedures that jurisdictions could adopt in authorising the sterilisation of children who have an intellectual disability[1]. Ultimately, however, the SCAG abandoned this draft Bill in 2008, declaring that there would be limited benefit from developing model legislation. Instead, the Government 'agreed to review current arrangements to ensure that all tribunals or bodies with the power to make orders concerning the sterilisation of minors with an intellectual disability are required to be satisfied that all appropriate alternatives to sterilisation have been fully explored and/or tried before such an order is made' (Standing Committee of Attorneys-General 2008, p. 7).

There is no evidence to date that those reviews were conducted. In 2009, the Australian Government formally declared to the UN that a comprehensive review undertaken in Australia showed that sterilisations of children with an intellectual disability had declined since 1997 to very low numbers (Australian Government 2009 as cited in Frohmader 2013). However, there was again no evidence to support that a comprehensive review had been undertaken (Frohmader 2013).

Furthermore, the issue of forced sterilisation in Australia has received ample international scrutiny. Since 2005, UN treaty monitoring bodies have continuously and formally recommended that the Australian Government enact uniform national legislation outlawing the sterilisation of girls, except where there is a serious threat to their health or life, and adult women with disabilities without their free and informed consent. These bodies include the Committee on the *Convention on the Rights of the Child* (Convention on the Rights of the Child 1990) (CRC), the Committee on the *Convention on the Elimination of all Forms of Discrimination Against Women* (CEDAW) (Convention on the Elimination of all Forms of Discrimination against Women 1981) and the UN Human Rights Council (Committee on the Rights of the Child 2012; Committee on the Elimination of Discrimination against Women 2010; Committee on the Rights of the Child 2005; UN General Assembly Human Rights Council 2011). The Australian Government is yet to comply with any of the recommendations (Frohmader 2013). In 2011, after WWDA lodged a formal complaint, UN Special Rapporteurs Anand Grover and Rashida Manjoo wrote to the Australian Government seeking a formal response on the issue of forced sterilisation (Frohmader 2013, Appendix 2). The Government's response confirmed the absence of a uniform national approach to the authorisation of sterilisation of women and girls with disabilities, and reinforced the Government's view that there are situations in which it can and should be permitted (Frohmader 2013, Appendix 3). International medical bodies, such as the International Federation of Gynaecology and Obstetrics, World Medical Association, International NGO Council on Violence against Children and the WHO, have also become involved, developing new protocols and calls for action to eliminate the practice of forced sterilisation (World Medical Association and the

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[1] *Children with Intellectual Disabilities (Regulation of Sterilisation) Bill* 2006.

International Federation of Health and Human Rights Organisations 2011; International NGO Council on Violence against Children 2012; World Health Organisation 2014). Despite the abundance of debate and discussion around this issue, the forced sterilisation of women and girls with disabilities remains legal and practiced in Australia (Frohmader 2014).

It is also worrying to note that, often due to the cost and formality of court processes in Australia, families and carers wishing to have an individual with a disability sterilised are starting to circumvent the formal procedures. In a 2003 Four Corners report, Peter and Dot King spoke of how they had their 15-year-old daughter Trish sterilised in secret. She was booked into the hospital under her mother's name, and the procedure was carried out without any substantial questions being asked (ABC 2003a). Dr and Mrs Carter, in their submission to the recent Senate inquiry, stated that they 'are aware of instances where parents have taken their daughters to Thailand or New Zealand to have a hysterectomy because their request to have a hysterectomy performed in Australia was rejected' (Carter and Carter 2013, p. 3). It is clear that the current law is continually failing to protect vulnerable individuals at risk of forced sterilisation in numerous ways and that steps need to be taken to ensure that the rights of these individuals are protected on an equal basis with others.

3. International Obligations

WWDA have declared that 'forced sterilisation clearly breaches every international human rights treaty and declaration to which Australia is a party' (Frohmader 2013, p. 70). These include the CRPD, the CRC, the CEDAW, the *International Convention on Civil and Political Rights* (International Convention on Civil and Political Rights 1976), the *International Covenant on Economic, Social and Cultural Rights* (International Covenant on Economic, Social and Cultural Rights 1976) and other key international and national standards and frameworks (Frohmader 2013). This report will focus on the CRPD, in particular how allowing involuntary sterilisation to continue puts Australia in breach of articles 12 and 16.

Australia ratified the CRPD on 17 Australia 2008 and the Optional Protocol on 21 August 2009. It must be noted that in entering into the treaty, Australia declared its view that the Convention allows for substituted decision-making and compulsory medical treatment (Convention on the Rights of Persons with Disabilities 2008b). Whilst the Committee on the CRPD (the Committee) may make recommendations that the Government in Australia take specific action, the CRPD has no binding effect in Australia. To date, no domestic legislation has been enacted that protects the rights affirmed under the CRPD. Whilst bodies such as the Committee can be influential in shaping Australia's policy, it is ultimately the Australian Government's responsibility to enact legislation to enforce Australia's international obligations.

3.1. Article 12: Equal Recognition before the Law

Article 12 provides that persons with disabilities have the right to recognition everywhere as persons before the law. This includes recognising that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. This positive right requires States to take appropriate measures to provide access for persons with disabilities to the support they may require in exercising their legal capacity. It also requires States to ensure that effective safeguards are in place in all measures that relate to the exercise of legal capacity to prevent abuse of human rights (Convention on the Rights of Persons with Disabilities 2008a).

Numerous stakeholders hold the view that article 12 prohibits substituted decision-making. The Committee has clearly stated that article 12 mandates the replacement of substituted decision-making systems with supported decision-making (Committee on the Rights of Persons with Disabilities 2011). WWDA submit that article 12 means that 'an individual's right to decision-making cannot be substituted by decision-making of a third party, but each individual without exception has the right to make their own choices and to direct their own lives, whether in relation to living arrangements, medical treatment or family relationships' (Frohmader 2013, p. 71). People With Disabilities Australia

(People with Disabilities Australia 2013, p. 18) argue that the 'implementation of article 12 requires establishing supported decision-making alternatives to substituted decision-making regimes [and] effective safeguards to be introduced in relation to supported decision-making arrangements to prevent abuse in accordance with international human rights law'. Flynn and Arstein-Kerslake (Flynn and Arstein-Kerslake 2014) also propound that article 12 requires a proactive approach from state parties, where measures are put in place to support individuals in the exercise of their legal capacity, rather than assessing their mental capacity before their decisions will be legally recognized. This article therefore prohibits substituted decision-making regimes, such as that provided in the *Guardianship and Administration Act 1986* (Vic)[2] (Guardianship Act) or at common law in relation to the sterilisation of girls with disabilities.

3.2. Article 16: Freedom from Exploitation, Violence and Abuse

Article 16 requires that States take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects. It also compels States to provide information, education, assistance and support for persons with disabilities and their families on how to avoid, recognise and report instances of exploitation, violence and abuse. Further, it mandates that States put in place effective legislation and policies, including those focused on the protection of women and children, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted (Convention on the Rights of Persons with Disabilities 2008a).

As will be argued later in this paper, forced sterilisation can be classified as a form of violence. Thus, article 16 requires state parties to take measures to protect individuals from this practice. This includes providing education and support and enacting legislation to prohibit occurrences of forced sterilisation. Under the CRPD, therefore, state parties are prevented from facilitating procedures, such as those in place in Australia, in which the practice of forced sterilisation can be lawfully authorised.

3.3. Other Relevant Articles

Article 23(1)(c) requires States to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that persons with disabilities, including children, retain their fertility on an equal basis with others (Convention on the Rights of Persons with Disabilities 2008a). Allowing women and children with disabilities to be sterilised without their consent clearly violates this provision, as the same law does not affect, on an equal basis, women and girls without disabilities.

4. Australian Legislative Framework and Court Processes

Australia's international treaty obligations are given effect through federal, state and territory legislation. There is much disparity in the legislation and court processes between the states and territories. As such, this paper will focus solely on the Victorian jurisdiction.

4.1. Girls with Disabilities

In Victoria, jurisdiction has not been expressly conferred on any Australian court or tribunal to hear child sterilisation cases. The sterilisation of children with disabilities is dealt with by the common law following the leading decision in *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion's Case*)[3]. In that case, the High Court heard an application for

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[2] *Guardianship and Administration Act 1986* (Vic).

[3] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion's Case*).

the sterilisation of a 13-year-old girl with an intellectual disability. Marion's parents, who brought the application, were concerned about fertility control and menstruation with its psychological and behavioural problems[4]. The High Court held that, in cases where the child is not 'legally competent', the Family Court is required to give approval before a child is sterilised, unless sterilisation occurs because of an appropriate 'therapeutic' procedure carried out to address an actual health issue (Office of the Public Advocate 2013, p. 6). This case confirmed that the Family Court's child welfare jurisdiction under section 67ZC of the *Family Law Act 1975* (Cth)[5] (Family Law Act) empowers the court to make orders for the sterilisation of a child (Senate Community Affairs References Committee 2013). It also established that it is only for the Courts to decide on such fundamental questions of human rights as the right to reproduce, rather than parents, carers or medical practitioners (Dowse 2004). There were two main reasons for this. Firstly, the risk of making the wrong decision is significant, and secondly, the consequences of a wrong decision would be particularly grave.[6] Before making an order for sterilisation, the Family Court must be satisfied that two conditions are met. First, that the sterilisation is, in the circumstances of the particular case, in the child's best interests, and second, that alternative and less invasive procedures have failed or it is certain that no other procedure or treatment will work (Senate Community Affairs References Committee 2013). Sections 60CB to 60CG of the Family Law Act outline how a court is to determine what is in the child's best interests. However, it must be noted that these provisions were not designed specifically for sterilisation cases; rather, they were enacted to deal with situations in which matters such as where the child will live are being decided (Senate Community Affairs References Committee 2013). Therefore, in hearing child sterilisation cases, the Family Court will apply the general principles regarding the best interests and the welfare of the child in Part VII of the Family Law Act, the factors detailed in Marion's Case in determining that particular child's best interests, as well as the *Family Law Rules 2004* (Cth)[7] developed to govern applications for 'medical procedures'.

Marion's Case was thought to be progress in the human rights sphere, as it considered the rights of children with disabilities through a 'best interests' lens and aimed to prevent parents from being able to sterilise their child without an order of the court. One of the intentions of the decision was to prevent unnecessary sterilisations (Rhoades 1995; ABC 2003b). However, Marion was quickly deemed 'legally incapable' and at no point did any member of the proceedings attempt to understand what Marion's wishes were. This is a trend in most court decisions on sterilisation, and there has been negligible deliberation in the judgements over this issue compared to decisions in cases relating to children without a disability (Steele 2008). Furthermore, the majority of the High Court held that the views of the parents are a relevant consideration for the Family Court, and anticipated that the outcome in sterilisation cases would ordinarily coincide with their wishes[8] (Rhoades 1995). The extent to which Marion's Case tangibly progressed the rights of people with disabilities is therefore debatable, as there was never any discussion of the empowerment of people with disabilities to make decisions. It has also been argued that judicial decisions following Marion's Case have failed to give full effect to its promise. There has been concern that the legal requirements set out in Marion's Case have not consistently been followed and that some sterilisations are being performed illegally with parent approval only, as opposed to court approval (Office of the Public Advocate 2013). Further, it has been said that within the medical practice the distinction between 'therapeutic' and 'non-therapeutic' sterilisations has become blurred (Naik 2012, p. 453). The Family Court has been criticised for effectively ignoring its own rhetoric regarding the rights of women and girls with disabilities and reverting to an archaic and discredited model (Rhoades 1995). It is clear that both legislative reform and greater guidance for

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[4] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion's Case*).

[5] *Family Law Act 1975* (Cth).

[6] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion's Case*).

[7] *Family Law Rules 2004* (Cth).

[8] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion's Case*), at p. 260.

decision makers are required to ensure the rights of women and girls with disabilities do not continue to be violated.

4.2. Women with Disabilities

For women over 18 with disabilities, court proceedings differ across States and Territories. In Victoria, the Guardianship Act (s. 39) empowers the Victorian Civil and Administrative Tribunal (VCAT) to make an order giving consent to special medical treatment for persons 18 years of age or older who are incapable of giving consent to the proposed treatment. 'Special procedure' includes any procedure that is intended or is reasonably likely to have the effect of rendering a person permanently infertile (Guardianship Act, s. 3). A person is considered to be incapable of providing consent if he or she is incapable of understanding the general nature and effect of the proposed procedure or treatment, or is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment (Guardianship Act, s. 36). If it is found that the person does not have capacity to consent, the court or tribunal is to decide whether to authorise the sterilization (Guardianship Act, s. 39).

The tribunal may consent to the carrying out of a special procedure only if it is satisfied that the person is incapable of giving consent and is not likely to be capable, within a reasonable time, of giving consent and the special procedure would be in the person's best interests (Guardianship Act, s. 42E). In determining a patient's best interests, the tribunal must take into account the person's wishes and the wishes of any relative, the consequences if the treatment is not performed, any alternative treatment available, the nature and degree of any significant risks associated with the treatment or any alternative treatment and whether the treatment is to be carried out only to promote and maintain the person's health and wellbeing (Guardianship Act, s. 38). By requiring the tribunal to consider the views of relatives, this legislation explicitly incorporates the opinions and needs of persons other than the individual concerned in the determination of *their* best interests (Senate Community Affairs References Committee 2013).

It is an offence subject to imprisonment for two years and/or a fine of up to $36,400 for a registered practitioner to conduct a special procedure without tribunal consent (Guardianship Act, s. 42G). However, it is not an offence, or professional misconduct, for the registered practitioner to act in response to a medical emergency or in good faith reasonably believing that consent had been obtained (Guardianship Act, s. 42A). It is also an offence to purport to give consent to special medical treatment. A person who gives consent to treatment knowing that he or she is not authorised to do so is guilty of an offence subject to a fine not exceeding 20 penalty units (Guardianship Act, s. 42). In 2016, this means the maximum fine would be around $3300, hardly an excessive figure (Victorian State Government 2016).

Additional regulatory requirements in relation to sterilisation exist at the State and Territory level. States and territories have adopted the Australian Guardianship and Administration Council's *Protocol for Special Medical Procedures (Sterilisation)*[9] (the Protocol), which applies to both women and girls and is intended to promote consistency in similar sterilisation cases regardless of the jurisdiction in which the case is heard. Phase 2 of the Protocol requires tribunals to adopt a two-stage inquiry process. First, the tribunal must consider whether an individual has the capacity to consent to sterilization (the Protocol, cl. 5.8). This involves determining whether the person understands the nature and effect of their decision, whether they are freely and voluntarily making a decision and whether they can communicate their decision in some way (the Protocol, cl. 5.11). However, even though the Protocol requires tribunals to consider capacity as a threshold question, it does not prohibit tribunals from hearing a case where it is determined that the individual does have capacity (Senate Community Affairs References Committee 2013). Second, before authorising a procedure, the tribunal must consider

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[9] *Protocol for Special Medical Procedures (Sterilisation).*

whether sterilisation is required, in the sense that other options have been explored and decided against (the Protocol, cl. 5.17).

5. Current Rationales for the Sterilisation of Women and Girls with Disabilities

WWDA classifies the main contemporary justifications for the sterilisation of a woman or girl with a disability into four broad categories: the genetic/eugenics argument, the good of the state, community or family argument, the incapacity for parenthood argument and the prevention of sexual abuse argument (Frohmader 2013). These rationales are all strongly rooted in the medical model of disability. The medical model views disability as a deficiency or disorder that is a tragedy and causes dependence on others. It sees disability as an essential trait of the person (Parker 2012). Under this model, the focus is placed on 'diagnosis and treatment of what are seen as cognitive and adaptive deficits, measured against norms of intelligence and independent functioning' (Parker 2012, p. 522).

5.1. The Genetic/Eugenic Argument

Historically, the rationale for sterilisation of women and girls with disabilities was a pseudo-scientific theory called eugenics. The aim of sterilisation under the eugenics movement was to stop non-productive members of society from reproducing for the 'benefit' of the rest of society (Gallichan 1929 and Ford 1996 as cited in Spicer 1999). Whilst this justification has been eradicated from legislation in most countries, remnants of it still remain within the attitudes of some sectors of the community (Frohmader 2013). This argument centres on the misconceived fear that women with disabilities will produce children with undesirable genetic 'defects'. The contemporary version of this justification disguises itself behind a 'best interests' veil, attempting to smother any trace of its connections to the Nazi era and genetic 'cleansing'. A recent example is the 2004 case of *BH v CCH* [2004][10] FamCA 496 in which the Family Court authorised the sterilisation of a 12-year-old girl with an intellectual disability and Tuberous Sclerosis. There was a 50% chance that any child she had would be born with Tuberous Sclerosis (TS). Although one in two people born with TS will lead a 'normal' life, the Court nonetheless considered that this was a factor weighing in favour of sterilisation.

5.2. The Good of the State, Community or Family Argument

This justification focuses on the 'burden' that women and girls with disabilities and their potentially disabled children place on the resources and services provided by the state and community (Frohmader 2013). It is also based on the burden of care that the management of menstruation and contraception places on families and carers due to 'conditions' such as challenging or unmanageable behaviour and hygiene issues (Steele 2008; Frohmader 2013). There have been numerous instances where the Court has authorised the sterilisation of women and girls with disabilities for menstrual management[11] (*Attorney-General (QLD) v Parents (In Re S)* (1989) 13 Fam Lr 660; *Re Angela* [2010] FamCA 98[12]; *BH v CCH* [2004] FamCA 496).

The most concerning aspect of this rationale is that it is being used to authorise sterilisations before the individual has even begun menstruating. In *Re Angela* [2010] FamCA 98, the Family Court authorised the hysterectomy of an 11-year-old girl with Rett Syndrome to prevent menstruation. In *Re Katie* (1995) 128 FLR 194,[13] a 15-year-old girl was sterilised at the onset of her menstruation. In *Attorney-General (QLD) v Parents (In Re S)* (1989) 13 Fam Lr 660 and *Re M (An Infant)* (1992) 106 FLR 433,[14] 12-year-old and 15-year-old girls, respectively, were sterilised before they had begun menstruating. Stella Young has also divulged the story of how at the age of four, when being treated

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[10] *BH v CCH* [2004] FamCA 496.

[11] *Attorney-General (QLD) v Parents (In Re S)* (1989) 13 Fam Lr 660.

[12] *Re Angela* [2010] FamCA 98.

[13] *Re Katie* (1995) 128 FLR 194.

[14] *Re M (An Infant)* (1992) 106 FLR 433.

for a broken leg, her doctor had suggested to her parents that they perform a hysterectomy to prevent having to deal with the 'inconvenience of menstruation' in the future (Young 2013, p. 1).

As WWDA have promulgated, 'the denial of a young women's human rights through the performance of an irreversible medical intervention with long term physical and psychological health risks is wrongly seen as the most appropriate solution to the social problem of lack of services and support (Frohmader 2013, p. 42). Sterilisation is often easier, faster and less costly than providing the programs, services and supports to enable young women and girls with disabilities to obtain and understand information and competencies about their bodies, relationships, sex, safety and rights (Frohmader 2013). Evidence indicates that the concerns and problems that arise at the onset of menstruation of women and girls with disabilities are often the same types of concerns as for women and girls without disabilities (Brady and Grover 1997 as cited in Spicer 1999). It also indicates that even individuals with high support needs can be accommodated with approaches similar to those taken for non-disabled women (Frohmader 2013). When parents and carers are given the necessary resources and support, the justification of menstrual management loses credibility.

The flip side to this argument focuses on the loss of dignity and reduction in quality of life associated with an inability to manage menstruation. Carter and Carter (Carter and Carter 2013, p. 1) stated that, 'there are many moderate-severe intellectually disabled women who are extremely distressed due to their inability to cope with menstruation leading to loss of dignity'. They stress that menstruation can cause a significant reduction in quality of life and hence damage to an individual's emotional or psychological health. They give the example of instances where 'an intellectually disabled woman has remained in the bathroom at the supported employment with blood over her clothes, due to the onset of menstruation' (Carter and Carter 2013, p. 1).

5.3. The Incapacity for Parenthood Argument

This rationale is based on widely held societal attitudes that women with disabilities, especially intellectual disabilities, are incapable of being good parents. This ideology creates pressure to prevent pregnancy in women with disabilities (Frohmader 2013). Women with disabilities are often seen as perpetually child-like, asexual or over-sexed and therefore inadequate parents (Committee on the Rights of Persons with Disabilities 2013; STAR 1991). Stella Young touches on this misconception in her submission to the recent Senate inquiry, recounting how she was laughed at when telling a doctor that she was sexually active (Young 2013, p. 1).

In Australia, a parent with a disability is up to ten times more likely to have a child removed from their care than a parent without a disability (Victorian Office of the Public Advocate 2012). Often, the removal of a child from a parent with a disability is carried out on the basis of the person's disability, rather than incapacity to care for the child (Victorian Office of the Public Advocate 2012). The mere fact that the parent has a disability is often mistakenly taken for prima facie evidence that they are unable to be a good parent or pose a risk to the child (Frohmader).

5.4. The Prevention of Sexual Abuse Argument

This justification rests on the fact that women and girls with disabilities are particularly vulnerable to sexual abuse, and thus should be sterilised to prevent them from abuse and/or its consequences. For example, in *Re Katie* (1995) 128 FLR 194, it was said that the attractive looks of the girl made her more of a target for sexual predators, and this formed part of the Court's rationale for her to be sterilised at age 16. In other cases, the young girls' over-sexualised or inappropriate behaviour towards men was taken into account in authorising their sterilisation before menstruation (*In re Elizabeth* (1989) 96 FLR 248[15]; *Attorney-General (QLD) v Parents (In Re S)* (1989) 13 Fam Lr 660).

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[15] *In re Elizabeth* (1989) 96 FLR 248.

The incongruous nature of this rationale can be seen immediately: it is not about preventing abuse, but about preventing the consequences of abuse, i.e., unwanted pregnancies. Research has shown that sterilisation can actually increase the risk of sexual abuse rather than protect against it, as there is no chance of the individual becoming pregnant. This is especially so for women with psychosocial or intellectual disabilities, women in psychiatric or other institutions and women in custody (Committee on the Rights of Persons with Disabilities 2016; Sobsey and Doe 1991). Instead of taking appropriate measures to combat sexual abuse and the reasons why it occurs, sterilisation is used as a Band-Aid solution that places the responsibility on girls and women with disabilities for preventing the consequences that accompany it. As Stella Young so eloquently put it: ‘the fact that this burden rests on the shoulders of some of our most vulnerable citizens is a disgrace; it’s an insight into how people with disabilities, particularly women, are denied some of the most basic rights of personhood that should be afforded to all human beings, and we should be deeply ashamed of it’ (Young 2013, p. 2).

6. Should Forced Sterilisation Be Made Illegal?

6.1. Positions Taken by Stakeholders

WWDA argue for an outright ban of involuntary sterilisation for women and girls with disabilities. ‘Forced sterilisation is an act of violence, a form of social control and a clear and documented violation of the right to be free from torture. It is internationally recognized as a harmful practice based on tradition, culture, religion or superstition’ (International NGO Council on Violence against Children 2012 as cited in Frohmader 2013, p. 8). They recognise that the issue is part of a more widespread pattern of denial of human and reproductive rights, which includes exclusion from appropriate health care, information and services (Dowse and Frohmader 2001 as cited in Frohmader 2013).

The CRPD Committee has formally asserted that involuntary sterilisation of women and girls with disabilities, and other kinds of reproductive discrimination, violates multiple provisions of the CPRD (Nowak 2008). It has urged state parties to abolish the administration of sterilisation of children and adults with disabilities without the full and informed consent of the individual concerned, including all forms of forced sterilisation, forced abortion and non-consensual birth control (Committee on the Rights of Persons with Disabilities 2013; Committee on the Rights of Persons with Disabilities 2016). In particular, the Committee has recommended that Australia ‘enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilisation of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent’ (Committee on the Rights of Persons with Disabilities 2013; Committee on the Rights of Persons with Disabilities 2016, p. 8).

The Australian Government argues that an outright ban is inappropriate, stating that it ‘potentially denies the rights of persons with disabilities to access all available medical support on an equal basis with persons without a disability. It is a ‘one size fits all’ solution to a complex problem’ (Senate Community Affairs References Committee 2013, p. 94). The Government suggests that all sterilisation should be banned where an individual has the capacity to consent, and if they may develop capacity to consent in the future, then irreversible sterilisation should be banned. It recommends that state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that it is presumed that persons with disabilities have the capacity to make their own decisions unless objectively assessed otherwise. Finally, it submits that state and territory legislation be amended to clearly dictate that a court of tribunal does not have authority to hear an application for sterilisation where a person has legal capacity (Senate Community Affairs References Committee 2013).

6.2. Forced Sterilisation Should Be Criminalised

No woman or girl with a disability should ever be sterilised without her consent, save for very exceptional circumstances. Involuntary sterilisation is a form of violence, permits gross violations of human rights and puts Australia in breach of its international obligations. Urgent action must be taken to prevent the continued occurrence of this blatant disregard for human rights.

6.2.1. Forced Sterilisation Is a form of Violence

The sterilisation of a woman or girl without her consent is a form of violence. This is recognised by the Committee on the Rights of Persons with Disabilities (Committee on the Rights of Persons with Disabilities 2016) which has stated that forced, coerced and otherwise involuntary sterilisation may be considered not only violence, exploitation and abuse but also cruel, inhuman or degrading treatment or punishment. It is broadly recognized that forced sterilisation has life-long physical and psychological effects, 'permanently robbing women of the reproductive capabilities and causing severe mental pain and suffering' (Frohmader 2013, p. 60). By taking away such a basic bodily function as the ability to reproduce, the physical and mental wellbeing of a woman is adversely impacted and her physical and bodily integrity is violated (Sifris 2010 as cited in Frohmader 2013). Steele (Steele 2013) has called it 'legal violence', which is violence that is made possible by and sanctioned by the law.

It is concerning to note that, despite the significant amount of academic, medical and parental discourse around this issue, there is next to no discussion about sterilisation publicly available from women and girls with disabilities themselves. A prime example is the 2013 Senate Inquiry titled 'Involuntary or Coerced Sterilisation of People with Disabilities in Australia'. A clear majority of the submissions to the Senate Inquiry were made by disability activist bodies and parents arguing for and against forced sterilisation. There are a very limited number of case studies available to demonstrate the real and tangible harm that forced sterilisation causes to women and girls with disabilities. A small insight was provided at a conference held by STAR, where women spoke of experiences such as "I went to hospital and instead of having my appendix out, I had a tubal ligation" and "after trying to have a baby for a long time I finally found out I had been sterilised when I was 14 living in an institution" (STAR 1991). These types of blatant violations of bodily integrity clearly fall within the ambit of violence and abuse. By not only failing to criminalise this practice, but authorising this form of violence to be perpetrated against both women and children, Australia is breaching article 16 of the CRPD.

Australia is further in breach of article 16 by declining to enact effective legislation and policies to ensure that the forced sterilisation of women and girls does not occur. Article 16 specifically mandates that gender-specific legislation and policies be enacted locally. There is currently no legislation prohibiting or even regulating the sterilisation of girls under 18 with disabilities. The legislation regulating the sterilisation of women over 18 with disabilities legalises this form of violence if the individual is deemed by a court not to have 'decision-making capacity', a notion that is arbitrary and decided on a case-by-case basis. This lack of effective legislation is unacceptable and falls far short of meeting the requirements of the CRPD.

Finally, article 16 explicitly dictates that state parties are to provide support and education to avoid, recognise and report instances of exploitation, violence and abuse. The failure to provide appropriate and sufficient assistance, support, information and education for women and girls with disabilities and their families and carers makes the current Australian position inconsistent with its obligations under the CRPD.

6.2.2. Substituted Decision-Making Is Prohibited by the CRPD

As well as the obvious breaches of article 16 mentioned above, the current capacity considerations and 'best interests' tests put Australia further in breach of its human rights obligations. Currently, there is a heavy focus on capacity considerations before an application for the sterilisation of a woman or girl with a disability can be authorised. If an individual is deemed not to have capacity, a decision is made about what is in her best interests according to the court. This means that 'in practice, the choices of women with disabilities, especially women with psychosocial or intellectual disabilities, are often ignored and their decisions are often substituted by those of third parties, including legal representatives, service providers, guardians and family members' (Committee on the Rights of Persons with Disabilities 2016, p. 11). This provision for substituted decision-making violates article 12 of the CRPD, which requires the provision of support for persons with disabilities to exercise their legal capacity. The UN Special Rapporteur on Torture has recently reiterated that the law should never distinguish between individuals on the basis of capacity or disability in order to permit sterilisation, specifically of girls and women with disabilities (Méndez 2013). Flynn and Arstein-Kerslake (Flynn and Arstein-Kerslake 2014) argue that upholding cognition as a prerequisite for personhood or the granting of legal capacity results in the exclusion of people with cognitive disabilities. 'Irrespective of decision-making ability, every person has an inherent right to legal capacity and equal recognition before the law' (Flynn and Arstein-Kerslake 2014, p. 83). This right to be recognized as a person before the law and have one's decisions legally recognized calls for a system of supported decision-making to replace the current substituted decision-making model that allows third parties to make decisions on behalf of individuals. Flynn and Arstein-Kerslake (Flynn and Arstein-Kerslake 2014) note that in recent years there has been growing support for the idea that almost every human being is able to express her will and preferences with the right support. They also argue that 'for the most part, we know very little about how people make decisions and, as a consequence, we should be slow to deny the right to have one's decisions respected by the law to anyone, even when it is difficult to decipher the person's wishes or where the individual has a different worldview, even one which may seem irrational or ill-formed' (Flynn and Arstein-Kerslake 2014, p. 82). The Committee on the Rights of Persons with Disabilities (Committee on the Rights of Persons with Disabilities 2016) has recognised that restricting or removing legal capacity can actually facilitate forced interventions, such as sterilization, abortion or contraception. As such, the current allowance for substituted decision-making is unacceptable.

The 'best interests' test has received a spate of criticism from disability rights advocates. Amnesty International Australia (Amnesty International Australia 2013, p. 44) maintain that the use of a best interests test is prohibited under international law, stating, 'claims that forcing or coercing women and girls into sterilisation is in their 'best interests' contradict the general principles of respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons set out in article 3(a) of the CRPD'. The main concern about the best interests test is that it is amorphous, undefined and slanted to give weight to the views and needs of carers (Senate Community Affairs References Committee 2013). It is a 'malleable concept that can fail to address the needs and human rights of persons with disabilities' (Senate Community Affairs References Committee 2013, p. 123). The test provides no adequate safeguards and may allow courts and tribunals to put the wishes of family members or carers above those of the individual with a disability. In the past, the best interests test has been used to justify the authorisation of sterilisations based on inappropriate considerations such as those mentioned in Section 5 of this paper. In reality, the best interests approach has little to do with the individual involved and more to do with the interests or wishes of others, in particular families and carers (Frohmader 2013). Legislative reform must be put into effect, which eliminates capacity considerations and implements a supported decision-making regime to prevent further violations of human rights.

6.2.3. Exceptional Circumstances

There are undoubtedly situations that give rise to a 'moral grey area' and make proposing legislative and policy reforms a toilsome task. These difficult cases necessitate exceptions to an outright ban on sterilisation without consent. This paper does not have the scope to consider a completely comprehensive solution to these controversial issues. However, they must be taken into consideration in any future legislative or policy reform in Australia.

The most obvious such circumstance is where an individual is in a coma or permanent vegetative state, and thus completely unable to make a decision (Flynn and Arstein-Kerslake 2014). Any new legislation would need to be flexible enough to allow for an exception in which a third party may make a decision on the basis of what the individual's will and preference would have been. This may be very difficult to ascertain, but difficulty should not preclude an effort to understand what the individual would have wanted in the circumstances.

Another problematic situation may arise where an individual refuses life-saving treatment. For example, if a woman with an intellectual disability is diagnosed with cancer and requires a hysterectomy to live, but refuses to undergo the operation, should the legislation be drafted such that she is allowed to refuse the treatment and ultimately die? It must be considered that women without disabilities have the right to refuse life-saving treatment, and as such, women with disabilities should be afforded the same right provided they have been supported in making an informed decision. Future legislative drafters would need to consider protecting medical practitioners who comply with the wishes of people with disabilities to refuse lifesaving treatment. Any legislation criminalising forced sterilisation would be otiose if medical practitioners were made liable for declining to perform a sterilisation procedure without the consent of an individual. Different considerations apply to minors. In general, minors are not considered able to make their own decisions in regards to medical treatment as they lack the necessary experience, knowledge and maturity (O'Connor 2009). A further exception may therefore be required for girls under the age of 18 where sterilisation without their consent is necessary due to a serious threat to their health or life.

6.2.4. Other Factors in Favour of Criminalisation

Whilst this paper does not have the scope to deeply delve into this complex subject, the interrelated issue of sexual autonomy weighs in favour of prohibiting forced sterilisation. The Australian Association of Development of Disability Medicine Inc. (Australian Association of Developmental Disability Medicine Inc. 2013, p. 1) has stated that, 'people with disabilities have the same rights as other people to exercise choices regarding sexual expression and relationships and have freedom over their body to make such choices'. The ability of individuals with disabilities to have their sexual and reproductive rights recognized on an equal basis with others should be taken into consideration when drafting rights-protecting legislation and reform.

7. Recommendations

As has been discussed, Australia's current legislative and policy framework regarding forced sterilisation of women and girls with disabilities is failing to protect those at risk of being sterilised without their consent. This paper proposes that a departure from the medical model ideology is needed, and that a new regime founded on the social model of disability should be developed. The social model recognises that disability results from the interaction between persons with impairments and the attitudinal and environmental barriers surrounding them (Parker 2012). This carries the implication that the environment must change to enable individuals living with a disability to participate in society on an equal basis with others. It recognises people with disabilities as an oppressed group in society and distinguishes between impairments and disability; disability being imposed on top of impairments by the way individuals are isolated and excluded from participating fully in society (Davis 2013). Thus, the focus should be shifted from performing a 'quick-fix' on the person who is seen as the problem, and placed on the environmental factors that are contributing to the issues that sterilisation is purportedly trying to address. This includes providing more support, education, resources and information to people with disabilities, their families and carers to enable them to better manage things such as menstruation and behavioural changes. It includes training for medical practitioners to try and change the archaic attitudes within the profession towards the sterilisation of people with disabilities. It includes a national uniform legislative regime to ensure that individuals are provided with consistent treatment regardless of geographical location. It includes the elimination of considerations of capacity and the 'best interests' of the individual, and the introduction of a supported decision making system to allow individuals to make informed decisions about sterilisation. It includes research to obtain a greater understanding of the prevalence of forced sterilisation in Australia. Furthermore, it includes harsher punishment for those who attempt to circumvent the formal procedures.

7.1. Support, Education, Resources and Information

There is an appalling lack of support and resources available for people with disabilities to assist them with choices about relationships and sexuality, sexual and reproductive health and menstrual management (Senate Community Affairs References Committee 2013). Women with disabilities are often denied access to information, communication and education around these issues because of 'harmful stereotypes that assume that they are asexual and do not therefore require such information on an equal basis with others' (Committee on the Rights of Persons with Disabilities 2016, p. 10). Even where there are educational resources available, sex education is often not targeted appropriately, and is undermined by the message that people with disabilities are different and that sex education does not apply to them in the same way that it does to people without disabilities (Senate Community Affairs References Committee 2013). The increase of information, education and support in areas of sex, reproduction and menstruation for both individuals with disabilities and their carers will assist in alleviating some of the stresses that are experienced when dealing with matters such as menstrual management. The Senate has (rightly, in my opinion) recommended that such access to support services should be tailored to each individual, not a one-size-fits-all program (Senate Community Affairs References Committee 2013). An increased level of funding and devoted resources would assist in bridging the gap and providing individuals with disabilities and their families and carers the support they need to realise their rights on an equal basis with others. Further, it would bring Australia in line with its obligation under article 16 of the CRPD to provide support and resources to prevent instances of violence from occurring.

7.2. Training for Medical Practitioners

Medical practitioners are not presently provided with adequate education, training and professional development in relation to people with disabilities, sexual and reproductive health, informed consent, how to assess capacity, and how to communicate with people with disabilities and their carer or advocates effectively (Senate Community Affairs References Committee 2013). This is particularly problematic given that medical professionals are often influential in the decision to sterilise women and girls with disabilities (Frohmader 2013). The judgments of medical professionals are made from a particular perspective that women or girls with disabilities are basically the sum of their biology or physiology (Dowse and Frohmader 2001 as cited in Frohmader 2013). This ideology reinforces notions of the medical model and allows for medical professionals to hold the view that sterilisation will 'fix' the 'problems' that individuals face due to their impairments. Providing more effective education and training for medical practitioners will assist in re-shaping these misconceived attitudes and help to prevent instances of forced sterilisation occurring. This would also enable Australia to more effectively fulfil its obligations under article 16 of the CRPD.

7.3. Legislative Reform

Currently, it cannot be guaranteed that a person with a disability will receive the same treatment regardless of their geographic location. The principal differences between jurisdictions include the requirement of capacity as a threshold issue, the availability of legal representation and the factors considered when determining whether to authorise a sterilisation procedure (Senate Community Affairs References Committee 2013). Uniform national legislation should thus be developed to provide a coherent and consistent framework that criminalises sterilisation for girls, and for women without their free and informed consent. As mentioned, article 16 of the CRPD mandates that legislation be enacted to prevent instances of violence from occurring. Developing legislation to prohibit forced sterilisation would make Australia compliant with this requirement.

This paper will not attempt the arduous task of drafting proposed legislation. However, there are three matters that should undoubtedly be considered in drafting any future legislation:

1. For the reasons submitted, considerations of capacity as a threshold issue should be eliminated. The provision for a substituted-decision making regime once an individual is deemed not to have capacity should also be excluded from any future legislation. Instead, a supported decision-making model should be developed to assist women with disabilities in making free and informed decisions about any sterilisation procedures. This would ensure that Australia realises its obligations under article 12 of the CRPD.
2. Following that, the 'best interests' test should be rejected. This test undermines human rights and would be redundant in a supported decision-making model.
3. As discussed, the provision of a small number of limited exceptions will be necessary to handle exceptional circumstances. These include where an individual does not have any ability to make a decision as they are in a coma or vegetative state, or, where a minor requires life-saving treatment. Any exceptions would need to be very carefully defined and limited in their scope to prevent the existing human rights violations arising from substituted decision-making from happening in the future.

It is vital that any drafters of future legislation keep in mind the general principle that women with disabilities, like all women, have the right to 'have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence' (Committee on the Rights of Persons with Disabilities 2016, p. 10).

7.4. Harsher Punishment for Those Trying to Circumvent Formal Procedures

There have been reported instances of families taking their children to other jurisdictions to have them sterilized (Senate Community Affairs References Committee 2013). To address this issue, similar provisions to the Female Genital Mutilation (FGM) offences under the *Crimes Act 1900* (NSW)[16] could be adopted. Section 45 makes it an offence to aid, abet, counsel or procure a person to perform an FGM act on another person. It carries a penalty of imprisonment for 21 years. Section 45A makes it an offence to take a person or arrange for a person to be taken from the State with the intention of having FGM performed on that person. This also carries a penalty of imprisonment for 21 years. Similar provisions may be implemented to criminalise aiding, abetting or procuring a person to perform a sterilisation procedure on an Australian resident or taking an Australian resident outside of the State to have a sterilization procedure performed without consent. In addition to this, the Law Institute of Victoria (Law Institute of Victoria 2013) recommended that a system be put in place to allow the Australian Federal Police to put a child on an Airport Watch List if necessary. This would ensure that authorities were alerted if a family that had unsuccessfully applied for a sterilisation procedure were attempting to remove an individual from the country.

7.5. Redress for Victims

Article 16 of the CRPD requires that parties take appropriate measures to promote the recovery, rehabilitation and social reintegration of persons with disabilities who become victims of violence. After identifying that forced sterilisation is a form of violence, it is necessary that the Australian Government provide redress to the women and girls who have suffered from this practice. Whether this be in the form of an apology or compensation WWDA recommends that both occur (Frohmader 2013), it is appropriate that the Government publicly recognise that harm has been caused to the individuals affected, and attempt to assist these individuals in their rehabilitation.

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[16] *Crimes Act 1900* (NSW).

7.6. Data Recording

As mentioned, there is currently a substantial lack of information regarding the exact numbers of forced sterilisations that are occurring in Australia. The Government has not conducted any comprehensive reviews or research to shed light on this issue. It is therefore recommended that a uniform national approach to data recording be implemented to gain a more holistic understanding of the present number of sterilisations being performed and authorised in Australia.

8. Conclusions

Despite the copious attention that the issue of forced sterilisation of women and girls with disabilities in Australia has received from national and international stakeholders in recent years, little to no progress has been made. The Government remains apathetic and indifferent towards this issue. The persistent theme throughout this paper, and in recommendations from disability advocates and international bodies, is the violation of human rights. The current legislative and policy framework is impermissible from a human rights perspective. It puts Australia in breach of not only the CRPD, but almost all other human rights treaties to which it is a party. This paper has propounded that forced sterilisation is a form of violence. Legally authorising violence to be perpetrated against women and children with disabilities is unacceptable and cannot be allowed to continue in Australia. The prevention of this flagrant disregard for human rights begins with a national legislative scheme criminalising forced sterilisation. Coupled with further support and education for individuals with disabilities, their carers, and medical professionals, these reforms will provide a backbone for momentous progress in the Australian human rights sphere. Whilst the recommendations in this paper may not provide a complete and comprehensive solution to the issue of forced sterilisation, they will guide Australia down a path towards the ultimate goal: justice for the victims of this violence.

References

ABC. 2003. Walk in our Shoes. *Four Corners*. June 16. Available online: http://www.abc.net.au/4corners/content/2003/transcripts/s880681.htm (accessed on 7 May 2016).

ABC. 2003. Interview with Chief Justice Alastair Nicholson. *Four Corners*. May 12. Available online: http://www.abc.net.au/4corners/content/2003/20030616_sterilisation/int_nicholson.htm (accessed on 17 June 2017).

Amnesty International Australia. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 48 to Senate Community Affairs References Committee; Broadway: Amnesty International Australia.

Australian Association of Developmental Disability Medicine Inc. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 59 to Senate Community Affairs References Committee; Brisbane: Australian Association of Developmental Disability Medicine Inc.

Australian Human Rights Commission. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*; Submission No. 5 to Senate Community Affairs References Committee; Sydney: Australian Human Rights Commission.

Brady, Susan M., and Sonia Grover. 1997. *The Sterilisation of Girls and Young Women in Australia—A Legal, Medical and Social Context*; Sydney: Australian Human Rights Commission.

Brady, Susan, John Britton, and Sonia Grover. 2001. *The Sterilisation of Girls and Young Women in Australia: Issues and Progress*; Sydney: Australian Human Rights Commission. Available online: https://www.humanrights.gov.au/our-work/disability-rights/projects/sterilisation-girls-and-young-women-australia-issues-and (accessed on 8 May 2016).

Carter, John, and Merren Carter. 2013. Involuntary or Coerced Sterilisation of People with Disabilities in Australia. Submission No. 20 to Senate Community Affairs References Committee. Available online: https://sydney.edu.au/health-sciences/cdrp/Sterilisation_Submission%2021.pdf (accessed on 8 May 2016).

Committee on the Elimination of Discrimination against Women. 2010. *Concluding Observations of the Committee on the Elimination of Discrimination against Women: Australia*; Geneva: UN Committee on the Elimination of Discrimination against Women (CEDAW). Available online: http://www.refworld.org/docid/52dd07654.html (accessed on 8 May 2016).

Convention on the Elimination of all Forms of Discrimination against Women. 1981. Opened for signature 1 March 1980, 1249 UNTS 13 (entered into force 3 September 1981). Available online: http://www.ohchr.org/Documents/ProfessionalInterest/cedaw.pdf (accessed on 7 May 2016).

Convention on the Rights of Persons with Disabilities. 2008. Opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008). Available online: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (accessed on 7 May 2016).

Convention on the Rights of Persons with Disabilities: Declarations and Reservations (Australia). 2008. Opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008). Available online: http://indicators.ohchr.org/ (accessed on 27 June 2017).

Committee on the Rights of Persons with Disabilities. 2011. *Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations of the Committee on the Rights of Persons with Disabilities—Spain*; Geneva: UN Committee on the Elimination of Discrimination against Women (CEDAW). Available online: http://www.refworld.org/docid/54992a7a4.html (accessed on 7 May 2016).

Committee on the Rights of Persons with Disabilities. 2013. *Concluding Observations on the Initial Report of Australia*; Geneva: UN Committee on the Elimination of Discrimination against Women (CEDAW). Available online: http://www.refworld.org/docid/5280b5cb4.html (accessed on 17 June 2017).

Committee on the Rights of Persons with Disabilities. 2016. *General Comment No. 3 (2016) on Women and Girls with Disabilities*; 13th sess. UN Doc CRPD/C/GC/3 25 November 2016. Geneva: UN Committee on the Elimination of Discrimination against Women (CEDAW). Available online: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/3&Lang=en (accessed on 7 May 2016).

Convention on the Rights of the Child. 1990. Opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990). Available online: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx (accessed on 7 May 2016).

Committee on the Rights of the Child. 2005. Consideration of Reports Submitted by States Parties under Article 44 of the Convention, Concluding Observations: Australia. Available online: http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf (accessed on 7 May 2016).

Committee on the Rights of the Child. 2012. *Consideration of Reports Submitted by States Parties under Article 44 of the Convention, Concluding Observations: Australia*; Geneva: Committee on the Rights of the Child (CRC). Available online: http://www2.ohchr.org/english/bodies/crc/docs/co/CRC_C_AUS_CO_4.pdf (accessed on 7 May 2016).

Davis, Lennard J. 2013. *The Disability Studies Reader*, 4th ed. London: Routledge.

Dowse, Leanne. 2004. Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia. Paper presented at the Disabled Peoples' International (DPI) World Summit, Winnipeg, MB, Canada, September 8–10. Available online: http://wwda.org.au/issues/sterilise/sterilise2001/steril3/ (accessed on 8 May 2016).

Family Law Council. 1994. *Sterilisation and Other Medical Procedures on Children*; Melbourne: Family Law Council. Available online: https://www.ag.gov.au/FamiliesAndMarriage/FamilyLawCouncil/Documents/Sterilisation%20and%20Other%20Medical%20Procedures%20on%20Children.doc (accessed on 8 May 2016).

Flynn, Eilionoir, and Anna Arstein-Kerslake. 2014. Legislating personhood: Realising the right to support in exercising legal capacity. *International Journal of Law in Context* 10: 81–104. [CrossRef]

Frohmader, Carolyn. *Parenting Issues for Women with Disabilities in Australia: A Policy Paper*; Tasmania: Women with Disabilities Australia. Available online: http://wwda.org.au/wp-content/uploads/2013/12/parentingpolicypaper09.pdf (accessed on 8 May 2016).

Frohmader, Caroyln. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 49 to Senate Community Affairs References Committee; Canberra: Senate Community Affairs Committee Secretariat.

Frohmader, Carolyn. 2014. *Fact Sheet: Forced Sterilisation*; Tasmania: Women with Disabilities Australia. Available online: https://www.pwd.org.au/documents/temp/FS_Sterilization.pdf (accessed on 10 March 2016).

International Convention on Civil and Political Rights. 1976. Opened for signature 19 December 1966, 993 UNTS 171 (entered into force 23 March 1976). Available online: http://www.ohchr.org/Documents/ProfessionalInterest/ccpr.pdf (accessed on 7 May 2016).

International Covenant on Economic, Social and Cultural Rights. 1976. Opened for signature 19 December 1966, 993 UNTS 3 (entered into force 3 January 1976). Available online: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (accessed on 7 May 2016).

International NGO Council on Violence against Children. 2012. Violating Children's Rights: Harmful Practices Based on Tradition, Culture, Religion or Superstition. A report from International NGO Council on Violence against Children. New York: International NGO Council on Violence against Children. Available online: http://srsg.violenceagainstchildren.org/document/_844 (accessed on 7 May 2016).

Law Institute of Victoria. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 79 to Senate Community Affairs References Committee; Melbourne: Law Institute of Victoria.

Méndez, Juan E. 2013. *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*. 22nd sess. Agenda Item 3, UN Doc A/HRC/22/53 (1 February 2013). Available online: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (accessed on 7 May 2016).

Naik, Lesley. 2012. When is the sterilisation of an intellectually disabled child "therapeutic"? A practical analysis of the legal requirement to seek court authorisation. *Journal of Law and Medicine* 20: 453–63. [PubMed]

Nowak, Manfred. 2008. *Report of the Special Rapporteur on Torture and other Inhuman or Degrading Treatment or Punishment*. 7th sess. Agenda Item 3, UN Doc A/HRC/7/3. 15 January 2008. Available online: http://www.ohchr.org/EN/Issues/Torture/SRTorture/Pages/SRTortureIndex.aspx (accessed on 31 May 2017).

O'Connor, Christopher M. 2009. What rights do minors have to refuse medical consent? *Journal of Lancaster General Hospital* 4: 63–65.

Office of the Public Advocate. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 14 to Senate Community Affairs References Committee; Carlton: Office of the Public Advocate.

Parker, Malcolm. 2012. Bioethical Issues: Forced Sterilisation: Clarifying and challenging intuitions and models. *Journal of Law and Medicine* 20: 512–27.

People with Disabilities Australia. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Submission No. 50 to Senate Community Affairs References Committee; Redfern: People with Disabilities Australia.

Rhoades, Helen. 1995. Intellectual Disability and Sterilisation—An Inevitable Connection? *Australian Journal of Family Law* 9: 234–52.

Senate Community Affairs References Committee, Parliament of Australia. 2013. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*; Canberra: Commonwealth of Australia. Available online: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/First_Report (accessed on 10 March 2016).

Shakespeare, Tom. 2002. The social model of disability: an outdated ideology? *Research in Social Science and Disability* 2: 9–28.

Sobsey, Dick, and Tanis Doe. 1991. Patterns of sexual abuse and assault. *Sexuality and Disability* 9: 243–59. [CrossRef]

Spicer, Cathy. 1999. *Sterilisation of Women and Girls with Disabilities—A Literature Review*; Tasmania: Women with Disabilities Australia. Available online: http://wwda.org.au/issues/sterilise/sterilise1995/steril/ (accessed on 7 May 2016).

Standing Committee of Attorneys-General. 2008. Communique. March 28. Available online: http://www.nswbar.asn.au/circulars/scag.pdf (accessed on 31 May 2017).

STAR. 1991. *On The Record—A Report on the 1990 STAR Conference on Sterilisation: 'My Body, My Mind, My Choice'*; Melbourne: Victorian Action on Intellectual Disability (STAR). Available online: http://wwda.org.au/issues/sterilise/sterilise1995/record/ (accessed on 17 June 2017).

Steele, Linda. 2008. Making sense of the Family Court's decisions on the non-therapeutic sterilisation of girls with intellectual disability. *Australian Journal of Family Law* 22: 1–23.

Steele, Linda. 2013. Involuntary or Coerced Sterilisation of People with Disabilities in Australia. Submission No. 44 to Senate Community Affairs References Committee; February 24. Available online: http://www.aph.gov.au/DocumentStore.ashx?id=9880795d-9a5b-4a00-8614-72fb4bad7b6a&subId=16147 (accessed on 7 May 2016).

UN General Assembly Human Rights Council. 2011. *Draft Report of the Working Group on the Universal Periodic Review: Australia*; 10th sess. UN Doc A/HRC/WG.6/10/L. 8 (3 February 2011). Available online: https://www.ag.gov.au/RightsAndProtections/HumanRights/United-Nations-Human-Rights-Reporting/Documents/UniversalPeriodicReview-ReportoftheWorkingGroup.pdf (accessed on 27 June 2017).

Victorian Office of the Public Advocate. 2012. *The Removal of Children from Their Parent with a Disability*. Position Statement; Carlton: Office of the Public Advocate.

Victorian State Government. 2016. Penalties and Values (11 March 2016) Justice and Regulation. Available online: http://www.justice.vic.gov.au/home/justice+system/fines+and+penalties/penalties+and+values/#breadcrumbs (accessed on 10 May 2016).

World Health Organisation. 2014. *Eliminating Forced, Coercive and Otherwise Involuntary Sterilisation: An Interagency Statement*; Geneva: World Health Organisation. Available online: http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf (accessed on 7 May 2016).

World Medical Association and the International Federation of Health and Human Rights Organisations. 2011. Global Bodies Call for end to Forced Sterilisation. Press Release. 5 September 2011. Available online: http://wwda.org.au/issues/sterilise/sterilise2011/sterilwma2011/ (accessed on 7 May 2016).

Young, Stella. 2013. Involuntary or Coerced Sterilisation of People with Disabilities in Australia. Submission No. 68 to Senate Community Affairs References Committee.

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Some Parents Are More Equal than Others: Discrimination against People with Disabilities under Adoption Law

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Abstract: Article 23 of the Convention on the Rights of Persons with Disabilities (CRPD) explicitly includes 'the adoption of children' as a right to which people with disabilities are equally entitled. Despite the CRPD having been in force for over nine years, research is yet to consider whether CRPD signatory states have brought their respective adoption regimes in line with their obligations under art 23 of the CRPD. Using the laws of the Australian state of Victoria by way of case study, this article aims to shed light on the difficulties people with disabilities still face when attempting to adopt children. In terms of methodology, this article conducts an interpretive critique of Victoria's adoption law against art 23 of the CRPD, which it interprets mainly through the lens of the social model of disability. Ultimately, this article finds that Victoria's adoption framework closely resembles the adoption regimes of many other CRPD signatories, yet it clearly fails to uphold Australia's obligations under the CRPD. This is both as a result of the words of the legislation as well as their implementation in practice. This article proposes a suite of changes, both legislative and cultural, to bring Victoria's adoption framework in line with art 23, which it hopes will serve as a catalyst for change in other CRPD signatory states.

Keywords: adoption; adoption law; CRPD; disability; disability rights; people with disabilities; social model; medical model; Victorian adoption law

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1. Introduction

Parenthood is held out to be a transformative part of human life (Chapman et al. 2015). It is therefore unsurprising that many people with disabilities desire to be parents (Shakespeare et al. 1996; Frohmader 2009). While critiques of society's privileging of parenthood exist, these do not detract from the claims of people with disabilities to this right (Warner 2000).

Despite this, recent research has shown that people with disabilities face disproportionate difficulty becoming and being parents—be it as a result of forced sterilisation (Kempton and Kahn 1991; Fennell 1992; Arstein-Kerslake 2015), higher rates of child removal (Llewellyn et al. 2003; Booth et al. 2005; IASSID 2008), over-representation in out-of-home care (Australian Institute of Family Studies 2016) or lack of access to assisted reproductive technologies (Frohmader 2009). Most of this research has focused on supporting the right of people with disabilities to conceive children or to retain custody of children often presumed to be their biological children. Where research has considered the ability of people with disabilities to become parents by other means, it has mostly considered assisted reproductive technologies like in vitro fertilisation (IVF). For example, a recent consideration of parenting laws in a report by the Victorian Law Reform Commission (VLRC 2007) identified disability as a significant barrier to IVF. In contrast, its consideration of adoption was far shorter and identified same-sex attraction as the only hurdle to adoption.

Limited research does exist on the discrimination faced by people with disabilities who attempt to become parents through adoption (Wates 2002; National Council on Disability 2012; Fleming 2015). Yet, often this research stops short of critiquing the legal systems that govern adoption, instead focusing on the prejudices of adoption workers and relinquishing parents (i.e., the biological parents of the adopted child). More importantly, no research has considered adoption as a right protected by the Convention on the Rights of Persons with Disabilities (CRPD)[1]. While art 23 of the CRPD explicitly guarantees the right of people with disabilities to adopt, the question of whether or not CRPD signatory states have actually implemented their art 23 obligations through domestic legislation has so far evaded scrutiny. Now that the CRPD has been in force for over nine years, there is a need for such analysis.

This article seeks to fill this gap in research by conducting an interpretive legal analysis of the adoption regime of one CRPD signatory state, and critiquing that regime against art 23 of the CRPD. Using the adoption regime of the Australian state of Victoria by way of case study, this article will argue that people with disabilities are systematically prevented from becoming parents by the legal systems that govern adoption, in breach of their human rights under the CRPD.

In terms of structure, Part II contextualizes this article by outlining the strong political, social and theoretical connections between adoption and other threads of disability advocacy. Part III discusses this article's methodology, namely how it uses the state of Victoria as a case study to explore how the adoption rights are governed through written law. Part IV discusses the theories of disability relevant to this essay, namely the medical model, the social model and Shelley Tremain's deconstructionist critique of the social model. Part V introduces art 23 of the CRPD which protects people with disabilities' right to adopt. Part VI provides a break-down of the legal structure through which adoption occurs in the state of Victoria. Part VII analyses Victoria's adoption regime against the requirements of the CRPD, which it interprets primarily through the lens of the social model. Part VIII provides recommendations for the Victorian Parliament, the Committee on the Rights of Persons with Disabilities and disability advocates and allies to pursue change to Victoria's adoption regime and more broadly. Part IX discusses the related but tangential issue of 'passing', and how the distinction between hidden and visible impairments can further affect the impact of an adoption system on the disability community.

While this article may sometimes refer to three broad classes of disability—physical, intellectual and mental health—it makes every effort not to conflate all people with disabilities during the course of analysis, and not to extrapolate broad stroke solutions that do not reflect this diversity within the disability community.

2. Snapshot of Adoption in Australia

Adoption is the legal process by which a couple (the 'adoptive parents') become the legal parents of a child under the age of 18, replacing the child's birth or biological parents (which the Victorian legislation refers to as 'relinquishing parents'). Legally speaking, an adoption order extinguishes all rights of the relinquishing parents in relation to the child (unless it specifically mentions such rights), and entitles the adopted child to all the rights of a biological child in their new adoptive family.

This said, there are different types of adoption (and other forms of caregiving), many of which fall outside the scope of this essay. This Part will limit this article's scope of enquiry to local adoptions.

2.1. Local Adoption in Perspective

At the highest level, it is important to distinguish adoption from other ways that non-biological parents may care for children, namely out-of-home care (OOHC). OOHC is a state-based statutory system which includes relative care (where a child is cared for by a relative), foster care (where a child is cared for by an unrelated carer) and residential care (where a child is cared for in a communal

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[1] Convention of the Rights of Persons with Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008).

residential building). From the outset, it must be stated that the number of adoptions is minuscule compared to the number of children in out-of-home care. In the Australian Institute of Health and Welfare's (AIHW) latest reporting period, there were only 278 adoptions in Australia (Australian Institute of Health and Welfare 2016). This compares to 11,581 Australian children admitted to OOHC in 2014–2015 (Australian Institute of Family Studies 2016).

OOHC can be informal or formal. Informal OOHC is where a biological parent consents to their child going into the OOHC system, whereas formal OOHC occurs as a result of the state forcibly removing a child through a care and protection court order. It is important to establish that biological parents with disabilities, as well as children with disabilities, are both over-represented in the OOHC system (Senate Community Affairs References Committee 2015). While this issue lies outside the scope of the article, future research should focus on this phenomenon, as the rights of such parents clearly also come within the scope of art 23 of the CRPD.

Of the 278 adoptions which occurred in Australia in 2015–2016, there are different types of adoption. This article only deals with Australian child adoption, as distinct from intercountry adoption. Local adoptions accounted for 196 (or 71%) of the adoptions in the last reporting period, compared to 82 intercountry adoptions (29%) (Australian Institute of Health and Welfare 2016). While many of the same processes and issues discussed in this article remain relevant to intercountry adoption, intercountry adoption involves less clear-cut Australian regulation, is highly dependent on the Hague Convention and the legal regimes of foreign jurisdictions and involves other complex issues (such as the consent of birth parents) that can obscure the operation of disability human rights.

Of these adoptions, some are considered 'local adoptions' while others are considered 'known child adoptions'. Local adoptions are where the adopted child has had no previous contact or relationship with the adoptive parents. In contrast, known child adoptions are where such contact has occurred (e.g., where a child adopted by a step-parent or relative). In the latest reporting period, there were 45 local adoptions (23%) versus 151 known child adoptions (77%) in Australia. As the successful adoptive parents in known child adoptions are chosen by virtue of their pre-existing relationship with a child (erasing the need to assess whether they would be good parents), known child adoptions obviously lie outside the scope of this article.

Importantly, the AIHW (Australian Institute of Health and Welfare 2016) report confirms that consent of relinquishing parents is obtained 100% of the time in the case of 'local adoptions'. The presence of consent in cases of local adoption is important for this article, as the input of the relinquishing parent is a factor later discussed. This said, it is important to acknowledge the oftentimes problematic circumstances in which parents 'consent' to the removal of a child, such as duress and economic hardship (Anthony and Rijswijk 2012).

Notably, the statistics relevant to the consent of the relinquishing parents in the case of 'known child adoptions' are omitted from the AIHW report (Australian Institute of Health and Welfare 2016). As parents with disabilities are already known to disproportionately lose their children to state caregivers, the experiences of relinquishing parents in known child adoptions is an important area for other research to consider.

2.2. Demographics of Local Adoption

There are very few publicly available statistics to do with the relinquishing and adoptive parents involved in local adoptions. In their latest article, the AIHW reports only on age and marriage status of relinquishing parents. The median age of relinquishing mothers was 26 (5 years below median age of all Australian mothers), with range of 14–42, and that 93% were unmarried. As for adoptive parents, almost all (96%) were married and 94% were aged 30 or more.

These statistics perhaps create the illusion of a harmonious system where willing birth parents give up children to loving adoptive parents, and obscure the operation of complex societal factors such as race, class and Indigenous status. In its report on the OOHC system, the Senate Community Affairs References Committee (2015) shed light on some of the factors which can prevent biological parents from caring for their children such as family violence, drug and alcohol misuse, poverty and homelessness and lack of family support services. They also pointed to Indigenous Australians and people with disabilities as two groups disproportionately at risk of losing children to a formal child care court order. It would be logical to assume that these same factors play some kind of role in the decision-making of relinquishing parents involved in adoption as well.

Having now established the specific field of enquiry, this article will discuss the context for choosing this field of enquiry, and the important interplay between this field of enquiry and other threads of disability research and advocacy.

3. Context and Critical Connections

Given the relative rarity of adoption, let alone local adoption, the question arises: why focus on adoption? First, the rarity of adoption does not diminish the claim of people with disabilities to this right. An important reason for the choice of this article's topic is, of course, that people with disabilities desire to become parents, including via adoption (Shakespeare et al. 1996; Frohmader 2009).

Second, no country's adoption regime exists in a vacuum. Adoption law is just one aspect of how a country governs how and when its citizens are allowed to parent. In the Australian context, state governance of family formation has a long and sad history which includes the forcible removal of children not only from people with disabilities, but also from Indigenous Australians (known as the Stolen Generations) (Attwood 2001) and more recently, from migrants (Horin 2010). In the context of disability advocacy, adoption law is merely one instance in a well-documented history of the Australian government interfering in the family formation of people with disabilities, from the forcible removal of children to restricted access to alternative parenting procedures like IVF (Frohmader 2009; Arstein-Kerslake 2015). Underpinning and entwining these different restrictions on the parenting rights of people with disabilities is the same unwritten notion that the parenting abilities of people with disabilities are different and lesser, and therefore that it is the state's role to control the reproductive and caring rights of people with disabilities.

Given this interconnectedness between adoption and all the other ways that the state denies people with disabilities the right to parent, writing about—and fighting for—greater adoption rights for people with disabilities has other important legal, political and social consequences for people with disabilities. As adoption is one part of an integrated legal system overseen by a central government, reforming this one part of the system will help spur change in other parts of the system. Often (but not always), these consequences will be positive, in that fighting for greater rights via adoption often reinforces the same arguments that will help people with disabilities achieve advances in other parenting rights. For example, the argument developed in this article that people with disabilities have an equal parenting ability to people without disabilities when societal barriers are removed, could equally be used to argue for greater rights for people with disabilities in relation to IVF, or to argue that people with disabilities should not be sterilised.

Third, on top of developing the topic of disability parenting generally, this article argues that adoption law is a particularly important signpost for how the government—and society more broadly—views the parenting ability of people with disabilities. Adoption differs from other issues to do with the parenting rights of people with disabilities such as child removal, sterilization and IVF in that it is not about restricting the ability of people with disabilities to have or care for their own children. On the contrary, it is about selecting—often from extremely large pools of prospective adoption applicants—the 'ideal' family for a given adoptive children. It therefore has to do with how the government views the idea of family, and how people with disabilities fit into that conception. Accepting that law has the ability to shape societal views (Gelber and McNamara 2015), Victorian adoption law thus has important connections to how our society views the parenting capabilities of people with disabilities.

Having stated these reasons, it is also important to acknowledge that fighting for greater adoption rights does not always align exactly, theoretically speaking, with the other rights movements emanating from within the disability community. An important example of this are the significant issues to do with the forcible removal of children from parents with disability and the over-representation of children with disabilities in state care (Llewellyn et al. 2003; Booth et al. 2005; IASSID 2008). In the context of that debate, strong emphasis is often put on the inalienable and irrevocable rights of the biological parent(s) (Senate Community Affairs References Committee 2015). The issue of adoption by a parent or parents with a disability, by contrast, tends to set up a dichotomy between the rights of the biological or relinquishing parents, and those of the adoptive parents (with a disability).

As is the case with all minorities, not all rights movements emanating from within the one community will always align exactly. Yet, it is important not to eschew progress that has been made in other related fields, nor to close off the opportunity of future progress in those fields. In this instance, where an argument can be used to justify greater rights of adoptive parents can also be used bolster the state's ability to remove children from people with disabilities, then that argument is not preferable because it gives people with disabilities not real net gain in terms of rights. Therefore, this article sees these two issues as inextricably connected and seeks to temper all its arguments—and suggested solutions—so as not to reinforce the phenomenon of child removal from people with disabilities.

Furthermore, it is still possible to advocate for greater adoption rights for people with disabilities without supporting the notion that the state can take children away from people with disabilities. An important distinction to draw between local adoption and the forced removal of children from parents with disabilities is that only in the former situation have the parents consented to the removal of their child. Already, this provides a basis on which the views of the relinquishing parents in local adoptions can be attributed given different weight to the views of relinquishing parents in situations where the state is forcibly removing children.

Therefore, adoption law is an important field of enquiry both in and of itself, as well as because of its important connections to theoretical and political constructions of family. While fighting for greater rights for adoptive parents could, at a surface level, be seen to erode the rights of people with disabilities seeking to maintain custody of their children, it is this article's argument that progress in one sphere is not mutually exclusive with progress in the other. Through nuanced conversation, disability advocates from all theoretical perspectives can bring their causes forward at the same time. This article endeavours to play a part in that conversation.

4. Methodology

This article is concerned with words. More specifically, it is concerned with the capacity of words in legal instruments—from official Acts of Parliament to the regulations and manuals created by bureaucrats—to oppress and to liberate. This article does not only concern itself with the beliefs and prejudices of those who oversee the adoption process; it also seeks to illuminate how the behavior of those decision-makers is often predetermined by the laws, regulations and manuals that they are legally obliged to follow. In this way, this article posits that, despite the common notion of law serving an anti-discrimination function, discrimination can also be insidiously embedded in legal systems (Hellman and Moreau 2013).

It is, however, impossible to speak about the impact of words in the abstract. In order to elucidate how discrimination emanates from the legal instruments that govern adoption, this article has chosen a concrete case study: the adoption regime of the Australian state of Victoria. Methodologically speaking, this article is an interpretative analysis of legal instruments: namely, the CRPD and the myriad legislative instruments that govern adoption in Victoria.

While it may appear that an analysis of Victorian law is of limited import when it comes to addressing the discrimination faced by people with disabilities worldwide, it should be noted that Victoria's adoption regime possesses many of the characteristics typical of adoption regimes around the world: statutorily enshrined health requirements; court orders that a person is a suitable candidate for adoption; and wide-ranging discretion conferred to adoption workers and relinquishing parents.

For example, one problem intrinsic to Victorian law is that in order adopt, a person with a disability will be assessed against legislative criteria such as 'health' and 'financial circumstances' to determine whether they are a 'fit and proper person' to adopt. These very same criteria are present in the equivalent New South Wales[2], Queensland[3] and Western Australian legislation (Department for Child Protection and Family Support 2016). Beyond Australia, Adoption Panels in the UK also assess a person's 'suitability to parent' by considering both health and financial circumstances (Department for Education 2014). The same is true in many states of the United States (Fleming 2015). Hence, the plain words of adoption legislation around the world is often very similar, and even when the words change, the ideas and structures within that legislation that give rise to discrimination against people with disabilities often remain the same.

Other problems discussed in this article—such as the prejudice held by adoption workers and relinquishing parents, or how adoption agencies fail to provide services or information specific to people with disabilities—have nothing to do with the specific words of Victorian legislation, and everything to do with discriminatory attitudes and prejudice against people with disabilities. Such attitudes are well proven to exist far beyond the state of Victoria and therefore such analysis remains relevant to any CRPD signatory state (Sutherland 1981).

Equally, the solutions offered in this article can also have application beyond Victoria. While this article offers the specific wording that the Victorian Parliament should adopt in amending the Adoption Act 1984 (Vic)[4], lawyers and disability advocates could read these suggested changes for their purposive effect, and then advocate for amendments to their own laws that would achieve the same outcome. The legislative amendments suggested by this article seek to bring Victoria's adoption laws in line with Australia's obligations under the CRPD, and therefore they remain relevant to any country that is a signatory to the CRPD who is therefore bound by the same obligations as Australia.

Therefore, this article concerns itself with discrimination through written law. While many of the examples used will come from Victorian legislation, this article is hoping to engage in a larger conversation around how adoption is currently governed, and how existing adoption regimes can be changed to adhere to the CRPD.

5. Theoretical Underpinnings

Disability literature provides several theoretical models through which this article will argue its thesis. As in all bodies of scholarship, there exists a variety of voices and not all those voices are always perfectly reconcilable. In this section, this article will present the main schools of thought to which it refers or relies, while pointing out the various unresolved tensions which exist.

5.1. The Medical Model

The earliest, and sadly the most prevalent, model of disability is the medical model. While the medical model of disability is no longer orthodoxy in academic circles or for disability advocates, it nonetheless continues to pervade societal thinking about people with disabilities (Frohmader 2009).

In essence, the medical model tells us that disability is determined by reference to, and is a result of, a person's 'biological deficit' or impairment (Shakespeare 2013). Inherent in the medical model paradigm is a norm of able-bodiedness from which people with disabilities deviate. Under the medical model, people with disabilities are yoked to their impairment in a way that makes them inherently less functional than a person without a disability (Sutherland 1981; Shakespeare 2002). Under this model, any difficulties that a person with a disability faces flow causally from their impairment. A person with a disability is perceived and studied as a 'personal tragedy' (Barnes and Mercer 1997), and the

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[2] Adoption Regulation 2015 (NSW) reg 45.

[3] Adoption Act 2009 (Qld) ss 122 and 124

[4] Adoption Act 1984.

corresponding role of research and treatment is to reduce, obscure or otherwise 'cure' the disability or its impact (Hunt 1966; Kayess and French 2008).

Applied in the context of parenthood, the medical model tells us that people with disabilities will be less capable parents on account of their impairment. This is because implicit in the medical model conception of parenthood is the idea that there is a normal way to parent a child (Frohmader 2009; Radcliffe 2008). By virtue of their impairment, people with disabilities are viewed as 'naturally unsuited' to the 'nurturant reproductive' role of parenthood (Frohmader 2009; Collins 1999). The medical model thus offers a zero sum and static conception of parenting: it is not enough that a person with a disability could fulfill the same function in a different way; or moreover, that they would simply provide a different but equally valid version of parenting altogether.

The medical model emerged from the Enlightenment period and dominated academic discourse about people with disabilities until three decades ago (Shakespeare 2002, 2013). At its height, the medical model dominated all discourse—medical, academic, political and mainstream—about disability. For example, in 1980, the World Health Organisation (WHO) essentially enshrined a medical model conception of disability in its International Classification of Impairments, Disabilities and Handicaps by defining disability as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'. Worse still, the medical model was harnessed to justify numerous eugenic policies and laws: under the medical model, people with disabilities possessed defective genetic material, and by sterilizing, segregating or otherwise preventing people with disabilities from having children, you could ostensibly remove this genetic material from society (Arstein-Kerslake 2015).

While such eugenic policies thankfully became less common (though by no means absent), the medical model continued to shape academic perceptions of people with disabilities' fitness to parent even into the 1990s. For example, a spate of flawed psychological research from the 1980s and 1990s found that 'disability severely limits parenting ability and often leads to maladjustment in children' (Kirshbaum and Olkin 2002; Crawford 2003). Only in the 2000s was it uncovered that these findings, while presented as fact deduced from scientific experimentation and sociological research, were actually pathological assumptions based on the authors' own prejudices (Kirshbaum and Olkin 2002; Crawford 2003).

And while the medical model is now much more taboo in most academic circles, it is still insidiously prevalent in wider society. As recently as last year, the Office of the Public Advocate strongly castigated the widely held but 'mistaken belief that a diagnosis of disability, particularly cognitive disability or mental disorder, constitutes a static and irremediable barrier to effective parenting' (Carter 2016). One reason for the medical model's continued predominance in the social consciousness is that 'the voices and experience of women with disabilities are almost non-existent in the literature on reproduction and parenting' (Frohmader 2009). A second reason is that matters of family are seen to be distinctively private, and so are resistant to lobbying and advocacy efforts (Frohmader 2009). A third reason is that where parents with disabilities ask for help, this is used against them as 'proof' that they are inadequate parents, creating an environment in which people with disabilities are pressured to parent behind closed doors (Grue and Laerum 2002; Frohmader 2009).

When it comes to adoption legislation, the medical model is directly relevant in three ways to the parenting rights people with disabilities enjoy. First, Victoria's—and other countries'—adoption regimes were written and passed by Parliament long before the medical model became so taboo; therefore, in many instances, the old words of the legislation still mirror medical model ideas. Second, adoption regimes from around the world, including Victoria's, almost always involve the unfettered decision-making of caseworkers and relinquishing parents. As the medical model continues to pervade societal thinking about people with disabilities, many decision-makers will logically hold medical model views (Frohmader 2009). Third, it is important to remember that even successful adoptive parents will likely face stigma based on medical model thinking even if they are successful in adopting a child: 'community attitudes rather than their physical limitations caused the major problems for mothers with disabilities' (Westbrook and Chinnery 1995; Frohmader 2009). While this article focuses on change needed to allow people with disabilities to adopt in the first place, future research must explore how to support successful adoptive parents with disabilities to overcome that stigma.

5.2. The Social Model

The social model was the first paradigm shift to occur in thinking about disability since the medical model came to dominate medical and societal discourse. Specifically, the social model refers to the structural analysis of people with disabilities' exclusion that emerged from Britain in the 1970s (Malacredia 2009). Its central thesis is perhaps best expressed by the following statement from the Union of Physically Impaired Against Segregation (UPIAS) (1974), an advocacy network instrumental in the development and propagation of the social model:

> [I]t is society that disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.

The social model is a structural model because it explains disability in relation to, and as a direct result of, 'contemporary social organisation' (UPIAS 1974). Under the social model, disability is a 'social creation' (Shakespeare 2013) resulting from the 'lack of fit between a body and its social environment' (Goering 2015). Essentially, disability is reimagined as a form of social oppression (Oliver 1996; Finkelstein 1980; Abberley 1987), analogous to the exclusion of other minority groups (Hahn 1988). Further, the social model reverses the causal chain suggested by the medical model: it is not people's impairments themselves but rather socially constructed barriers that cause disability (Barnes and Mercer 1996).

At the heart of the social model is a distinction between impairment and disability (Shakespeare 2013). Under the medical model, the concept of impairment is yoked to the concept of disability by virtue of the fact that disability is defined as the possession of an impairment (Sutherland 1981; Shakespeare 2002). In contrast, the social model severs these two terms: while the former is a 'private reality', the latter is a societal construct (Goering 2015). This idea is encapsulated in UPIAS' (1974) definition of disability as '[t]he disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments'.

Applied in the context of parenting, the social model tells us that if people with disabilities face difficulties when parenting, it is only because of the way society is structured to make raising a child easiest for those without a disability (Frohmader 2009). Thomas and Curtis (1997) posit that these barriers infiltrate many layers of society: they are 'attitudinal, institutional and environmental'. Further, Frohmader (2009) explains that these barriers pervade every stage of parenthood, at least for women: 'when they think about having a child, become pregnant, come into contact with maternity and related services and when they become parents'.

Perhaps the best evidence of socially constructed barriers to parenting is the testimony of parents with disabilities who describe the creative and ingenious measures they take to overcome such barriers. For example, the Facebook group Wheelie Good Moms (2016) features mothers who are also wheelchair users. On the group's page, they share the ways they amend their daily routine to overcome barriers to parenting, such as modifications to change tables, cots and strollers so as to be wheelchair-friendly. Such modifications throw into harsh relief the minutiae of everyday life—down to the height of change tables—that stand to make parenting difficult for people with disabilities.

The social model is relevant to this article mainly because of its explicit endorsement in the CRPD, the legal instrument that guarantees the right of people with disabilities to adopt. As this article will discuss in Part III, the CRPD explicitly endorses the social model as the appropriate paradigm through which to interpret the legal obligations of signatories (see the preamble and art 1).

More broadly, it is also a normative benchmark for how adoption law and practice should operate in general. Within disability scholarship, it has significant 'currency' (Goodley 2011). Normatively speaking, Shakespeare (2013) argues that the social model is a better way of thinking about people with disabilities for three reasons: first, it is helpful instrumentally in allowing researchers to identify the barriers facing people with disabilities; second, it is effective politically because it is 'is easily explained and understood'; third, it is helpful psychologically because it places the onus for creating change on society, not the individual.

5.3. Beyond the Social Model

While for a significant time, the social model of disability was considered 'orthodoxy' in the disability community (Barnes 2003; Shakespeare 2013), this is no longer the case. Initial critiques focused on the separation between the theoretical social model and the daily bodily experiences of impairment felt by many people with disabilities (Shakespeare 2013). This critique was particularly pertinent in the context of parenting: Chapman et al. (2015) found that some parents 'placed illness and impairment at the very centre of their parenting'. They gave such examples as 'a parent feels sad at not being able to pick their child up to comfort them when they have hurt themselves, or to carry a child upstairs to put them in bed when they are asleep'. Despite these critiques, the social model still remained 'orthodoxy' from a theoretical perspective, at least in the early years after the turn of the millennium.

More recently, however, disability scholarship has questioned the social model, also from a theoretical perspective. One of the most well-known critiques is that offered by Shelley Tremain (the *deconstructionist* critique). At the heart of Tremain's critique is a deconstruction of the impairment/disability dichotomy set up by the social model of disability (Goodley 2011). As discussed, the social model of disability concedes that impairments are 'essential, biological characteristics of a 'real' body upon which recognizably disabling conditions are imposed' (Tremain 2002). Tremain (2002) deconstructs the impairment/disability dichotomy which underpins the social model of disability, by arguing that the concept of impairment is as constructed and illusionary as the concept of disability which it allegedly underlies. This is because impairments only exist in comparison of 'rather culturally specific regulatory norms and ideals about human function and structure, competence, intelligence, and ability'. While the social model posits that culture acts on impairments to create disability, Tremain argues that cultures creates both disability and impairments: 'impairment has been disability all along'.

In turn, and applying Michel Foucault's concept of *biopower*, she argues that conceptualising impairments as intrinsic biological attributes helps sustain oppressive power structures. She argues that the social model of disability is actually damaging for people with disabilities because it 'legitimise[s] the disciplinary regime that generated it in the first place'. It does this by perpetuating the myth of a healthy or normal body, in contrast to which people with disabilities remain categorized as *other* and therefore receive differentiated, and lesser, treatment. Goodley (2011), summarising Tremain's work, posits that 'Tremain has made the case that this conception of impairment as a naturalized phenomenon endangers the potentially critical work of disability studies'.

Tremain's critique has important consequences for adoption law. As it is a predominantly discursive theory, these consequences often have to do with language. For example, the social model might celebrate explicit legislative protections for adoptive parents with impairments, whereas Tremain's theory suggests that such affirmative protections still relegate people with disabilities to a category of *otherness* and therefore jeopardise their integration in society.

5.4. Which Model Then?

It is hardly surprising that not all disability writers agree on the theoretical basis of disability advocacy. Even outside of the approaches listed in this article, disability writers in different parts of the world each have their own way of articulating disability theory (e.g., the cultural model in the US and Canada and the relational model in Nordic countries) (Goodley 2011). In addition, critiques of old models such as Tremain's, as well as new models such as the human rights model (Blanck et al.), continue to emerge.

Yet, it has long been a guiding and fundamental principal of disability research that writing remain grounded in emancipation and prioritise progress over theoretical squabbles (Barnes 2003). To this end, this article posits that no one approach need be understood as the sole or guiding theoretical basis of change to adoption regimes. A better approach is perhaps one which finds the synchronicities between them and draws on their respective strengths. The social model and Tremain's critique are not mutually exclusive in all respects. Both models seek to illuminate the social barriers currently facing people with disabilities, and place the onus squarely on governments and other power structures (as opposed to people with disabilities themselves) to bring about the required change.

This said, one important difference between the social model and Tremain's critique is that only the former is explicitly referred to in the CRPD as the lens through which each article is to be read. As such, the social model of disability is legally binding on signatories: it is incumbent on signatory states to adopt the social model as a purposive approach when implementing their treaty obligations. For this reason, this article will rely most heavily on the social model in interpreting the articles of the CRPD. In doing so, this article acknowledges that arguments underpinned by the social model hold the most weight, legally speaking, and may therefore provide the quickest and most sure route to emancipation for people with disabilities. Nevertheless, this article will, where possible, also draw on Tremain's and other critiques and theories to develop a notion of best practice with regard to adoption regulation.

6. The Human Right to Adopt

As a benchmark against which to measure the Victorian adoption framework, this article refers to art 23 of the CRPD.

6.1. The Convention

Before the implementation of the CRPD in 2006, there were very few protections for people with disabilities to be found in international instruments. Despite a plethora of instruments explicitly naming other minority groups and granting them affirmative protections, such affirmative protections were virtually inexistent for people with disabilities[5] (art 25 of the Universal Declaration of Human Rights (1948) was an exception to this, yet even then it only guaranteed an 'adequate' standard of living for people with a 'disability'). While broad-brush instruments like the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights purported to prevent discrimination against any person (including people with disabilities)[6], these generic instruments ultimately failed to generate the kind of protections that people with disabilities were asking for and desperately needed (Freeman et al. 2015; Kayess and French 2008).

The CRPD was the first binding international human rights instrument to explicitly address disability. It goes beyond a mere anti-discrimination treaty: it creates new state obligations—both positive and negative—which were absent from any prior treaty. Further, the CRPD is binding on all signatories (as at the time of writing, there are 160, including Australia) and includes an international monitoring mechanism: the Committee on the Rights of Persons with Disabilities (the Committee) (Freeman et al. 2015). The CRPD represented the first real pan-national attempt to protect the rights of people with disabilities, and explicitly enshrined the social model of disability in its interpretive principles (see Part B) (Goodley 2011; Kayess and French 2008).

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[5] Art 25 of the Universal Declaration of Human Rights. GA Res 217A (III), UN GAOR, 3rd Sess, 183rd Plen Mtg, UN Doc A/810 (entered into force 10 December 1948).

[6] International Covenant on Civil and Political Rights. Opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

The CRPD's legitimacy as a benchmark flows not just from its passage as a United Nations General Resolution, but also from the method of its construction and implementation. It entailed unprecedented 'centrality of persons with disability and their respective organisations in the CRPD negotiation process' (Kayess and French 2008). For example, disability rights non-governmental organisations (NGOs) were active members of the Ad Hoc Committee charged with drafting the CRPD (Kayess and French 2008). Further, people with disabilities continue to be involved in the implementation and monitoring of the CRPD, with a majority of the eighteen Committee members identifying as people with disabilities (Office of the High Commissioner on Human Rights 2016).

6.2. Article 23

Article 23 of the CRPD is titled 'Respect for Home and Family'. It purports to deal with 'all matters relating to marriage, family, parenthood and relationships', and speaks to many issues pertinent to parents or prospective parents with disabilities, from consenting to marriage to retention of fertility.

This article is concerned with art 23(2) which provides:

> States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship and adoption of children or similar institutions'; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance of persons with disabilities in the performance of their child-rearing responsibilities (emphasis added).

6.3. Interpretation of Article 23(2)

6.3.1. Words

By its plain words, art 23(2) gives a two-tier protection for people with disabilities with regard to adoption.

First, it purports to guarantee the 'rights and responsibilities' of persons with disabilities 'with regard to . . . adoption of children or similar institutions'. This frames adoption as an inalienable right, and puts (at least) a negative obligation on states not to take that right away from people with disabilities. This section applies the general prohibitions against discrimination in arts 4 and 5 of the CRPD in the context of adoption.

Second, art 23(2) puts an obligation on signatory states to render 'appropriate assistance to persons with disabilities in the performance of child-rearing responsibilities'. This goes further than the obligation to guarantee their rights: it puts a positive obligation on Parties to assist people with disabilities to exercise their rights as parents. While the plain words of that section leave it open whether the obligation to provide 'appropriate assistance' extends to helping people with disabilities become adoptive parents in the first place, previous Committee jurisprudence and the purpose of the document strongly suggest that it does.[7]

6.3.2. Purpose

Paragraph (e) of the CRPD Preamble makes it clear that the CRPD and its articles are to be understood by reference to the social model:

> [Signatories are] [r]ecognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

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[7] UNCRPD (United Nations Committee on the Rights of Persons with Disability). Draft General Comment on Article 6: Women with Disabilities. CRPD/C/14/R.1. 2015.

While certain commentators point out that the CRPD perpetuates the medical model by using the term 'persons with disabilities' (Kayess and French 2008), jurisprudence from the Committee has reiterated the need for a purposive approach to interpretation of the CRPD in line with the social model (Kayess and French 2008).

Interpreting art 23 through the lens of the social model supports the idea that it carries both negative and positive obligations. Where difficulties carrying out parenting responsibilities are caused by societal barriers, it is logical that the state would need to provide 'additional assistance' to people with disabilities to help them overcome societal barriers to parenthood, including assistance to access the right to adopt.

In addition, art 3 lists the 'general principles' which are to guide the interpretation of all articles of the CRPD and include 'non-discrimination', 'full and effective participation and inclusion in society' and 'equality of opportunity'. These equally support the idea that the CRPD and art 23 puts a positive obligation on the state to provide additional assistance to people with disabilities to allow them to achieve the state of full integration suggested by these principles.

6.3.3. Other Articles

Of course, no article of the CRPD is designed to be stand-alone. Other articles also elaborate on what meaning should be given to art 23. Specifically, art 2 of the CRPD defines 'discrimination on the basis of disability' as follows:

> "Discrimination on the basis of disability" means 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 . . .

Importantly, this definition captures and prohibits both direct and indirect discrimination. The difference between them is as follows (Doyle 2007):

- Direct discrimination occurs where the legislative framework explicitly treats someone unfavorably because they are a person with a disability;
- Indirect discrimination occurs where the legislative framework does not mention disability but has the practical effect of disadvantaging people with disabilities.

In relation to art 23, this means both direct and indirect discrimination constitute a failure to ensure the 'rights and responsibilities' of people with disabilities with regard to adoption. That is, it is immaterial whether the rights of people with disabilities are curtailed explicitly or implicitly, because the obligation to uphold the right of people with disabilities to adopt remains unmet.

6.3.4. Best Interests of the Child

It is important to note the two-prong protection offered to people with disabilities is tempered by the assertion in art 23 that in all cases 'the best interests of the child shall be paramount'. These words come from the United Nations Convention on the Rights of the Child[8], and are equally present in the Victorian adoption legislation. Disability literature has shown how the words 'best interests' (whether used in relation to children or people with disabilities themselves) is a societal construct used by decision-makers to curtail the rights of people with disabilities (Arstein-Kerslake 2015). As such, these words seriously jeopardise the effectiveness of art 23 (and the related Victorian adoption legislation) in practice and their inclusion in art 23 is problematic.

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[8] Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS **3** (entered into force 2 September 1990).

'Best interests' is a term peppered throughout nearly all adoption legislation (be it international, national or state). While it is beyond the scope of this article to historicise the concept of 'best interests', it is sufficient to say that the term has been strongly criticized by disability and other writers for obscuring the interests and rights of parents with disabilities. Even more problematically, questions remain as to what term, if any, could fill its place and whether such a term could avoid creating the same problems (Steele 2016).

This said, a strict social model interpretation resolves some, if not all, of the tension created by the words 'best interests of the child'. That is, where the state provides adequate resources to people with disabilities to overcome the hurdles to parenting they face, their parenting will match that of any person without a disability and logically, the best interests of the child are not threatened (Frohmader 2009).

6.3.5. Committee Jurisprudence

In its State Reports, Concluding Observations and General Comments, the Committee provides concrete guidance on how the articles of the CRPD are to be read. Regrettably, there is little Committee jurisprudence that pertains to article 23; and in the instances the Committee has spoken to art 23, it has never specifically mentioned adoption.

Nevertheless, other Committee jurisprudence can still inform how art 23 is to be interpreted. For example, in its Draft General Comment on Women with Disabilities released May 2015, the Committee identified that in order to protect the rights of women under art 6 ('Women with disabilities'), 'it is necessary to ensure universal accessibility [and] design [of] product, objects, instruments and devices' related to motherhood.[9] The Comment gives the examples of 'babies' bottles with handles, prams designed to be clipped on to wheelchairs or pushed with one hand, wheelchair-accessible nappy changers'.[1] The Committee's long list of universally accessible parenting tools exemplifies the wide scope of services likely captured by the words 'additional support' under art 23. This could extend beyond assistive technology to include financial support and free or affordable healthcare.

The Committee went on to say that, for the purposes of art 12 ('Equal recognition before the law'), ' … effective measures must be adopted to provide women with disabilities access to the support they may require in exercising their legal capacity'.[11] Significantly, the Committee required 'effective measures' despite art 12 making no direct reference to such measures or additional assistance. This strongly suggests that the reference to 'additional assistance' in art 23 extends to effective measures to help people with disabilities access the right to adopt in the first place (not just assistance once they have adopted). The Committee is clearly of the view that the rights enshrined in the CRPD are not worth stating unless they carry a positive obligation on signatories to help people with disabilities enjoy those rights, whether or not language alluding to such a positive obligation is present.

The CRPD is thus a complex and powerful instrument. While this article focuses on art 23, it draws on the whole text and history of the CRPD, as well as Committee jurisprudence, to extrapolate the obligations imposed on signatory states to do with adoption by people with disabilities.

7. The Victorian Adoption Framework

There are many different types of adoption and the adoption process is jurisdiction-specific, even between Australian states. This section will distinguish local adoption from other types of adoption, before describing how local adoption occurs in Victoria.

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[9] UNCRPD (United Nations Committee on the Rights of Persons with Disability) Draft General Comment on Article 6: Women with Disabilities. CRPD/C/14/R.1. 2015.

[1] Convention of the Rights of Persons with Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008).

[11] UNCRPD (United Nations Committee on the Rights of Persons with Disability) Draft General Comment on Article 6: Women with Disabilities. CRPD/C/14/R.1. 2015.

7.1. The Instruments

In Australia, local adoption legislation is the responsibility of state rather than federal parliament (VLRC 2007). Nevertheless, Victoria's adoption framework is shaped by international, national and local instruments.

At an international level, Australia is a signatory to the United Nations Convention on the Rights of the Child. The treaty requires that the best interests of the child are the paramount consideration. This is enshrined directly in the Adoption Act 1984 (Vic) (the Act).

At the national level, the Commonwealth has endeavoured to standardise national adoption practices via the 1997 National Principles in Adoption (the Principles) (Department of Health and Human Services 1997) as well as the Standards in Adoption 1986 (the Standards) (Department of Health and Human Services 1986). Protocol in Victoria requires caseworkers to make reference to the Principles in assessing couples' suitability for an adoption order.

In Victoria, these international and national obligations are enshrined in the Act and the Regulations[12]. The Department of Health and Human Services (the Department), a branch of Victorian executive government, issues the Adoption and Permanent Care Procedures Manual (the Manual). The Manual interprets the Act and the Regulations, effectively setting out a two-stage process for the selection of adoptive parents.

7.2. The Decision-Makers

The Act vests decision-making power with regard to adoption processes in the County Court, the Secretary of the Department and the principal officer of an approved agency.

The Court's involvement is limited to the start and end of the adoption process: they affirm or dispense with the consent of the relinquishing parents and they make the final adoption order. Given that adoption hearings are only called once a successful couple has been chosen by a caseworker, the most input a judge could feasibly have on the process of selecting adoptive parents is the rejection of a proposed couple.

As a result, all substantive decision-making power with regard to the choice of successful adoptive parents rests with the Secretary of the Department (the Secretary) or the principal officer of an approved agency (essentially providing for adoption to be undertaken by both public and private adoption agencies). In practice, the decision-making power of the Secretary and the principal officer is delegated to adoption caseworkers, who are obliged to follow the Manual in carrying out their work. In referring to 'caseworkers', this article is referring to adoption workers in both the public and private sectors.

7.3. The Approval Stage

There are two stages to the adoption process and disability is considered—both explicitly and implicitly—during both stages. The first is approval for a 'section 13 order' from the Secretary or the principal officer (i.e., a caseworker) that a person is a 'fit and proper person to adopt a child'.

The only substantive requirement for a section 13 order coming from the Act is that an applicant must be married or in a de facto couple for two years (see s 11 of the Act). According to the relevant second reading speech, s 13's purpose is 'for a child to be adopted by persons who are able to provide a secure and lasting family relationship', however the Minister did not elaborate further[13]. In this way, the Act itself is largely silent with regard to the impact of a disability on 'a section 13 order.

As such, it falls to the Regulations to set out the substantive criteria for a section 13 order. The following criteria are relevant in the context of this article:

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[12] Adoption Regulations 2008.

[13] Hansard (Victorian Legislative Council). 12 April 2000. Parliamentary Debates (H reg Thomson, Minister for Small Business).

> Reg 35(a) The health of the applicants, including emotional, physical and mental health, is suitable; and
>
> Reg 35(d) The applicants' financial circumstances are suitable.

To obtain a section 13 order, prospective couples must put their application in writing, supply evidence and attend information sessions and interviews with their allocated caseworker (Department of Health and Human Services 2001).

7.4. The Linking Stage

A section 13 order is no guarantee of an adoption order: approval for a section 13 order merely grants a couple the right to be considered during the linking stage. Linking refers to the process by which a decision is made to place a particular adoptive child with a couple who has obtained a section 13 order. The decision-making power with regard to linking is once again vested in the Secretary or the principal officer and delegated to caseworkers.

This phase of the selection process is much less transparent than the approval phase. First, the factors used to link a child with an adoptive family are less defined than those that govern the s 13 order. The Manual lists only these factors:

> The age of the respective parties, race, national, cultural and social background, religion, educational capacities, personalities, geographic location, availability of support services, expectations of contact and capacities in regard to any disability (emphasis added).

Second, it is unclear who makes the decision to link a child with an adoptive couple. The plain words of the Act and the Regulations suggest all decision-making power rests with the Secretary or the principal officer (see s 20(1) of the Act and reg 36 of the Regulations), notwithstanding that they are obliged to consider 'any wishes expressed by a parent of the child in relation to the religion, race or ethnic background of the proposed adoptive parents' under s 15(1)(b) of the Act. However, General Principle 23 of the National Principles says that 'birth parents have the right to . . . be involved in the planning for the placement of the child'. Such involvement is also expressly provided for by the Manual, which requires that at the time of relinquishing a child, 'birth parents are asked if they wish to be actively involved in selecting an adoptive family'. If they so wish, the Manual provides for a two-step shortlisting process undertaken by the caseworkers and birthparents together (Department of Health and Human Services 2001):

(1) Caseworkers make an initial shortlist of 'two to three' profiles that 'have been assessed as suitable for the child';
(2) The relinquishing parent is then able 'to indicate the couple with whom they would prefer the child to be placed'.

The Manual states that 'it is unlikely that a link would be pursued where a birth parent was opposed to that link' (Department of Health and Human Services 2001). Therefore, in practice, both relinquishing parents and caseworkers hold a degree of decision-making power during the linking stage, against the plain words of the Act and the Regulations.

In Victoria, much like in other countries, adoption thus occurs through a multi-layered, multi-tiered system involving different decision-makers with different levels of power. These stages are dictated and governed by an eclectic mix of state and federal legislation and international instruments. In the next Part, this article will discuss how the decision-making process dictated by these instruments discriminates against people with disabilities and fails to meet the obligations imposed by the CRPD.

8. Analysis

Having established both the obligations of art 23 of the CRPD as well as the way that the Australian state of Victoria regulates local adoption, this article will now directly compare the two to see whether they align. What follows is a stage-by-stage analysis of Victoria's adoption regime, which fails in myriad ways to implement Australia's obligations under the CRPD.

8.1. Direct Discrimination during the Approval Stage

The first source of discrimination under Victoria's adoption framework occurs during the approval process for a section 13 ('fit and proper person') order. Under the Regulations, the caseworker is obliged to consider reg 35(a): the 'health of the applicants, including emotional, physical and mental health'. (While beyond the scope of this essay, reg 35(a) has important parallels to the criteria used to justify removal of children from parents with disabilities and their placement in OOHC.)

The Act's inclusion of questions of disability in the medicalised language of 'health' is problematic. This is because it focuses the analysis on the 'health of the applicants' (emphasis added), as opposed to the way society does not cater for their impairment. However, this is not a per se a breach of art 23—it all depends on what is done with the health information that a person discloses. If caseworkers use the health information disclosed by a person with a disability as a way of providing that person more tailored assistance, then reg 35(a) could well be argued to uphold art 23 of the CRPD.

Unfortunately, the Standards and the Manual provide an interpretation of reg 35(a) which offends the CRPD. According to the Standards and the Manual, being of 'physical and emotional health' means being 'able to provide for the needs of the child at least until the child achieves social and emotional independence' (Department of Health and Human Services 2001). In making such a determination, the caseworker is obliged to consider 'any health related issues raised by the applicant and its implications for parenting on a day-to-day and long term basis' (emphasis added). An example given is an impairment that 'affect[s] day-to-day coping such as limitations of mobility' (Department of Health and Human Services 2001).

In effect, the Manual requires that, for a person with a disability to be deemed 'healthy', they must be able to explain how their impairment will not affect their ability to 'provide for the needs of the child'. That is, 'fitness to parent' and disability are presumed to be negatively correlated, and the onus is on the person with a disability to disprove that assumption holds true in their personal case.

The Department's view that disability is a necessary hindrance to a section 13 order is further evidenced by the following explanation on a Department website. Under the heading 'What if I have a disability?' the response is that '[f]ull medical checks and histories are required to make sure you have the ability to care for a child now and into the future' (Department of Health and Human Services 2013).

The assumption that people with disabilities are less able to provide for the needs of a child, which the Manual forces caseworkers to adopt in assessing prospective parents, constitutes direct discrimination. This assumption prevents people with disabilities from obtaining section 13 orders, without which they cannot adopt. As such, it is a breach of the negative obligation contained in art 23 of the CRPD, not to curtail the rights of people with disabilities with respect to adoption.

8.2. Indirect Discrimination during the Approval Stage

8.2.1. Regulation 35(d): 'Suitable Financial Circumstances'

Under reg 35(d) the Secretary or authorised agency must consider the applicant's financial circumstances in determining suitability for a section 13 order.

Unfortunately, people with disabilities face significant day-to-day financial hurdles (Deane 2009). The higher cost of living faced by people with disabilities is well established (under the social model, this is because people with disabilities are forced to invest in overcoming social barriers such as ableist design) (Deane 2009). In addition, Attwood (2001) data has demonstrated that people with disabilities are less likely to be employed, thereby forcing people with disability to rely on the Disability Support Pension (DSP) to cover these costs. However, it is almost universally agreed within the disability community that the DSP is insufficient (Deane 2009). Paradoxically, it is a requirement of Australia's DSP that people with disabilities have below a certain amount in their bank accounts before becoming eligible for the income support (Deane 2009), even though the Regulations explicitly prioritise adoptive parents with high bank balances.

In light of these proven financial barriers faced by people with disabilities, reg 35(d) falls short of the negative obligation contained in art 23 of the CRPD not to curtail the rights of people with disabilities with regard to adoption. While disability does not form an explicit part of the criteria, people with disabilities will be less able than others to fulfill the requirement of 'suitable financial circumstances' on account of the financial barriers they disproportionately face.

Broadly, the inclusion of 'health' and 'financial circumstances' as two stand-alone criteria in the legislation, despite the obvious connections between these two criteria for people with disabilities, evidences at best a complete ignorance for the societal barriers faced by people with disabilities. At worst, the legislation can be accused of slipping into eugenics era notions of 'biologically fit' parents, with essentially no room in the legislation for people with disabilities to become parents through adoption.

8.2.2. Section 11(1): Married/De Facto Couple 'for Not Less Than Two Years'

A second potential source of discrimination is the requirement that adoptive parents be married or in a de facto relationship for two years. Putting to one side the queer critique of requiring someone to be in a couple to adopt which lies outside the scope of this article (Warner 2000), it is relevant to make two points.

First, people with disabilities are excluded from forming sexual and/or loving relationships more than people without a disability (Kempton and Kahn 1991; Fennell 1992; Arstein-Kerslake 2015; Young 2012). Given this, people with disabilities are less likely to be able to fulfill the requirement of coupledom in the Act and so are indirectly excluded from adoption. This is another failure to meet the negative obligation in art 23.

A second concern is that if a person with a disability engages in a relationship with another person with a disability, the direct and indirect discrimination that occurs under regs 35(a) and 35(d) could occur two-fold (i.e., in relation to both parents).

8.3. Direct Discrimination during the Linking Stage

As discussed, linking is, in practice, a two-stage joint decision by the caseworker and the relinquishing parent(s): the former makes a shortlist of suitable families, and the latter chooses the specific family to become the adoptive family.

The first risk of discrimination lies in the Manual's requirement that caseworkers consider adoptive parents' 'capacities in regard to any disability' (Department of Health and Human Services 2001). In a similar way to reg 35(a), this language alludes to the medical model idea that disability is a hurdle to good parenting, without being prima facie discriminatory.

The more insidious risk of discrimination, however, is the unclear vesting of decision-making capacity between caseworker and relinquishing parent, as well as the lack of other substantive criteria which these decision-makers must follow. This means both the short-listing and the final decision stand to be influenced not only by the personal prejudices of the caseworker, but also those of the relinquishing parent(s). As discussed above, the medical model of disability continues to shape societal views of parenting ability. As such, prejudice is a real and very likely risk. In light of this likely discrimination, this article argues that the Manual's abdication of decision-making power to relinquishing parents is a breach of the negative obligation art 23 not to curtail the adoption rights of people with disabilities. Committee jurisprudence suggests that art 23 contemplates that adoption processes would at least be governed by enumerated criteria and include the possibility of judicial review.[14]

At the very least, the abdication of decision-making power to relinquishing parents during the linking stage is a failure to meet the positive obligation contained in art 23. As discussed, the words 'additional assistance' in art 23 put a positive obligation on states to provide help to people with disabilities to overcome social barriers to adoption. Social barriers likely include prejudicial attitudes. This phase of the adoption framework thus falls short of the obligation to provide 'additional assistance' because it knowingly subjects people with disabilities to a decision-making process where they stand to be discriminated against.

Handing over this decision-making power is a complete abdication of power by the state and the courts to the broader population. It is akin to letting a population vote on the rights of a protected minority. Further, it completely undoes any other protections which may have been achieved by the legislation for people with disabilities. As the next Part will discuss, the CRPD does not dictate that relinquishing parents cannot be involved in the decision-making process; however, it does require that the state intervene—such as through education or by giving them criteria to follow—so that people with disabilities are not discriminated against.

8.4. Lack of Publicly Available Information

A widely identified problem with the provision of parenting information is that it fails to cater for people with disabilities (Frohmader 2009). Unsurprisingly, this same problem applies to information about adoption. In Victoria, the only targeted information for people with disabilities relating to local adoption is the uncomfortable reminder on a generic adoption site that '[f]ull medical checks and histories are required to make sure you have the ability to care for a child now and into the future' (Department of Health and Human Services 2013).

This lack of information is a breach of the positive obligation contained in art 23. By requiring that countries take 'additional steps' to help people with disabilities exercise their right to parenthood, art 23 clearly contemplates that signatories will provide information and services which educate the relevant group how to take advantage of that right.[15]

This lack of public information is all the more problematic in a context where people with disabilities believe that they are less, or not at all, eligible to become adoptive parents. As it happens, this conception exists widely within the disability community. Grace (2014) says: 'So I got this idea that people would notice me with the kids and take them away if they saw me alone with them as I would be so clearly Autistic and disabled as to be disallowed from adoption'. Booth et al. (2005) echoes this sentiment, explaining: 'I dread that I'll be presumed incompetent from the outset and my child will be unnecessarily removed'.

Given people with disabilities hold these views, the positive obligation contained in art 23 is more extensive: 'additional assistance' likely extends to addressing such views until people with disabilities feel empowered to adopt, such as through public education campaigns. The online information about adoption currently provided to people with disabilities in Victoria manifestly falls below this benchmark.

As discussed, people with disabilities stand to be discriminated against both directly and indirectly by the plain words of the Victorian legislation and its interpretation by the Department's Manual. In addition, the unfettered decision-making power of relinquishing parents and a lack of publicly available information for people with disabilities looking to adopt, ensure that at every stage of the

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[14] UNCRPD (United Nations Committee on the Rights of Persons with Disability) Draft General Comment on Article 6: Women with Disabilities. CRPD/C/14/R.1. 2015, para. 43.

[15] UNCRPD (United Nations Committee on the Rights of Persons with Disability) Draft General Comment on Article 6: Women with Disabilities. CRPD/C/14/R.1. 2015, para. 38.

adoption process, people with disabilities stand to lose out. All these problems must be addressed for Victoria to bring its adoption regime in line with Australia's obligations under the CRPD.

9. Solutions

This article suggests the following changes to Victoria's local adoption framework. While these changes represent a significant overhaul of the current system, incorporating revision of legislation as well as cultural change within the Department and private adoption agencies, such an overhaul is necessary in order to bring Victoria's adoption framework in line with Australia's obligations under art 23. Such changes are explicitly required by art 4(b) of the CRPD, which mandates that signatories 'take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities'.

While these changes are discussed in relation to the Victorian adoption regime, many of them have broader application. The legislative changes suggested seek to enact art 23 obligations, and so can provide inspiration to lawmakers and advocates in any CRPD signatory state. Equally, the changes relating to education, information resources, and Committee and advocate action can be implemented anywhere in the world.

9.1. Action from the Victorian Parliament and the Department

9.1.1. Remove or Amend Criteria That Lead to Direct Discrimination during the Approval Stage

The direct discrimination which occurs during the approval process for a section 13 order has two sources, broadly speaking, both of which need to be addressed. First, it comes from the words of the Act and the Regulations: while these instruments do not compel caseworkers to look upon disability *disfavorably*, per se, they still compel those decision-makers to consider disability. Second, and more directly, discrimination during the approval stage derives from the Manual's interpretation of the statutory requirements. The Manual not only inversely correlates disability and fitness to parent, but it also requires that to be considered for a section 13 order, people with disabilities must explain their impairments by way of doctors' reports and medical documents (Department of Health and Human Services 2001). Such medical reports obviously encourage caseworkers to view an application from a person with a disability through the lens of the medical model, i.e., to consider that their impairment is a necessary burden on their capacity to parent.

As the Manual simply interprets the Act and the Regulations (and must be updated when the latter instruments are amended), the best option is to amend reg 35(a). However, the appropriate amendment may depend on whether a social model or deconstructionist approach is adopted. A pure proponent of the social model of disability might argue that the best option is to amend reg 35(a) by replacing the word 'health' with 'impairments', and to include a note to the effect of:

> In considering the impairments of the applicants, the Secretary or authorised agency should undertake a holistic assessment, considering both the challenges that a person's impairment might pose for their ability to parent and how they might overcome them.

Such an amendment would oblige the decision-maker to consider the ways that a person with a disability can offer a different but equally valid version of parenting.

In contrast, Tremain's deconstructionist critique of the social model revolves around the fact that the category of 'impairment' reinforces the segregation experienced by people with disabilities. Under this paradigm, the best option would be to remove reg 35(a) altogether so that there is no legislative basis on which to distinguish between people with and without disabilities. However, a risk of this approach is that it fails to account for, and combat, the conscious and unconscious bias likely exercised by caseworkers and relinquishing parents during their holistic analysis.

In this case, there are no easy answers and there is a need for consultation of the disability community on this question. Perhaps one option, which lies between the two theories, is to replace the word 'health' (in both the regulation and the accompanying note) with the word 'body' or 'person'. Such a holistic, neutral term avoids circumscribing to the notion that there is a normal 'healthy' body from which people with impairments deviate, but still leaves room for the decision- maker to consider how societal barriers might make it hard for people with certain bodily characteristics (be they related to physical, intellectual or mental health disabilities) to make it hard for someone to parent.

A more ambitious amendment of reg 35(a) might also include a statutorily enshrined mechanism for applicants to provide a personal statement outlining the social barriers they face and how they might overcome them. This would give the adoptive parents a way to frame any challenges they may face as deriving from society (as opposed to any bodily quality they possess themselves).

Notably, legislative change in this area is important not only because it enshrines the protection of people with disabilities in law, but also because it sends a powerful social message about the Victorian Parliament's commitment to people with disabilities. This can have the flow-on effect of destigmatising disability more broadly (Gelber and McNamara 2015). Obviously, the problem spoken about in this essay (that people with disabilities have difficulty adopting) connects to the systemic social problem of family formation for people with disabilities. Harnessing the signaling and symbolic power of law is but one of the useful mechanisms available to combat this broader social problem, particularly if it can get people speaking about the difficulties people with disabilities face—perhaps for the first time, in Australia.

9.1.2. Provide Financial Support to Compensate for Indirect Discrimination under reg 35(d)

Removing or amending criteria which lead to indirect discrimination would be counterproductive in this case. Not only is financial security considered by the Victorian government as necessary for successful parenting (going by reg 35(d)), but moreover, people with disabilities have consistently argued that they need greater financial support, including to raise children (Frohmader 2009; National Council on Disability 2012).

Instead, the appropriate solution is to provide people with disabilities additional support so they can meet those other criteria, including financial support. Currently, people with disabilities receive no special treatment or resources to help them become adoptive parents (Department of Health and Human Services 2013). Yet, financial and other support for people with disabilities looking to adopt would allow Victoria to discharge both its negative and positive obligations under art 23: it prevents people from disabilities from being discriminated against indirectly (by allowing them to satisfy the requirement of suitable financial circumstances), while also providing them with 'additional measures' to exercise their right to parenthood.

9.1.3. Legislate Caseworkers' Decision-Making Power during the Linking Stage

People with disabilities stand to face both conscious and unconscious discrimination from caseworkers during the short-listing phase of the linking stage. This can be mitigated by implementing criteria that caseworkers are obligated to follow during the short-listing process (similar to reg 35). Similar to the changes suggested for the s 13 order process, this would include a specific statement that a person will not be overlooked on account of an impairment.

9.1.4. Educate Relinquishing Parent(S), Caseworkers and Society More Broadly on the Parenting Ability of People with Disabilities

Discrimination from relinquishing parents during the linking process is a more complex obstacle. This is because the decision-making capacity of the relinquishing parent(s) is currently a protected aspect of the decision-making process, at international, national and state law. Notwithstanding that the protection of decision-making power of relinquishing parents is problematic, the government is powerless with regard to the attitudes and prejudices of relinquishing parents.

The unwillingness of relinquishing parents to consent to certain adoption orders on account of discriminatory attitudes was considered in the VLRC's report on Assistive Reproductive Technology and Adoption (VLRC 2007) albeit in relation to same-sex couple adoption and homophobia. In that report, the VLRC recommended that adoption be open to same-sex couples. In making that recommendation, the report contemplated that certain relinquishing parents would not want their child raised by same-sex parents on account of religious or other beliefs. This meant that same-sex couples stood to be discriminated against. To mitigate against this discrimination, the report recommended that caseworkers receive training to educate the relinquishing parents on the parenting ability of same-sex parents.

The same recommendation can be applied in this context. Without affecting a relinquishing parent's rights or autonomy, the Victorian Parliament can mandate that caseworkers educate relinquishing parents on the social model view of parenting with a disability: where people with disabilities are provided with support to overcome societal barriers, the inherent parenting ability of people with disabilities is no less than that of anyone else.

More broadly, these same educational campaigns need to be rolled out as grassroots programs for caseworkers as well as in Australian society more broadly. As discussed, the problem of adoption does not exist in a vacuum: it is intrinsically connected to the way the Australian state and society more broadly views the parenting capacities of people with disabilities. As such, the solution will require both a top-down and bottom-up approach which encompasses both immediate legal protections but also gradual re-education of the community from where a lot of ignorance and discrimination currently emanates.

9.1.5. Provide Tailored Information to People with Disabilities That Want to Adopt

As discussed, a lack of information catering for people with disabilities feeds an already pervasive societal perception that people with disabilities cannot or should not adopt. The Department needs to provide tailored, relevant information to people with disabilities about the adoption process as well as about parenting with an impairment. Even a devoted web page would be an improvement on the status quo, but other suitable services include special information sessions for people with disabilities and specialised caseworkers. This is not only required on account of the positive obligation in art 23, but is also explicitly required by art 4(h) which requires 'accessible information to persons with disabilities about . . . support services and facilities'.

9.1.6. Fund Universally Designed Technology and Programs

Even before people with disabilities investigate the possibility of adoption, many people with disabilities will be put off by the difficulties they will face being parents if they are successful in gaining an adoption order. While these difficulties are many and varied, and stem largely from societal ignorance, a specific difficulty which the government can directly combat is the lack of technology and facilities designed for people with disabilities. Not only are such technologies mandated by the positive obligation in art 23, but they are explicitly required by art 4(f) which requires that signatories 'undertake or promote research and development of universally designed goods, services, equipment and facilities'.

Such technologies and programs—from strollers to babies' bottles to parenting classes to easily intelligible parenting booklets—will have a bottom-up impact, encouraging more people with disabilities to seek to become parents (Llewellyn et al. 2010). This will increase the visibility of the current problem and further encourage change of the machinery which currently stops people with disabilities from adopting.

9.1.7. Give Support to Parents with a Disability Looking to Adopt a Child Who Also Has a Disability

In an interview with the author of this article, disability activist Booth et al. (2005) argued that parents with disabilities are sometimes uniquely placed to help a child with disabilities enjoy their full rights. She posits that children with disabilities have special needs that are better provided by parents with a similar or the same disability. This transcends knowing how to provide a child with the physical infrastructure to mitigate the effects of an impairment: it is also a mentoring role that a person without a disability is unable to offer. In her words, Booth et al. (2005) says: 'I think there are things that I, as a woman with a disability, can teach a child about living in a world that doesn't represent them'. From this point of view, not only are the best interests of children with disabilities compatible with the parenting of people with disabilities; their interests are sometimes better served with the involvement of parents with disabilities.

Under the current system, people with disabilities are paradoxically further removed from adopting children with disabilities. Such children are only linked with applicants who are considered exceptionally 'fit and proper' parents under the Manual's current (discriminatory) metric. Therefore, people with disabilities are less likely than a person without a disability to be linked with a child with a disability.

A similar scheme already exists for the adoption of Indigenous Australian children and/or children that have a particular religion (see reg 35(f) of the Regulations). A model such as this is particularly pertinent given children with disabilities are currently overrepresented in adoptive agencies (Australian Institute of Health and Welfare 2016; Department of Health and Human Services 2014). This scheme goes beyond just providing additional support to Indigenous parents or those of a particular religion; it actually prioritizes their application to be an adoptive parent.

Such a scheme could already be implemented under current legislation, by reading 'cultural identity' in reg 35(f) widely to include the disability community. However, this must go hand-in-hand with more funding for parents with disabilities looking to adopt, and re-training of caseworkers to enable them to see disability not as a burden, but as a benefit, for parenting.

Of course, a risk of such support is that it suggests that parents with disabilities only adopt children of their 'own kind', further segregating people with disabilities. For this reason, any such system must be thoroughly discussed with the disability community, and should probably opt toward simply giving support to parents who already want to adopt a child with a disability, instead of always pairing prospective parents with disabilities with children with disabilities.

9.2. Action from the Committee

In addition, the Committee must take action to provide Australia and other countries with more jurisprudence on art 23. Admittedly, the Committee must use its words wisely: its State Reports often address signatories whose human rights abuses against people with disabilities relate to other very pressing issues. Nevertheless, the current lack of clarity and substance to do with art 23 makes it difficult for disability advocates to lobby the Victorian government. A General Comment from the Committee on art 23 would be ideal. In the interim, the Committee should start mentioning art 23 in its State Reports.

9.3. Action from Disability Advocates and Allies

This article does not suggest that the onus is on those suffering human rights abuses to create the necessary change. For this reason, lobbying from disability allies remains a necessity. However, a key problem with lobbying efforts may be that the current framework operates behind closed doors—many people with disabilities do not speak publicly about the discrimination they face seeking to become parents (see Part V) (Frohmader 2009). As such, litigation could bring vital visibility to lobbying efforts.

Article 1 of the Optional Protocol to the CRPD allows for the making of individual complaints to the Committee about violations of the CRPD by signatories. While this article has identified a strong prima facie case for violation of art 23 by Victorian adoption law, art 2(d) of the CRPD requires that all domestic remedies have been exhausted before a complaint can be brought under the CRPD Optional protocol. Without offering a view on the merits of such claim, this article suggests that a useful direction for future research would be the viability of a claim brought by a person with a disability who has been denied a section 13 order under the Equal Opportunity Act 2010 (Vic) or the Charter of Human Rights and Responsibilities Act 2006 (Vic).

10. Hidden Impairments

While the overarching effect of Victoria's current scheme is to disenable people with disabilities from adopting, there is a potential exception to this rule: those with invisible or hidden impairments. Hidden impairments and impairments which are not outwardly visible (Montgomery 2001). There is significant academic literature on how people with hidden impairments are treated differentially on account of their impairment being less visible (Montgomery 2001; Samuels 2003; Ginsberg 1996). Where a person with a hidden impairment is treated as a person without a disability, this is referred to as passing (Ginsberg 1996).

Victoria's adoption framework is a prime example of a situation where passing is possible. While the Regulations require disclosure of all relevant 'health' information, they do not define the meaning or scope of the word 'health'. This means that people with certain disabilities might not be required to disclose, or might choose not to disclose, certain impairments. Such hidden impairments might include sensory impairment below a certain level, learning and cognitive differences and repetitive strain injuries (Samuels 2003).

There is dissensus within the disability community on the ethics of passing. Samuels (2003) defends the right of people with disabilities to 'pass' in order to gain a more beneficial position in society. This is because, under the social model, they are in no way responsible for the structural disadvantage which they are seeking to avoid (even if they may suffer feelings of 'misrecognition and internal dissonance' as consequences of passing) (Samuels 2003).

Other theorists propose that passing creates a splinter within the disability community. Where certain people with disabilities remain invisible, this makes the overall group look smaller and makes progress on disability human rights harder to achieve (Kleege 1999). Under this view, there is a positive obligation on people with disabilities to disclose their disability during the adoption process (Wendell 1996): '[p]assing is the sign of the sell out' (Walker 2001).

A third approach to passing is offered by Cal Montgomery: his approach is to reject the distinction between visible and non-visible identities that makes 'passing' possible in the first place (Montgomery 2001). Drawing on the social model, Montgomery (2001) argues that passing refers only to whether onlookers can see the barriers that a person with a disability faces, and not whether those barriers actually exist. Therefore, passing emerges from the gaze of society, and not the actions of an individual.

For the purposes of this article, it is sufficient to note that adoption legislation can facilitate passing; in the Victorian case, the adoption legislation provides a set of criteria which draw a line (albeit a blurry one) through the disability community, making it harder for some to adopt, but not others.

There is no provision of the CRPD that deals with this phenomenon. While it is beyond the scope of this article to offer a fully-fledged solution, it recommends that the Victorian Parliament—and other CRPD signatories—be cognisant of the visible/hidden impairment dynamic in creating solutions. Those solutions which carve out exceptions for certain types of disabilities (e.g., people with mobility impairments are entitled to a section 13 order) may reinforce the divide and make long-term change more unattainable for the entire disability community. This reinforces one of the recommendations above: that the Parliament should focus on change that allows caseworkers to make holistic assessments of parenting.

11. Conclusions

The difficulty faced by people with disabilities looking to adopt is an important issue in and of itself. The CRPD expressly names adoption as a right belonging to people with disabilities. In addition, given many adoption regimes, including Victoria's, hinge on a court or panel's assessment of whether a person could be a good parent, adoption systems have a lot to say about how the state views the family unit, and how people with disabilities fit into that conception. Given that law has the ability to shape societal views, adoption law also has important connections to how our society views the parenting capabilities of people with disabilities.

While research in the area of parenting rights (as well as Committee jurisprudence, for that matter) has tended to overlook significance of the right to adopt, this article has sought to restate its importance. Specifically, this article has shown that Victoria's adoption framework, both on article and in practice, violates Australia's obligations under art 23 of the CRPD. Paradoxically, the adoption framework that should implement Australia's obligations under art 23(2) has in fact become one of the societal barriers that Australia committed to eradicating by ratifying the CRPD.

Not only do the Act and the Regulations fail to contain any of the positive obligations envisaged by art 23(2), more worryingly, the Manual that implements Victoria's adoption law openly espouses a medical model conception of people with disabilities' ability to parent. In addition, the current framework hands over vast swathes of unfettered decision-making power to caseworkers and relinquishing parent(s), without providing affirmative protections for people with disabilities against discrimination by those decision-makers. The nuance between hidden and visible identities has the capacity to further complicate the effect of the adoption framework on the disability community.

More broadly, this article used Victoria as a case study to show that discrimination against people with disabilities does not just come from people's prejudices; it also hides insidiously within the words of adoption legislation. Any CRPD signatory with legislation which resembles Victoria's—which includes other Australian states, the UK and the many US states—must realise the discrimination emanating from their own legislative instruments and undertake meaningful reform to allow people with disabilities to adopt.

Future research must continue to explore the support which governments can offer people with disabilities once they succeed in becoming parents. Unfortunately, a more crucial first step toward adherence to art 23 for many CRPD signatories is the eradication of certain barriers to parenthood that people with disabilities face. This article has shown that one such barrier is often the adoption process.

References

Abberley, Paul. 1987. The Concept of Oppression and the Development of a Social Theory of Disability. *Disability, Handicap and Society* 2: 5–19. [CrossRef]

Anthony, Thalia, and Honni van Rijswijk. 2012. Parental 'consent' to child removal in Stolen Generations cases. In *Past Law, Present Histories*. Edited by Diane Kirkby. Canberra: ANU E-Press.

Arstein-Kerslake, Anna. 2015. Understanding sex: The right to legal capacity to consent to sex. *Disability & Society* 30: 1459–73.

Attwood, Bain. 2001. The Stolen Generations and genocide: Robert Manne's in Denial: The Stolen Generations and the Right. *Aboriginal History* 25: 163–72.

Australian Bureau of Statistics. 2012. Disability, Ageing and Carers, Australia: Summary of Findings. Available online: http://www.abs.gov.au/ausstats/abs@.nsf/lookup/A813E50F4C45A338CA257C21000E4F36?opendocument (accessed on 28 May 2017).

Australian Institute of Family Studies. 2016. Children in Care: CFCA Resource Sheet. Available online: https://aifs.gov.au/cfca/publications/children-care (accessed on 16 July 2017).

Australian Institute of Health and Welfare. 2016. Adoptions Australia 2015-16. Available online: http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129558075 (accessed on 17 July 2017).

Barnes, Colin. 2003. What a Difference a Decade Makes: Reflections on Doing 'Emancipatory' Disability Research. *Disability & Society* 18: 3–17.

Barnes, Colin, and Geoffrey Mercer. 1996. *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press.

Barnes, Colin, and Geof Mercer. 1997. Breaking the Mould? An Introduction to Doing Disability Research. In *Doing Disability Research*. Edited by Colin Barnes and Geof Mercer. Leeds: The Disability Press.

Blanck, Peter, Eilionóir Flynn, and Gerard Quinn. Forthcoming; *A Research Companion to Disability Law*. Galway: Ashgate.

Booth, Tim, Wendy Booth, and David McConnell. 2005. The Prevalence and Outcomes of Care Proceedings Involving Parents with Learning Difficulties in the Family Courts. *Journal of Applied Research in Intellectual Disabilities* 18: 7–17. [CrossRef]

Brown, Jax Jacki. 2015. Australia's Coming Around on Same-Sex Adoption, But Will It Ever Happen For People With Disability? Available online: http://junkee.com/australia-is-on-board-with-same-sex-adoption-but-will-things-ever-change-for-those-with-disability/71088#mPzv7RO2kBhRUh7Q.99 (accessed on 4 April 2016).

Carter, Barbara. 2016. Rebuilding the Village: Supporting Families Where a Parent Has a Disability. Available online: http://www.publicadvocate.vic.gov.au/our-services/publications-forms/241-rebuilding-the-village-supporting-families-where-a-parent-has-a-disability-report-2-child-protection-2015?path= (accessed on 28 May 2017).

Chapman, Rohhss, Sue Ledger, Louise Townson, and Daniel Docherty. 2015. *Sexuality and Relationships in the Lives of People with Intellectual Disabilities: Standing in My Shoes*. London: Jessica Kingsley Publishers.

Clarke, Harriet, and Richard Olsen. 2003. *Parenting and Disability: Disabled Parents' Experiences of Raising Children*. Bristol: The Policy Press.

Collins, Carol. 1999. Reproductive Technologies for Women with Physical Disabilities. *Sexuality and Disability* 17: 299–307. [CrossRef]

Crawford, Nicole. 2003. Parenting with a Disability. *Monitor on Psychology* 34: 68.

Deane, Kirsten. 2009. SHUT OUT: The Experience of People With Disabilities and Their Families in Australia. Available online: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia (accessed on 6 April 2016).

Department for Child Protection and Family Support. 2016. Thinking about Adoption? Available online: https://www.dcp.wa.gov.au/FOSTERINGANDADOPTION/ADOPTIONANDHOMEFORLIFE/PAGES/ALLABOUTADOPTION.ASPX#1 (accessed on 28 May 2017).

Department for Education. 2014. Draft Statutory Guidance on Adoption. Available online: http://minimumstandards.org/adoption_statutory_guidance_2014.pdf (accessed on 28 May 2017).

Department of Health and Human Services. 1986. Adoption Standards. Available online: http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/adoption-and-permanent-care-standards-1986 (accessed on 4 November 2016).

Department of Health and Human Services. 1997. National Principles in Adoption. Available online: http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/national-principles-in-adoption-1997 (accessed on 4 November 2016).

Department of Health and Human Services. 2001. Adoption and Permanent Care Manual. Available online: http://www.dhs.vic.gov.au/__data/assets/pdf_file/0012/589593/apc_procedure_manual_2aug04.pdf (accessed on 4 November 2016).

Department of Health and Human Services. 2013. Adoption and Permanent Care—Frequently Asked Questions. Available online: http://www.dhs.vic.gov.au/for-individuals/children,-families-and-young-people/adoption-and-permanent-care/adoption-and-permanent-care-frequently-asked-questions#content-heading-14 (accessed on 4 April 2016).

Department of Health and Human Services. 2014. Adoption. Available online: https://www.betterhealth.vic.gov.au/health/healthyliving/adoption (accessed on 4 April 2016).

Doyle, Oran. 2007. Direct Discrimination, Indirect Discrimination and Autonomy. *Oxford Journal of Legal Studies* 27: 537–53. [CrossRef]

Fennell, Phil. 1992. Balancing Care and Control: Guardianship, Community Treatment Orders and Patient Safeguards. *International Journal of Law End Psychiatry* 15: 205–35. [CrossRef]

Finkelstein, Victor. 1980. *Attitudes and Disabled People: Issues for Discussion*. Leeds: World Rehabilitation Fund.

Fleming, Grace. 2015. Disability Discrimination of Prospective Adoptive and Foster Parents. Master's thesis, University of Minnesota, Minneapolis, MN, USA.

Freeman, Melvyn Colin, Kavitha Kolappa, Jose Miguel Caldas de Almeida, Arthur Kleinman, Nino Makhashvili, Sifiso Phakathi, Benedetto Saraceno, and Graham Thornicroft. 2015. Reversing hard won victories in the name of human rights: A critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities. *The Lancet Psychiatry* 2: 844–50. [CrossRef]

Frohmader, Carolyn. 2009. Parenting issues for women with disabilities in Australia. Available online: http://wwda.org.au/wp-content/uploads/2013/12/parentingpolicyarticle09.pdf (accessed on 6 April 2016).

Gelber, Katherine, and Luke McNamara. 2015. The Effects of Civil Hate Speech Laws: Lessons from Australia. *Law and Society* 49: 631–64. [CrossRef]

Ginsberg, Elaine. 1996. *Passing and the Fictions of Identity*. Durham: Duke University Press.

Goering, Sara. 2015. Rethinking disability: The social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine* 8: 134–38. [CrossRef] [PubMed]

Goodley, Dan. 2011. *Disability Studies: An Interdisciplinary Approach*. London: SAGE Publications.

Grace, Elizabeth. 2014. Your Mama Wears Drover Boots. In *Criptiques*. Edited by Caitlin Wood. San Bernardio: May Day Publishing.

Grue, Lars, and Kristin Laerum. 2002. 'Doing Motherhood': Some experiences of mothers with physical disabilities. *Disability and Society* 17: 671–83. [CrossRef]

Hahn, Harlan. 1988. The Politics of Physical Differences: Disability and Discrimination. *Journal of Social Issues* 44: 39–47. [CrossRef]

Hellman, Deborah, and Sophia Moreau. 2013. *Philosophical Foundations of Discrimination Law*. Oxford: Oxford University Press.

Horin, Adele. 2010. Refugee Children Removed. The Sydney Morning Herald: Available online: http://www.smh.com.au/nsw/refugee-children-removed-20100418-smn6.html (accessed on 16 July 2017).

Hunt, Paul. 1966. A Critical Condition. In *Stigma: The Experience of Disability*. Edited by Paul Hunt. London: Geoffrey Chapman.

IASSID (International Association for the Scientific Study of Intellectual Disabilities). 2008. Parents Labelled with Intellectual Disability: Position of the IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 21: 296–307.

Kayess, Rosemary, and Phillip French. 2008. Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 8: 1–34. [CrossRef]

Kempton, Winifred, and Emily Kahn. 1991. Sexuality and People with Intellectual Disabilities: A Historical Perspective. *Sexuality and Disability* 9: 93–111. [CrossRef]

Kirshbaum, Megan, and Rhoda Olkin. 2002. Parents with Physical, Systemic or Visual Disabilities. *Sexuality and Disability* 20: 65–80. [CrossRef]

Kleege, Georgina. 1999. *Sight Unseen*. New Haven: Yale University Press.

Llewellyn, Gwynnyth, David McConnell, and Luisa Ferronato. 2003. Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect* 27: 235–51. [CrossRef]

Llewellyn, Gwynnyth, Rannveig Traustadottir, David McConnell, and Hanna Bjorg Sigurjonsdott. 2010. *Parents with Intellectual Disabilities: Past, Present and Futures*. Chichester: Wiley-Blackwell Publishing.

Malacredia, Claudia. 2009. Performing Motherhood in a Disablist World: Dilemmas of Motherhood, Femininity and Disability. *International Journal Qualitative Studies in Education* 22: 99–117. [CrossRef]

Montgomery, Cal. 2001. A Hard Look at Invisible Disability. Available online: http://www.ragged-edge-mag.com/0301/0301ft1.htm (accessed on 19 August 2017).

National Council on Disability. 2012. National Disability Policy: A Progress Report. Available online: https://ncd.gov/progress_reports/Aug202012 (accessed on 17 July 2017).

Office of the High Commissioner on Human Rights. 2016. Elected Members of the Committee on the Rights of Persons with Disabilities. Available online: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Membership.aspx (accessed on 17 July 2017).

Oliver, Michael. 1996. *Understanding Disability: From Theory to Practice*. New York: St. Martin's Press.

Radcliffe, Victoria. 2008. "Being Brave": Disabled Women and Motherhood. Master's dissertation, The University of Leeds, Leeds, UK.

Samuels, Ellen. 2003. My Body, My Closet: Invisible Disability and the Limits of Coming out. *Journal of Lesbian and Gay Studies* 9: 233–55. [CrossRef]

Senate Community Affairs References Committee. 2015. Out of Home Care. Available online: http://www.aph.gov.au/binaries/senate/committee/clac_ctte/completed_inquiries/2004-07/inst_care/report/report.pdf (accessed on 17 July 2017).

Shakespeare, Tom. 2002. The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability* 2: 9–28.

Shakespeare, Tom. 2013. The Social Model of Disability. In *The Disability Studies Reader*. Edited by Lennard Davis. New York: Routledge.

Shakespeare, Tom, Kath Gillespie-Sells, and Dominic Davies. 1996. *The Sexual Politics of Disability: Untold Desires*. New York: Cassell.

Steele, Linda. 2016. Court authorised sterilisation and human rights: Inequality, discrimination and violence against women and girls with disability. *UNSW Law Journal* 39: 1002–37.

Sutherland, Allan. 1981. *Disabled We Stand*. London: Souvenir Press.

Thomas, Carol, and Penny Curtis. 1997. Having a Baby: Some Disabled Womens' Reproductive Experiences. *Midwifery* 13: 202–9. [CrossRef]

Tremain, Shelley. 2002. On the Subject of Impairment. In *Disability/Postmodernity: Embodying Disability Studies*. Edited by Marian Corker and Tom Shakespeare. London: Bloomsbury Publishing.

UPIAS (Union of the Physically Impaired Against Segregation). 1974. Policy Statement. Available online: http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf (accessed on 28 April 2016).

VLRC (Victorian Law Reform Commission). 2007. Assisted Reproductive Technology & Adoption. Available online: http://www.lawreform.vic.gov.au/all-projects/art-adoption (accessed on 6 April 2016).

Walker, Lisa. 2001. *Looking Like What You Are: Sexual Style, Race and Lesbian Identity*. New York: New York University Press.

Warner, Michael. 2000. *The Trouble with Normal: Sex, Politics, and the Ethics of Queer Life*. Cambridge: Harvard University Press.

Wates, Michele. 2002. Disability and Adoption: How Unexamined Attitudes Discriminate against Disabled People as Parents. *Adoption and Fostering Journal* 26: 49–56. [CrossRef]

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.

Westbrook, Marry T., and Darien Chinnery. 1995. The Effect of Physical Disability on Women's Childbearing and Early Childrearing Experiences. *Australian Disability Review*, 3–17.

Young, Stella. 2012. Don't Look Past My Disabled Body. The Sydney Morning Herald. Available online: http://www.smh.com.au/lifestyle/life/citykat/dont-look-past-my-disabled-body--love-it-20120712-21ycy.html (accessed on 4 April 2016).