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Disability Human Rights Clinic

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GROUP 1 PROJECT

Advancing the Rights of Women and Girls with Disability to Give Consent to Abortion and Contraception: A Tool for Civil Society

Partner Organisation

Red por los Derechos de las Personas con Discapacidad (Latin American Network for the Rights of Persons with Disabilities)

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NORMATIVE FRAMEWORK THAT RECOGNISES AND GUARANTEES WOMEN WITH DISABILITIES' RIGHT TO GIVE CONSENT TO ABORTION

I INTRODUCTION

This document provides guidelines to assist States to comply with their obligations under the Convention on the Rights of Persons with Disabilities (CRPD) to recognise and guarantee the specific right to consent to abortion.¹ States have an obligation to take affirmative action to eliminate discrimination against women with disabilities and empower them.²

A What are the norms of international human rights law that recognise the right to sexual and reproductive health?

It is well established in the international human rights regime that a woman's right to health is inclusive of her sexual and reproductive health.³ Furthermore, all persons with disabilities have the right to marry and found a family, decide freely and responsibly on the number and spacing of their children, and retain their fertility on an equal basis with others.⁴

The CRPD also affirms that all persons with disabilities have the right to live independently and participate in all aspects of their life, and imposes obligations on states to ensure that persons with disabilities can access information, facilities and services on an equal basis with others.⁵

¹ The term 'women and girls' is used throughout this document in order to be consistent with the language in the CRPD. However, this framework is intended to be inclusive of all persons capable of becoming pregnant, including trans, intersex and gender diverse people.

² Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Guatemala*, CRPD/C/GTM/CO/1, 30 September 2016, para 20; *Convention on the Rights of Persons with Disabilities* (CRPD), Article 6.

³ *Convention on the Elimination of Discrimination against Women* (CEDAW), Article 11; United Nations Population Fund, 'Program of Action' (Adopted at *The International Conference of Population Development*, Cairo, 13 September 1994) [59]; United Nations Entity for Gender Equality and the Empowerment of Women, "Beijing Declaration and Platform for Action" (Adopted at the *Fourth World Conference on Women*, Beijing, 15 September 1995) [3, 91].

⁴ CRPD, Article 23.

⁵ CRPD, Article 9, 19.

The CRPD also reiterates the rights of all persons with disabilities to have their bodily integrity respected on an equal basis with others.⁶ It also states that free and informed consent must be given prior to any medical treatment.⁷

B What is the content and scope of the right to sexual and reproductive health?

The right to safe abortion services comprises a component of the right to sexual and reproductive health for women.⁸ Restricting access to safe abortion services also exposes women to unsafe abortion, which has the potential to violate their rights to bodily integrity.⁹

Laws, regulations and policies that relate to reproductive information and services should aim to eliminate discrimination that can lead to forced and coercive practices.¹⁰ Any criteria pertaining to administering an abortion in the absence of free and informed consent (for example, in the case of life-threatening emergency) must not distinguish between, or apply different criteria to, persons with and without disabilities.¹¹

C What constitutes a violation of the right to sexual and reproductive health?

Violations of women's sexual and reproductive health rights include denial of access to female-oriented services, making women's access to services subject to authorization by third parties, and performing procedures that relate to women's reproductive and sexual health – including abortion – without consent.¹² Women with

⁶ CRPD, Article 17.

⁷ CRPD.

⁸ Dr Carmel Shalev, *Rights to Sexual and Reproductive Health - the ICPD and the Convention on the Elimination of All Forms of Discrimination Against Women*, 18 March 1998, accessed online at <<http://www.un.org/womenwatch/daw/csw/shalev.htm>>

⁹ Ibid.

¹⁰ United Nations Population Fund, *State of World Population 2012: By choice, not by chance: family planning, human rights and development*, 2012, accessed online at <<http://www.unfpa.org/sites/default/files/resource-pdf/EN-SWOP2012-Summary.pdf>>; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(d)], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>

¹¹ Juan Méndez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, HRC Res 16/23, 22nd sess, Agenda Item 3, A/HRC/22/53, 1 February 2013, [66] accessed online at <http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf>.

¹² Ibid.

disabilities are often prevented from participating in decisions about their own personal health care and may be excluded entirely.¹³

1 What is abortion?

The World Health Organisation describes abortion as a procedure for deliberately terminating a pregnancy.¹⁴ It can be carried out surgically (through vacuum aspiration), or by medical methods including taking pharmacological drugs.¹⁵ Complications may arise following an abortion, including post-abortion infection and haemorrhage, which may require further health treatment.¹⁶

2 What is forced or coercive abortion?

The right to give consent to abortion is infringed when the medical intervention is coerced, or forced (including by obtaining third party consent but not the patient's consent).¹⁷ Circumstances where an abortion is forced also includes where the procedure is performed without the individual's knowledge, where it is administered after the individual has refused, or where the procedure is performed without prior consent being given.¹⁸

Coercion will occur where the patient agrees to the abortion because they are induced by incentives, 'including offers of food, money, land and housing' or because pressure is placed upon them by 'threats, fines or punishments' or intimidation.¹⁹

¹³ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [19], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹⁴ The Free Dictionary by Farlex, *Medical Dictionary: definition of 'abortion'*, <<https://medical-dictionary.thefreedictionary.com/abortion>>.

¹⁵ World Health Organization (WHO), *Safe Abortion: technical and policy guidance for health systems*, (2012, 2nd Ed) iv, accessed online at <http://apps.who.int/iris/bitstream/10665/70914/1/9789241548434_eng.pdf?ua=1>.

¹⁶ WHO, *Health worker roles in providing safe abortion care and post-abortion contraception*, (2015) 12, accessed online at <http://apps.who.int/iris/bitstream/10665/181041/1/9789241549264_eng.pdf?ua=1&ua=1>.

¹⁷ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [2, 9], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

¹⁸ European Parliament Directorate-General for Internal Policies, *Discrimination Generated by the Intersection of Gender and Disability* (2013) accessed online at <<http://www.aph.gov.au/DocumentStore.ashx?id=1995d0fb-977a-4a5a-a959-c516633c565a>>.

¹⁹ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [2, 10], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>; Open Society Foundations, *Against Her Will: Forced and Coerced Sterilization of Women Worldwide* (2011) accessed online at <<https://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf>> [2].

Providing misleading information is coercion. Requiring the patient's agreement to abortion as a condition to accessing medical care or employment is also coercion or pressure.²⁰

3 What is insufficient or no sexual education?

For women and girls with disabilities to enjoy rights to sexual and reproductive health on an equal basis with others, they must be able to access the same level of sexual education as that of women and girls without disabilities.²¹ Having a comprehensive sex education is critical to ensuring that consent to abortion and other procedures or treatments relating to sexual and reproductive health is free and informed.²²

D What are the norms of international human rights law that recognise the right to consent to abortion?

States are obligated to take all appropriate and effective measures to ensure that the legal capacity of persons with disabilities are recognised and respected.²³ Ensuring and supporting the exercise of free and informed consent to medical procedures, including abortion, is a significant aspect of this.²⁴

Forced or coerced abortions are a violation of several human rights. For instance, they constitute a clear violation of article 25(d) of the CRPD, which requires that health practitioners only treat patients on the basis of free and informed consent. Such forced interventions have been recognised by international human rights instruments and agencies as constituting violence, torture and cruel, inhuman or degrading treatment in breach of article 5 of the Universal Declaration of Human Rights, article 15 of the CRPD, article 7 of the International Covenant on Civil and

²⁰ Ibid [2]; WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [14], accessed online at

<http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

²¹ Chelsea Krupa and Shaniff Esmail, "Sexual health education for children with visual impairments: talking about sex is not enough" (2010) 104 6 *Journal of Visual Impairment and Blindness*, 327.

²² UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [paragraph 41].

²³ CRPD, Article 12

²⁴ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [10], accessed online at <[https://documents-dds-](https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement)

[ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement](https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement)>; The International Federation of Gynecology and Obstetrics (FIGO) Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, "Recommendations for Female Contraceptive Sterilisation", *Ethical Issues in Obstetrics and Gynecology* (2011) 125.

Political Rights and article 37(a) of the Convention on the Rights of the Child ('CRC').²⁵ Furthermore, administering medical treatment or procedures in the absence of free and informed consent, and legal compulsion, are forms of violence, exploitation and/or abuse against women and girls with disabilities, in breach of articles 6 and 16 of the CRPD, and article 19 of the CRC.²⁶ Finally, making decisions about abortion on behalf of women and girls with disabilities, or accepting the substituted consent of medical practitioners, family, caregivers, or other persons, also constitutes a violation of the right to equal recognition before the law in article 12 of the CRPD.

E How do stereotypes, misconceptions and misinformation play a role in rights violations?

Women with disabilities may be subject to intersectional discrimination, not only on the basis of their gender or disability, but also due to multiple, overlapping factors including race, ethnicity, religion or belief, age, class, caste or sexual orientation.²⁷ Discriminatory views, stigma and widespread misconceptions about the parenting skills of women with disabilities, wrongful eugenics-based concerns, and beliefs that persons with disabilities are unlikely or unable to engage in sex, perpetuate the assumption that girls and women do not need to access information or participate in education about reproductive health and abortion.²⁸ A further barrier is where this information is presented in a medium that is inaccessible to women with disabilities. These factors contribute to the prevalence of women with disabilities being denied their rights, including the right to health and the right found a family, by being coerced or even forced into undergoing an abortion.²⁹

²⁵ WHO, *Involuntary sterilization*, 1, accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>; CRPD, Articles 5, 12, 23 and 25.

²⁶ UN Committee on the Rights of Persons with Disabilities, *General comment No. 3 (2016) on women and girls with disabilities*, CRPD/C/GC/3, 25 November 2016, [31], [54].

²⁷ UN Committee on the Rights of Persons with Disabilities, *General Comment No. 3 (2016) on women and girls with disabilities*, CRPD/C/GC/3, 25 November 2016; UN Committee on the Elimination of Discrimination against Women, *General Recommendation No 28 on the Core Obligations of State Parties under Article 2 of the Convention of the Elimination of all Forms of Discrimination against Women*, CEDAW/C/2010/47/GC.2, 19 October 2010.

²⁸ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [19, 31], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

²⁹ *Ibid* [31].

II WHAT ACTIONS DO STATES NEED TO TAKE TO RECOGNISE AND GUARANTEE THE RIGHT TO GIVE CONSENT TO ABORTION?

1. Criminalise harmful and forced practices that affect sexual reproductive and health rights, including forced and coercive abortion, and ensure that offenders are prosecuted;³⁰
2. Introduce procedural safeguards to protect the right to free and informed consent to abortion;³¹
3. Implement legislation for access to supported decision-making processes at no or nominal cost;³²
4. Remove legal barriers that prevent girls and women with disabilities from accessing information regarding their sexual and reproductive health and rights information, good and services. This can extend to any legislation relating to guardianship that reduces legal capacity or diminishes their right to make their own decision;³³
5. Implement healthcare practices for safe and accessible abortion;³⁴
6. Ensure comprehensive sexuality education for girls and young women with disabilities is available and accessible, in formal and non-formal

³⁰ PLAN International, *Let Me Decide and Thrive: Global discrimination and exclusion of girls and young women with disabilities* (December 2017) 15, accessed online at <<https://plan-international.org/publications/let-me-decide-thrive-srhr-disability#download-options>>.

³¹ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(b)], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

³² UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [28]; See for example, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Tunisia, supra* [note 40], *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Spain*.

³³ Above n 32.

³⁴ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [11] accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

education settings. This education should be youth friendly and rights based;³⁵

7. Provide training and awareness-raising activities for relevant actors, including³⁶
 - Training for parents and educators to support girls and young women with disabilities to learn about their bodies, sexuality and relationships from a young age through to adulthood;³⁷
 - Training for health care practitioners on the requirement of obtaining free and informed consent prior to abortion;³⁸
8. Ratify and implement core conventions that relate to protecting the sexual and reproductive health and rights of women and girls with disabilities. This includes the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the CRPD;³⁹
9. Ensure access to justice by providing access through legal aid to judicial redress mechanisms;⁴⁰
10. Empower and require the appropriate public authority to investigate reports of forced abortion.⁴¹

A What is the minimum content of free and informed consent?

³⁵ Above n 32; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(e)] accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

³⁶ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [15], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>; see e.g. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Montenegro*, CRPD/C/MNE/CO/1, 22 September 2017 at [47].

³⁷ Above n 32.

³⁸ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [41].

³⁹ Above n 32.

⁴⁰ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [16], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

⁴¹ Ibid.

For a person to provide informed consent to medical intervention there must be more than mere acceptance of the procedure.⁴² The consent must be made voluntarily and after the woman has been sufficiently informed of the purpose, effects and risks of the intervention.⁴³

The International Federation of Gynaecologists and Obstetricians (FIGO) endorses the following definition of informed consent to medical procedures:

Informed consent is a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- a) *The diagnostic assessment;*
- b) *The purpose, method, likely duration and expected benefit of the proposed treatment;*
- c) *Alternative modes of treatment, including those less intrusive and;*
- d) *Possible pain or discomfort, risks and side effects of the proposed treatment.*⁴⁴

A corollary of the requirement of free and informed consent is that the patient has the right to refuse to consent if that is their will and preference.

B What formalities are required for obtaining consent?

Certain formalities must be completed in order for free and informed consent to be obtained. There must be a written record of an agreement (including an oral agreement) of consent or non-consent that accurately reflects the decision made by the woman or girl. To be inclusive of women and girls with disabilities, when seeking

⁴² Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 'Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms' HRC 6/29, 64th sess, Agenda Item 71(b), A/64/272, available at <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement>.

⁴³ Ibid.

⁴⁴ FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, "Guidelines Regarding Informed Consent", *Ethical Issues in Obstetrics and Gynecology* (2011) [14].

consent for an abortion, non-traditional methods may need to be adopted.⁴⁵ These may include:

- Recording verbal conversations for people who have limited literacy or written communication skills;
- Permitting or organising the presence of a support person to assist with communicating information and/or conveying the person's understanding and decision.⁴⁶ However, the support person's opinions or views should not be given undue weight or taken as substituted consent. Further information on supported decision-making and impermissible forms of substituted decision-making is provided below.
- Providing information in 'easy-to-read formats and augmentative and alternative modes and methods to persons with disabilities who use such formats, modes and methods'.⁴⁷ Examples are information in Braille or picture format, or provision of a sign language interpreter or an assistive communication device. The importance of accessible information is discussed further below.

C The importance of privacy and confidentiality in the decision-making process

If the patient indicates that a medical appointment and/or decision about treatment should be private and not disclosed to a parent or caregiver, then this must be respected.⁴⁸ Additionally, health practitioners should remember that the confidentiality of such decisions and discussions does not change merely because their patient has a disability.⁴⁹ Moreover, the practitioner should not disclose the matters discussed and the decisions reached during the consultation to the patient's caregiver without their consent.

D What information is needed for consent to be informed?

Certain information must be provided to a woman or girl before informed consent to abortion can be obtained:

⁴⁵Anna Arstein-Kerslake, 'Understanding sex: the right to legal capacity to consent to sex' (2015) 30 10 *Disability & Society* 1459.

⁴⁶Eilionor Flynn, Anna Arstein-Kerslake, 'Legislating Personhood: realising the right to support in exercising legal capacity' (2014) 10 1 *International Journal of Law in Context* 81 [85].

⁴⁷ UN Committee on the Rights of Persons with Disabilities, *General comment No. 2 (2014)*, CRPD/C/GC/2, 22 May 2014.

⁴⁸ WHO, *Safe Abortion: technical and policy guidance for health systems*, (2012, 2nd Ed) 4.1, accessed online at <http://apps.who.int/iris/bitstream/10665/70914/1/9789241548434_eng.pdf?ua=1>; CRPD, Articles 3(a) and 22.

⁴⁹ WHO, *Safe Abortion: technical and policy guidance for health systems*, (2012, 2nd Ed) 4.1, accessed online at <http://apps.who.int/iris/bitstream/10665/70914/1/9789241548434_eng.pdf?ua=1>

- Medically accurate information about abortion in a form that can be understood and recalled;
- Contraceptive information/services and referrals;
- Information about the (low) risks associated with properly performed abortions, noting that the vast majority of women who have undertaken a proper abortion will not suffer any long-term effects on general or reproductive health;⁵⁰
- Clear instructions as to how to recognise any complications following the procedure, and how to care for themselves. This may include:
 - A need to return to the health care facility following any pain bleeding or fever,
 - Emergency contraception.

Although international law recommends that safe and affordable abortion services be available, this may not always be the case.⁵¹ Therefore, in cases where abortion may be unsafe, women should be made aware of the relevant risks of complications such as infection, and potentially death.⁵²

E How can such information be made accessible?

Prior to administering an abortion on a woman or girl with disability, information provided should be comprehensible to the individual person, to ensure meaningful participation in the decision.⁵³ Properly trained personnel have a responsibility to convey accurate, clear information in a format readily understandable to the individual person, free from coercion.⁵⁴

Information should be presented in a way that is non-conventional if that is required for a patient to access and understand it.⁵⁵ Ensuring accessibility may be as basic as using simpler language, but it may also require the practitioner to engage in

⁵⁰ Ibid.

⁵¹ Dr Carmel Shalev, *Rights to Sexual and Reproductive Health - the ICPD and the Convention on the Elimination of All Forms of Discrimination Against Women*, 18 March 1998, accessed online at <<http://www.un.org/womenwatch/daw/csw/shalev.htm>>.

⁵² WHO Media Centre, *Preventing Unsafe Abortion: Fact Sheet* (September 2017) World Health Organization <<http://www.who.int/mediacentre/factsheets/fs388/en/>>.

⁵³ WHO, *Eliminating forced coercive and otherwise involuntary sterilization: An interagency statement - OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO* (2014) accessed online at: <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>; CRPD, Article 5.

⁵⁴ Ibid.

⁵⁵ CRPD, Articles 9 and 12.

communication with the assistance of visual aids, animated guides or other means the patient requires to access information. The need for non-conventional means of communication should not be deemed as a justification for substituted decision-making. That is, practitioners must prioritise their ethical and legal obligations to ensure that their patient (as opposed to a medical practitioner, family member or caregiver) is provided with all relevant information about the procedure being contemplated.⁵⁶ While the most appropriate method of communication for the patient may be ‘unintuitive’ or ‘time consuming’ for the practitioner to utilise, the CRPD requires that this must be provided as a ‘reasonable accommodation’ to ensure that the patient is ensured the right to free and informed consent on an equal basis to persons without a disability.⁵⁷

F What is supported decision-making?

Supported decision-making describes various support options that place the will and preference of the person with disability at the forefront of decision-making.⁵⁸ It involves one or more third party supporters providing support to a person to make their own decision. A crucial element of informed consent and supported decision-making is the provision of accessible and accurate information to enable a person to make a decision according to their will and preferences.⁵⁹ Support may take many forms, from assisting the person to access and interpret information, to interpreting the preferences and will of the person if they are communicated in a non-standard way and communicating the decision to third parties.⁶⁰

A person may already have systems of support for decision-making, such as peer support, community support networks and recovery oriented services. However, some people may not have access to support, or may require alternative forms of support for making decisions about abortion. States should consider whether policy or legislation is required to ensure support for decision-making is available to all women who would benefit from it.⁶¹ Such supports should be made available by

⁵⁶ FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women’s Health, “Ethical Guidelines for Gynecologic and Obstetric Care”, *Ethical Issues in Obstetrics and Gynecology* (2011) 12

⁵⁷ CRPD, Article 5(a).

⁵⁸ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [29].

⁵⁹ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [42].

⁶⁰ Above n 49 [85].

⁶¹ T Minkowitz, ‘The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from nonconsensual psychiatric interventions’ (2007) 34 2 *Syracuse Journal of International Law and Commerce* 405 [409].

states for free or only a nominal cost, so that limited financial resources are not be a barrier to accessing supported decision-making options.⁶²

Women should have the right to refuse support or terminate the support arrangement.⁶³ Additionally, states should provide training for girls and women receiving support when making a decision which equips them to decide when less support is needed or when they no longer require support in the exercise of their legal capacity.⁶⁴

Safeguards are necessary to prevent relationships where the supporting person has a conflict of interest or exercises undue influence.⁶⁵ This includes training medical practitioners, family members and caregivers about the meaning and purpose of supported decision-making to ensure that it is appropriately implemented.

G What training and awareness-raising is required?

States have a duty to enforce the responsibility of medical practitioners to obtain free and informed consent of women and girls to medical interventions.⁶⁶ Therefore states should ensure there is sufficient funding for training of health-care providers along with policy-makers (such as those who draft professional and ethical guidelines) of the requirements for obtaining free and informed consent.⁶⁷ Ethical and professional standards should be reviewed and updated to ensure they reflect the right to consent and to supported decision-making.⁶⁸

States should provide information and training which is directed at educating healthcare practitioners, family members and caregivers to consider what type of support or reasonable accommodation is needed for a woman to exercise her legal

⁶² Ibid [29](e).

⁶³ Ibid [29](g).

⁶⁴ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [24].

⁶⁵ WHO, *Involuntary sterilization*, [9], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>; UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [41].

⁶⁶ Human Rights Watch, *Submission to the Committee on the Rights of Persons with Disabilities on Article 6: Women with Disabilities* (24 July 2015) [paragraph 11] <<https://www.hrw.org/news/2015/07/24/submission-committee-rights-persons-disabilities-article-6-women-disabilities>>.

⁷⁰ WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>, see e.g. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Montenegro*, CRPD/C/MNE/CO/1, 18th sess, 22 September 2017 at [47].

⁶⁸ WHO, *Involuntary sterilization*, [13], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>

capacity to consent to abortion.⁶⁹ Such training should aim to facilitate a cultural shift away from the mistaken beliefs that mental or decision-making capacity is the same as legal capacity, and that non-traditional forms of communication preclude persons from giving free and informed consent.⁷⁰ This information should be codified in the form of professional guidelines for healthcare practitioners.⁷¹

III WHAT LAWS NEED TO BE REPEALED? WHAT PRACTICES NEED TO BE ABOLISHED?

States must take affirmative steps to recognise and guarantee the right to consent to abortion, including repealing or reforming laws that are contrary to this right.

1. Repeal laws that sanction abortion without free and informed consent of the patient, or impose forced or coercive abortion, either in institutions or in the community.⁷²
2. Repeal laws and policies that permit substitute decision-making regimes and mechanisms.⁷³

A What is substitute decision-making?

⁶⁹ Bach and Kerzner. A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, 'Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice' (2010), Commissioned by the Law Commission of Ontario, 58.

⁷⁰ Above n 49 [83]; Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (2010) commissioned by the Law Commission of Ontario [58]; UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [12 - 13]; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [46], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

⁷¹ WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>.

⁷² Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [40], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

⁷³ General Comment on Article 12 [28]; See for example, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Tunisia*, *supra* note 40, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Spain*.

Substitute decision-making cannot be used to obtain free and informed consent to abortion. This form of decision-making involves the removal of legal capacity (or failure to recognise it).⁷⁴ A substitute decision is a decision made by a third party such as a family member, guardian or medical practitioner, based on what they believe to be the objective ‘best interests’ of the woman or girl with a disability, and not what is subjectively the woman or girl’s own will and preference.⁷⁵ Formally, substitute decision-making can take the form of plenary guardianship, partial guardianship or judicial interdiction (a legal restraint upon a person preventing them from making their own legal decisions without the consent of someone else).⁷⁶ Informal substitute decision-making can also take place, such as where a medical practitioner seeks and receives consent from a parent or carer to an abortion on behalf of the patient.

The requirement to obtain free and informed consent will also not be met where the decision is coerced or made under pressure. Furthermore, a decision which is made on the basis of misleading or incorrect information, or where the information was not accessible to the patient, is not free and informed consent.

IV ENSURING ACCESS TO JUSTICE AND REMEDIES

Guaranteeing the right to access healthcare on the basis of free and informed consent, and other human rights relating to abortion, requires States to provide redress and remedies for rights infringements. A preliminary requirement is that States fund the dissemination of information to people who have been coerced into abortion about their legal rights to administrative and judicial redress.⁷⁷ Furthermore, access to justice should be ensured by providing access through legal aid to judicial redress mechanisms.⁷⁸ The appropriate public authority should be empowered to investigate reports of forced or coercive abortion.⁷⁹ Public prosecutors should have, and enforce, a policy of prosecuting medical practitioners or other individuals who carry out forced or coercive abortion.⁸⁰ The relevant industry authorities (such as medical boards) should have policies in place rendering professional disciplinary proceedings mandatory for medical practitioners who carry out abortion without free

⁷⁴ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [27].

⁷⁵ *Ibid* [27].

⁷⁶ *Ibid* [27].

⁷⁷ WHO, *Involuntary sterilization*, [15], accessed online at http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf..

⁷⁸ *Ibid* 16.

⁷⁹ *Ibid* 16.

⁸⁰ *Ibid* 12; Above n 32.

and informed consent.⁸¹ States should have in place mechanisms for ensuring effective remedies and remedies that victims may seek, including compensation, counselling, statements of regret or apology and guaranteeing access to assisted reproductive methods where this is clinically possible.⁸² All legal processes should be accessible to persons with disabilities, which may require the provision of reasonable accommodation, support for decision-making, or other measures.

⁸¹ WHO, *Involuntary sterilization*, [12], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>.

⁸² Ibid 15-16.

NORMATIVE FRAMEWORK THAT RECOGNISES AND GUARANTEES PERSONS WITH DISABILITIES' RIGHT TO GIVE CONSENT TO CONTRACEPTION AND STERILIZATION

I INTRODUCTION

This document provides guidelines to assist States to comply with their obligations under the Convention on the Rights of Persons with Disabilities (CRPD) to recognise and guarantee the specific right to consent to contraception and sterilization for all persons with disabilities. States have an obligation to take affirmative action to eliminate discrimination against persons with disabilities and empower them.⁸³

A What are the norms of international human rights law that recognise the right to sexual and reproductive health?

It is well established in the international human rights regime that the right to health is inclusive of sexual and reproductive health.⁸⁴ Furthermore, all persons with disabilities have the right to marry and found a family, decide freely and responsibly on the number and spacing of their children, and retain their fertility on an equal basis with others.⁸⁵

The CRPD also affirms that all persons with disabilities have the right to live independently and participate in all aspects of their life, and imposes obligations on states to ensure that persons with disabilities can access information, facilities and services on an equal basis with others.⁸⁶

⁸³ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Guatemala*, CRPD/C/GTM/CO/1, 30 September 2016, [paragraph 20]; *Convention on the Rights of Persons with Disabilities* (CRPD), Article 8.

⁸⁴ *Convention on the Elimination of Discrimination against Women* (CEDAW), Article 11; United Nations Population Fund, 'Program of Action' (Adopted at *The International Conference of Population Development*, Cairo, 13 September 1994) [59]; United Nations Entity for Gender Equality and the Empowerment of Women, "Beijing Declaration and Platform for Action" (Adopted at the *Fourth World Conference on Women*, Beijing, 15 September 1995) [3, 91].

⁸⁵ CRPD, Article 23.

⁸⁶ CRPD, Article 9, 19.

The CRPD also reiterates the rights of all persons with disabilities to have their bodily integrity respected on an equal basis with others.⁸⁷ It also states that free and informed consent must be given prior to any medical treatment.⁸⁸

B What is the content and scope of the right to sexual and reproductive health?

Laws, regulations and policies that relate to reproductive information and services should aim to eliminate discrimination that can lead to forced and coercive practices.⁸⁹

The United Nations Special Rapporteur on the Rights of Persons with Disabilities has noted that the right of everyone to enjoy the highest attainable standard of health means that persons with disabilities are entitled to reproductive health care services, goods and facilities.⁹⁰ These include contraceptive counselling, services and education in relation to prenatal care, safe delivery and postnatal care, and prevention and appropriate treatment of infertility and sexually transmitted and reproductive tract infections.⁹¹ These must be available in high quality and adequate numbers, and accessible physically, economically and without discrimination. Access to contraception is a component of the right to sexual and reproductive health. Access to contraceptive information and services can empower individual autonomy to decide when and whether to have children, whereas contraceptive inaccessibility can have devastating social, economic and public health consequences.⁹²

1 What is contraception and sterilization?

⁸⁷ CRPD, Article 17.

⁸⁸ CRPD.

⁸⁹ United Nations Population Fund, *State of World Population 2012: By choice, not by chance: family planning, human rights and development*, 2012, accessed online at <<http://www.unfpa.org/sites/default/files/resource-pdf/EN-SWOP2012-Summary.pdf>>; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(d)], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>

⁹⁰ Office of the United Nations High Commissioner for Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, accessed online at <<http://www.ohchr.org/EN/Issues/Health/Pages/SRRRightHealthIndex.aspx>>.

⁹¹ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [11], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

⁹² Office of the United Nations High Commissioner for Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, accessed online at <<http://www.ohchr.org/EN/Issues/Health/Pages/SRRRightHealthIndex.aspx>>

Contraception is designed to prevent pregnancy by interfering with the normal processes of ovulation, fertilization and implantation.⁹³ Sterilization is the only permanent form of contraception, and is a process or act that results in an individual being incapable of sexual reproduction.⁹⁴ Sterilization includes interventions with the particular aim of permanently suppressing fertility, and medical treatments that result in permanent loss of fertility but where this is not the primary intention of the treatment.⁹⁵

C What constitutes a violation of this right to sexual and reproductive health?

Violations of persons with disabilities' sexual and reproductive health rights may include denial of access to female-oriented services or to disability-accessible services, making access to services subject to authorization by third parties, and performing procedures that relate to a person's reproductive and sexual health without consent.⁹⁶ Persons with disabilities are often prevented from participating in decisions about their own personal health care and may be excluded entirely.⁹⁷

1 What is forced or coercive sterilisation or administration of contraception?

The right to give consent to sterilization or administration of contraception is infringed when the medical intervention is coerced or forced (including by obtaining third party consent but not the patient's consent).⁹⁸ Circumstances where a treatment is forced also includes where the procedure is performed without the person's knowledge, where it is administered in circumstances where the person has refused, or where the procedure is performed without prior consent being given.⁹⁹

⁹³ The Free Dictionary by Farlex, *Medical Dictionary: definition of 'contraception'*, <<https://medical-dictionary.thefreedictionary.com/contraception>>.

⁹⁴ The Free Dictionary by Farlex, *Medical Dictionary: definition of 'sterilization'*, <<https://medical-dictionary.thefreedictionary.com/sterilization>>; Mosby's Medical Dictionary, 8th edition, 2009, Elsevier; WHO, *Selected Practice recommendations for contraceptive use* (2016 3rd ed) [5], accessed online at: <<http://apps.who.int/iris/bitstream/10665/252267/1/9789241565400-eng.pdf?ua=1>>.

⁹⁵ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization*, 2014, 2, 1. Accessed online: http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf

⁹⁶ Ibid.

⁹⁷ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [19], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

⁹⁸ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [2, 9], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

⁹⁹ European Parliament Directorate-General for Internal Policies, *Discrimination Generated by the Intersection of Gender and Disability* (2013) accessed online at <<http://www.aph.gov.au/DocumentStore.ashx?id=1995d0fb-977a-4a5a-a959-c516633c565a>>.

Coercion will occur where the patient agrees to a sterilization procedure or administration of contraception because they are induced by incentives, ‘including offers of food, money, land and housing’ or because pressure is placed upon them by ‘threats, fines or punishments’ or intimidation.¹⁰⁰ Providing misleading information is coercion. Requiring the patient’s agreement to sterilization or contraception as a condition to accessing medical care or employment is also coercion or pressure.¹⁰¹ Seeking consent to sterilization or contraception when a person is in a temporary vulnerable state because they are requesting an abortion, are in labour, or have recently given birth, may also be coercive.¹⁰²

2 What is insufficient or no sexual education?

For persons with disabilities to enjoy rights to sexual and reproductive health on an equal basis with others, they must be able to access the same level of sexual education as that of persons without disabilities.¹⁰³ Having a comprehensive sex education is critical to ensuring that consent to contraception and sterilization is informed.¹⁰⁴

D What are the norms of international human rights law that recognise the right to consent to contraception and sterilization?

States are obligated to take all appropriate and effective measures to ensure that the legal capacity of persons with disabilities is recognised and respected.¹⁰⁵ Ensuring and supporting the exercise of free and informed consent to medical procedures, including contraception and sterilization, is a significant aspect of this.¹⁰⁶

¹⁰⁰ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [2, 10], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>; Open Society Foundations, *Against Her Will: Forced and Coerced Sterilization of Women Worldwide* (2011) accessed online at <<https://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf>> [2].

¹⁰¹ Ibid [2]; WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [14], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

¹⁰² FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women’s Health, “Ethical Guidelines for Gynecologic and Obstetric Care”, *Ethical Issues in Obstetrics and Gynecology* (2011) 123[8].

¹⁰³ Chelsea Krupa and Shaniff Esmail, “Sexual health education for children with visual impairments: talking about sex is not enough” (2010) 104 6 *Journal of Visual Impairment and Blindness*, 327.

¹⁰⁴ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [paragraph 41].

¹⁰⁵ CRPD, Article 12

¹⁰⁶ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [10], accessed online at

Forced or coerced administration of contraception and sterilization are a violation of many international human rights. For instance, they constitute a clear violation of article 25(d) of the CRPD, which requires that health practitioners only treat patients on the basis of free and informed consent. Such forced interventions have been recognised by international human rights instruments and agencies as constituting violence, torture and cruel, inhuman or degrading treatment in breach of article 5 of the Universal Declaration of Human Rights, article 15 of the CRPD, article 7 of the International Covenant on Civil and Political Rights and article 37(a) of the Convention on the Rights of the Child ('CRC').¹⁰⁷ Furthermore, the absence of free and informed consent, and legal compulsion, are forms of violence, exploitation and/or abuse against women and girls with disabilities, in breach of articles 6 and 16 of the CRPD, and article 19 of the CRC.¹⁰⁸ Finally, making decisions about sterilization or contraception on behalf of women and girls with disabilities, or accepting the substituted consent of medical practitioners, family, caregivers, or other persons, also constitutes a violation of the right to equal recognition before the law in article 12 of the CRPD.

E How do stereotypes, misconceptions and misinformation play a role in rights violations?

Persons with disabilities may be subject to intersectional discrimination, not only on the basis of their gender or disability, but also due to multiple, overlapping factors including race, ethnicity, religion or belief, age, class, caste or sexual orientation.¹⁰⁹ Discriminatory views, stigma and widespread misconceptions about the parenting skills of persons with disabilities, wrongful eugenics-based concerns, and beliefs that persons with disabilities are unlikely or unable to engage in sex, perpetuate the assumption that persons with disabilities do not need to access information or

<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>; The International Federation of Gynecology and Obstetrics (FIGO) Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, "Recommendations for Female Contraceptive Sterilisation", *Ethical Issues in Obstetrics and Gynecology* (2011) 125.

¹⁰⁷ WHO, *Involuntary sterilization*, 1, accessed online at http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf; CRPD, Articles 5, 12, 23 and 25.

¹⁰⁸ UN Committee on the Rights of Persons with Disabilities, *General comment No. 3 (2016) on women and girls with disabilities*, CRPD/C/GC/3, 25 November 2016, [31], [54].

¹⁰⁹ UN Committee on the Rights of Persons with Disabilities, *General Comment No. 3 (2016) on women and girls with disabilities*, CRPD/C/GC/3, 25 November 2016; UN Committee on the Elimination of Discrimination against Women, *General Recommendation No 28 on the Core Obligations of State Parties under Article 2 of the Convention of the Elimination of all Forms of Discrimination against Women*, CEDAW/C/2010/47/GC.2, 19 October 2010.

participate in education about reproductive health and abortion.¹¹⁰ A further barrier is where this information is presented in a medium that is inaccessible to persons with certain disabilities. These factors contribute to the prevalence of persons with disabilities being denied their rights, including the right to health and the right found a family, by being coerced or even forced into taking contraception and/or being subject to sterilization.¹¹¹

II WHAT ACTIONS DO STATES NEED TO TAKE TO RECOGNISE AND GUARANTEE THE RIGHT TO GIVE CONSENT TO CONTRACEPTION AND STERILISATION?

1. Criminalise harmful and forced practices that affect sexual reproductive and health rights, including forced sterilization or use of contraception and ensure that offenders are prosecuted;¹¹²
2. Introduce procedural safeguards to protect the right to free and informed consent to contraception and sterilization;¹¹³
3. Implement legislation for access to supported decision-making processes at no or nominal cost;¹¹⁴
4. Remove legal barriers that prevent persons with disabilities from accessing information regarding their sexual and reproductive health and rights information, good and services. This can extend to any

¹¹⁰ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [19, 31], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹¹¹ Ibid [31].

¹¹² PLAN International, *Let Me Decide and Thrive: Global discrimination and exclusion of girls and young women with disabilities* (December 2017) 15, accessed online at <<https://plan-international.org/publications/let-me-decide-thrive-srhr-disability#download-options>>.

¹¹³ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(b)], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹¹⁴ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [28]; See for example, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Tunisia*, *supra* [note 40], *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Spain*.

legislation relating to guardianship that reduces legal capacity or diminishes their right to make their own decision;¹¹⁵

5. Implement healthcare practices for safe and accessible contraception methods;¹¹⁶
6. Ensure that comprehensive sexuality education for persons with disabilities is available and accessible, in formal and non-formal education settings. This education should be youth friendly and rights based;¹¹⁷
7. Provide training and awareness-raising activities for relevant actors, including¹¹⁸
 - Training for parents and educators to support persons with disabilities to learn about their bodies, sexuality and relationships from a young age through to adulthood;¹¹⁹
 - Training for health care practitioners on the requirement of obtaining free and informed consent prior to a sterilization procedure or administration of contraception;¹²⁰
8. Ratify and implement core conventions that relate to protecting the sexual and reproductive health and rights of persons with disabilities. This includes the Convention on the Rights of the Child (CRC), the

¹¹⁵ Above n 32.

¹¹⁶ Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [11] accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹¹⁷ Above n 32; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [62(e)] accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹¹⁸ WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [15], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>; see e.g. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Montenegro*, CRPD/C/MNE/CO/1, 22 September 2017 at [47].

¹¹⁹ Above n 32.

¹²⁰ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [41].

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the CRPD;¹²¹

9. Ensure access to justice by providing access through legal aid to judicial redress mechanisms;¹²²
10. Empower and require the appropriate public authority to investigate reports of forced or coercive sterilization and administration of contraception.¹²³

A What is the minimum content of free and informed consent?

For a person to provide informed consent to medical intervention there must be more than mere acceptance of the procedure,¹²⁴ The consent must be made voluntarily and after the person has been sufficiently informed of the purpose, effects and risks of the intervention.¹²⁵

The International Federation of Gynaecologists and Obstetricians (FIGO) endorses the following definition of informed consent to medical procedures:

Informed consent is a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- a) *The diagnostic assessment;*
- b) *The purpose, method, likely duration and expected benefit of the proposed treatment;*

¹²¹ Above n 32.

¹²² WHO, *Eliminating forced, coercive and otherwise involuntary sterilization* (2014), [16], accessed online at <http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>.

¹²³ Ibid.

¹²⁴ Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 'Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms' HRC 6/29, 64th sess, Agenda Item 71(b), A/64/272, available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement>>.

¹²⁵ Ibid.

- c) *Alternative modes of treatment, including those less intrusive and;*
- d) *Possible pain or discomfort, risks and side effects of the proposed treatment.*¹²⁶

A corollary of the requirement of free and informed consent is that the patient has the right to refuse to consent if that is their will and preference.

B What formalities are required for obtaining consent?

The formalities required for the administration of contraception and sterilization are similar to those set out in the guidelines issued by the International Federation of Gynaecology and Obstetrics regarding female contraceptive sterilization and informed consent. There must be a written record of an agreement (including an oral agreement) of consent or non-consent that accurately reflects the person's decision.

Before action to administer contraception or sterilization is undertaken, the following steps should be followed:

- Seeking and obtaining the free and informed consent of the person herself or himself. Family members or legal guardians, carer or practitioners cannot consent to sterilization or contraception on behalf of the woman. Perceived mental incapacity does not invalidate this requirement.¹²⁷ This is discussed in more detail below in relation to supported and substituted decision-making.
- Persons with disabilities must be provided with adequate accessible information that details the procedure or medication being proposed, including (where appropriate) the permanency of sterilization and available alternatives, as well as the risks, benefits and alternatives of the procedures.¹²⁸ This should be provided in accessible formats, such as Braille and 'easy to understand' language, as appropriate to the individual's needs.¹²⁹

C The importance of privacy and confidentiality in the decision-making process

If the patient indicates their will that a medical appointment or decision about contraception or sterilization should be private and not disclosed to a parent or

¹²⁶ FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, "Guidelines Regarding Informed Consent", *Ethical Issues in Obstetrics and Gynecology* (2011) [14].

¹²⁷ Open Society Foundation, *Sterilization of Women and Girls with Disabilities*, 2011 Accessed online at <<https://www.opensocietyfoundations.org/sites/default/files/sterilization-women-disabilities-20111101.pdf>>

¹²⁸ Above n 28.

¹²⁹ Above n 28.

caregiver, then this must be respected.¹³⁰ Additionally, health practitioners should remember that the confidentiality of such decisions and discussions does not change merely because their patient has a disability.¹³¹ Moreover, the practitioner should not disclose the matters discussed and the decisions reached during the consultation to the patient's caregiver without their consent.

D What information is needed for consent to be informed?

Certain information must be provided to a person with disabilities before informed consent can be obtained. Non-directive counselling, advice or information by medical practitioners and health workers, should be provided about contraception and sterilization.

In relation to sterilization, it should contain the following information at a minimum:¹³²

- the permanency of the procedure;
- if there is a possibility that the person may want a child in future, that a different type of contraception should be chosen;
- alternative methods of contraception available;
- that sterilization is a surgical intervention with risks;
- the benefits of sterilization;
- side-effects and follow-up care;
- the ability to change one's mind and withdraw consent at any time after the initial consent;

¹³⁰ WHO, *Safe Abortion: technical and policy guidance for health systems*, (2012, 2nd Ed) 4.1, accessed online at <http://apps.who.int/iris/bitstream/10665/70914/1/9789241548434_eng.pdf?ua=1>; *CRPD*, Articles 3(a) and 22.

¹³¹ WHO, *Safe Abortion: technical and policy guidance for health systems*, (2012, 2nd Ed) 4.1, accessed online at <http://apps.who.int/iris/bitstream/10665/70914/1/9789241548434_eng.pdf?ua=1>

¹³² WHO, *Eliminating forced coercive and otherwise involuntary sterilization: An interagency statement - OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO* (2014) accessed online at: <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf> [9] citing Michel Desjardins – 'The Sexualised Body of the Child – Parents and the Politics of "Voluntary" Sterilization of People Labeled Intellectually Disabled' in Robert McRuer and Anna Mollow (eds) *Sex and Disability* (Duke University Press, 2012).

- sterilization does not protect against HIV and other sexually transmitted infections;
- sterilization does not protect against sexual abuse;
- the decision to undergo sterilization is entirely the patient's own.

In relation to other, non-permanent forms of contraception, the following information should be provided at a minimum:

- the reason for the contraception and what it does;
- the types of contraception available, and how they are used;
- the advantages and disadvantages of each type;
- possible side effects;
- how easily each type can be changed;
- the ability to change one's mind and withdraw consent at any time;
- contraception may not protect against HIV and other sexually transmitted infections;
- contraception does not protect against sexual abuse;
- the decision to use contraception is entirely the patient's own.

E How can such information be made accessible?

Prior to administering contraception or a sterilization procedure on a person with a disability, information provided should be comprehensible to the individual person, to ensure meaningful participation in the decision.¹³³ Properly trained personnel have a responsibility to convey accurate, clear information in a format readily understandable to the individual person, free from coercion.¹³⁴

Information should be presented in a way that is non-conventional if that is required for a patient to access and understand it.¹³⁵ Ensuring accessibility may be as basic as

¹³³ WHO, *Eliminating forced coercive and otherwise involuntary sterilization: An interagency statement - OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO* (2014) accessed online at: http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf; CRPD, Article 5.

¹³⁴ Ibid.

¹³⁵ CRPD, Articles 9 and 12.

using simpler language, but it may also require the practitioner to engage in communication with the assistance of visual aids, animated guides or other means the patient requires to access information. The need for non-conventional means of communication should not be deemed as a justification for substituted decision-making. That is, practitioners must prioritise their ethical and legal obligations to ensure that their patient (as opposed to a medical practitioner, family member or caregiver) is provided with all relevant information about the procedure being contemplated.¹³⁶ While the most appropriate method of the communication for the patient may be ‘unintuitive’ or ‘time consuming’ for the practitioner to utilise, the CRPD requires that this must be provided as a ‘reasonable accommodation’ ought to be provided to ensure that the patient is ensured the right to free and informed consent on an equal basis to persons without a disability.¹³⁷

F What is supported decision-making?

Supported decision-making describes various support options that place the will and preference of the person with a disability at the forefront of decision-making.¹³⁸ It involves one or more third party supporters providing support to a person to make their own decision. A crucial element of informed consent and supported decision-making is the provision of accessible and accurate information to enable a person to make a decision according to their will and preferences.¹³⁹ Support may take many forms, from assisting the person to access and interpret information, to interpreting the preferences and will of the person if they are communicated in a non-standard way and communicating the decision to third parties.¹⁴⁰

A person may already have systems of support for decision-making, such as peer support, community support networks and recovery oriented services. However, some people may not have access to support, or may require alternative forms of support for making decisions about contraception or sterilization. States should consider whether policy or legislation is required to ensure support for decision-

¹³⁶ FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women’s Health, “Ethical Guidelines for Gynecologic and Obstetric Care”, *Ethical Issues in Obstetrics and Gynecology* (2011) 12

¹³⁷ CRPD, Article 5(a).

¹³⁸ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [29].

¹³⁹ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [42].

¹⁴⁰ Above n 49 [85].

making is available to all women who would benefit from it.¹⁴¹ Such supports should be made available by states for free or only a nominal cost, so that limited financial resources are not be a barrier to accessing supported decision-making options.¹⁴²

People should have the right to refuse support or terminate the support arrangement.¹⁴³ Additionally, states should provide training for people receiving support when making a decision which equips them to decide when less support is needed or when they no longer require support in the exercise of their legal capacity.¹⁴⁴

Safeguards are necessary to prevent relationships where the supporting person has a conflict of interest or exercises undue influence.¹⁴⁵ This includes training medical practitioners, family members and caregivers about the meaning and purpose of supported decision-making to ensure that it is appropriately implemented.

G What training and awareness-raising is required?

States have a duty to enforce the responsibility of medical practitioners to obtain free and informed consent to medical interventions.¹⁴⁶ Therefore states should ensure there is sufficient funding for training of health-care providers along with policy-makers (such as those who draft professional and ethical guidelines) of the requirements for obtaining free and informed consent.¹⁴⁷ Training and awareness for healthcare providers should include information around how sterilization and the administration of contraception can amount to violation of human rights if

¹⁴¹ T Minkowitz, 'The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from nonconsensual psychiatric interventions' (2007) 34 *2 Syracuse Journal of International Law and Commerce* 405 [409].

¹⁴² *Ibid* [29](e).

¹⁴³ *Ibid* [29](g).

¹⁴⁴ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [24].

¹⁴⁵ WHO, *Involuntary sterilization*, [9], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>; UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [41].

¹⁴⁶ Human Rights Watch, *Submission to the Committee on the Rights of Persons with Disabilities on Article 6: Women with Disabilities* (24 July 2015) [paragraph 11] <<https://www.hrw.org/news/2015/07/24/submission-committee-rights-persons-disabilities-article-6-women-disabilities>>.

⁷⁰ WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>, see e.g. Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of Montenegro*, CRPD/C/MNE/CO/1, 18th sess, 22 September 2017 at [47].

performed in the absence of free and informed consent of the individual.¹⁴⁸ Ethical and professional standards should be reviewed and updated to ensure they reflect the right to consent and to supported decision-making.¹⁴⁹

States should provide information and training which is directed at educating healthcare practitioners, family members and caregivers to consider what type of support or reasonable accommodation is needed for a person to exercise their legal capacity to consent to contraception and sterilization.¹⁵⁰ Such training should aim to facilitate a cultural shift away from the mistaken beliefs that mental or decision-making capacity is the same as legal capacity, and that non-traditional forms of communication preclude persons from giving free and informed consent.¹⁵¹ This information should be codified in the form of professional guidelines for healthcare practitioners.¹⁵²

III WHAT LAWS NEED TO BE REPEALED? WHAT PRACTICES NEED TO BE ABOLISHED?

States must take affirmative steps to recognise and guarantee the right to consent to contraception and sterilization, including repealing or reforming laws that are contrary to this right.

1. Repeal laws that sanction contraception and sterilization without free and informed consent of the patient, or impose forced or coercive contraception and sterilization, either in institutions or in the community.¹⁵³

¹⁴⁸ WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>.

¹⁴⁹ WHO, *Involuntary sterilization*, [13], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>

¹⁵⁰ Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (2010) commissioned by the Law Commission of Ontario [58];

¹⁵¹ Above n 49 [83]; Above n 69 [58]; UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [12 - 13]; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [46], accessed online at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>>.

¹⁵² WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>.

¹⁵³]; Catalina Devandas, Special Rapporteur on the rights of persons with disabilities, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, note by Secretary General, HRC Res 35/6, 72nd sess, Agenda Item 73(b), A/72/133, 14 July 2017, [40], accessed online at

2. Repeal laws and policies that permit substitute decision-making regimes and mechanisms.¹⁵⁴

A What is substitute decision-making?

Substitute decision-making cannot be used to obtain free and informed consent to contraception or sterilization. This form of decision-making involves the removal of legal capacity (or failure to recognise it).¹⁵⁵ A substitute decision is a decision made by a third party such as a family member, guardian or medical practitioner, based on what they believe to be the objective ‘best interests’ of the person with a disability, and not what is subjectively the person’s own will and preference.¹⁵⁶ Formally, substitute decision-making can take the form of plenary guardianship, partial guardianship or judicial interdiction (a legal restraint upon a person preventing them from making their own legal decisions without the consent of someone else).¹⁵⁷ Informal substitute decision-making can also take place, such as where a medical practitioner seeks and receives consent from a parent or carer to an abortion on behalf of the patient.

The requirement to obtain free and informed consent will also not be met where the decision is coerced or made under pressure. Furthermore, a decision which is made on the basis of misleading or incorrect information, or where the information was not accessible to the patient, is not free and informed consent.

IV ENSURING ACCESS TO JUSTICE AND REMEDIES

Guaranteeing the right to access healthcare on the basis of free and informed consent, and other human rights relating to contraception and sterilization, requires States to provide redress and remedies for rights infringements. A preliminary requirement is that States fund the dissemination of information to people who have been forced or coerced into sterilization or the use of contraception on their legal

<https://documents-dds-ny.un.org/doc/UNDOC/GEN/N17/214/63/PDF/N1721463.pdf?OpenElement>.

¹⁵⁴ General Comment on Article 12 [28]; See for example, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Tunisia, supra* note 40, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Spain*.

¹⁵⁵ UN Committee on the Rights of Persons with Disabilities, *General Comment No.1 (2014)* (CRPD/C/GC/1), 19 May 2014 [27].

¹⁵⁶ *Ibid* [27].

¹⁵⁷ *Ibid* [27].

rights to administrative and judicial redress.¹⁵⁸ Furthermore, access to justice should be ensured by providing access through legal aid to judicial redress mechanisms.¹⁵⁹ The appropriate public authority should be empowered to investigate reports of forced or coercive sterilization or contraception.¹⁶⁰ Public prosecutors should have, and enforce, a policy of prosecuting medical practitioners or other individuals who carry out forced or coercive sterilization or contraception.¹⁶¹ The relevant industry authorities (such as medical boards) should have policies in place rendering professional disciplinary proceedings mandatory for medical practitioners who administer contraception and sterilization procedures without consent.¹⁶² States should have in place mechanisms for ensuring effective remedies and remedies that victims may seek, including compensation, counselling, statements of regret or apology and guaranteeing access to assisted reproductive methods where this is clinically possible.¹⁶³ All legal processes should be accessible to persons with disabilities, which may require the provision of reasonable accommodation, support for decision-making, or other measures.

¹⁵⁸ WHO, *Involuntary sterilization*, [15], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>..

¹⁵⁹ Ibid 16.

¹⁶⁰ Ibid 16.

¹⁶¹ Ibid 12; Above n 32.

¹⁶² WHO, *Involuntary sterilization*, [12], accessed online at <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf>.

¹⁶³ Ibid 15-16.

GROUP 2 PROJECT

Right to Free and Informed Consent of People with Disability

Partner Organisation

United Nations Special Rapporteur on Disability, Catalina Devandas

Group Members

Alex Callahan

Beth Dixon

Courtney Remington



The documents produced by Group 2 are confidential and not suitable for release.

GROUP 3 PROJECT

NDIS and Access to Justice: Exploring the Possibilities

Partner Organisation

Australian Disability Discrimination Commissioner, Alastair McEwan

Group Members

Johanna Heaven

Nathaniel McCracken



The documents produced by Group 3 are confidential and not suitable for release.

GROUP 4 PROJECT

General Comment on Equality and Non-discrimination

Partner Organisation

United Nations Committee on the Rights of Persons with Disabilities

Group Members

Dinithi De Awis

Luke Thomas

Victoria Cook



The documents produced by Group 4 are confidential and not suitable for release.

GROUP 5 PROJECT

Right to Access to Cultural Materials: Impact of Positive Images of Disability in Media and Popular Culture

Partner Organisation

Attitude Foundation

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Janelle Koh

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OVERVIEW

The Convention of the Rights of Persons with Disabilities¹ (CRPD) aims to enable persons with disabilities to participate in society on an equal basis with others in every aspect of life. In their attempts to change the negative attitudes society holds towards persons with disabilities, the Attitude Foundation can promote Australia's compliance with its obligations under Article 30 of the CRPD, in particular, Australia's obligation to provide positive representations of persons with disability in media and popular culture.

This report begins with a legal analysis, substantiating the claim that Australia indeed has the aforementioned obligations. This analysis will firstly look at the content of Art 30 of the CRPD, which provides a right to participate in cultural life, and will suggest that Art 30, when read in conjunction with other Arts of the CRPD, can be interpreted as founding a state obligation to provide positive representations. Furthermore, the parent rights of Art 30 as found in fundamental human rights conventions support this interpretation. The legal analysis will be followed by a literature review, which looks at the disciplines of critical disability studies, education and media and communication to clarify what an obligation to provide positive representation of persons with disabilities might entail. Finally, a set of case studies showing various examples of representations of persons with disabilities in popular culture will be evaluated in light of the literature to show that positive portrayals of persons with disabilities in the traditional media and social media are a necessary element to achieving equal enjoyment of cultural life in Australia for persons with disabilities.

PART I – HUMAN RIGHTS LEGAL ANALYSIS

A. The rights within the Convention on the Rights of Persons with Disabilities

Introduction

The CRPD is an international treaty that addresses the needs of persons with disabilities.² It was ratified by Australia and came into force on 3 May 2008. It has been described as a Convention that does not create new rights or entitlements, but rather re-articulates more clearly existing human rights as they apply to persons with disabilities.³ However, this characterisation of the CRPD has been challenged by some scholars, who argue that

¹ *Convention of the Rights of Persons with Disabilities*, GA Res 61/611, 61st sess, UN Doc A/61/611 (13 December 2006), (entered into force 3 May 2008), (CRPD).

² Rosemary Kayess and Philip French, 'Out of the Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8.1 *Human Rights Law Review* 125, 144.

³ *Ibid.*

the CRPD creates rights broader than their ‘parent rights’, traditionally found in the International Covenant on Civil and Political Rights (ICCPR) or International Covenant on Economic, Social and Cultural Rights (ICESCR).⁴ Understood in this context, the Art 30 right to participation in cultural life⁵ draws upon other broader foundational concepts of equality and non-discrimination, but is more explicitly founded upon the Art 15 right to take part in cultural life,⁶ found in the ICESCR.⁷

What are the individual rights and state obligations in Article 30 of the CRPD?

The rights and corresponding obligations referred to in Art 30 are broad. Article 30.1 addresses the right to take part on an equal basis with others in cultural life. The first element of this obligation is to take all appropriate measures to ensure that persons with disabilities enjoy access to cultural materials,⁸ television programmes, films, theatre and other cultural activities in accessible formats.⁹ Additionally all State parties to the Convention, including Australia must take appropriate measures to ensure persons with disabilities can enjoy access to places for cultural performances and services; this includes access to monuments and sites of national cultural importance. Significantly the right to take part and enjoy access is on an equal basis with others. Therefore, the level of access provided must be equal.

Within this right (Art 30.1) the language ‘take part’ on an ordinary reading of the words, would demand that persons with disabilities not only have the right to access buildings and materials in formats they can enjoy, but also to participate and become involved on an equal basis with others. The state is under an obligation to remove any barriers preventing this right from being fulfilled. Therefore, state measures must be taken to reduce and remove negative representations and stigma-generating media to enable persons with disabilities to “enjoy” cultural material on an equal basis with others.

Article 30.2 places an obligation upon States, including Australia, to take appropriate measures to ensure there are opportunities for persons with disabilities to develop and utilise their creative, artistic and intellectual potential. As discussed above, this Article acknowledges that enabling this for persons with disabilities is not only for their benefit

⁴ Above n 2, 154.

⁵ CRPD Art 30.

⁶ CRPD Art 15.

⁷ *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976), art 15, (ICESCR).

⁸ CRPD Art 30.1(a).

⁹ CRPD Art 30.1(b); Paul Harpur, ‘Access to Information Communication Technologies, Universal Design and the New Disability human Rights paradigm Introduced by the Convention on the Rights of Persons with Disabilities’ in *Discrimination, Copyright and Equality: Opening the e-book for the Print-Disabled*, Cambridge University Press 32.

but also for the enrichment of society. This is a right to full participation in cultural life, not only through existing cultural materials and access to cultural buildings and sites, but also through contributing to Australian cultural materials as participants and creators.

Under Art 30.4, persons with disabilities have a right to recognition of and support for their specific cultural and linguistic identity, on an equal basis with others. Originally the draft of this sub-article was to focus only on the rights of the deaf community.¹⁰ Instead the final language of the provision says ‘including the sign languages and the deaf community.’ This article acknowledges in particular that the deaf community have strong cultural practices and language that should be embraced by Australia as a valued part of our culture. However, by incorporating all persons with disabilities into Art 30.4 the CRPD emphasises that each individual has a right to recognition of their own linguistic and cultural needs.

Article 30.5 focuses around obligations upon Australia to take specific measures that ‘enable persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities.’ The obligations include not only access to venues and equipment but more broadly to the encouragement of participation and access to appropriate instruction, training and resources for all recreational activities on an equal basis with others.

Under Art 4.2 of the CRPD, social and cultural rights are to be attained progressively, by active efforts by the state, including Australia. Australia must promote awareness raising while also creating and funding policies and standard setting that enables persons with disabilities to attain their rights under Art 30.

B. Is there a state obligation to ensure that disability is portrayed positively in the media and popular culture?

If found in the CRPD, does the obligation stem from Art 30 or elsewhere?

Articles 5, 8, 9 and 30 of the CRPD establish an obligation on Australia to address discrimination and attitudinal barriers connected to access to cultural materials, such as stereotyping and stigmatisation.

¹⁰ ‘Draft Article 24 Participation in cultural life, recreation, leisure and sport’ (2004) *Department of Economic and Social Affairs Division of Social Policy and Development* [accessed from: <http://www.un.org/esa/socdev/enable/rights/ahcwgreporta24.htm>].

As outlined above, the rights set out in Art 30 demand a high level of not only access to cultural materials (inclusive of media and popular culture) but also a right to participation and opportunities to create cultural materials. Article 30 does not directly state that States (including Australia) have an obligation to ensure disability is portrayed positively in cultural materials. The language of the provision instead demands that persons with disabilities enjoy access on an equal basis with others. However, Art 8 of the CRPD defines an obligation on Australia to adopt immediate, effective and appropriate measures to raise awareness regarding persons with disabilities and foster respect for their rights and dignity. Australia is also under an obligation to combat stereotypes, prejudices and harmful practices relating to persons with disabilities in all areas of life, and to promote awareness of capabilities and contributions of persons with disabilities. To achieve these ends, Australia must: ‘promote positive perceptions and greater social awareness towards persons with disabilities’¹¹; promote recognition of the skills, merits and abilities of persons with disabilities;¹² and encourage all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention.¹³

Alongside the CRPD is an Optional Protocol which provides an enforcement framework which can be utilised when there are violations of the rights and obligations owed under the CRPD. The jurisdiction of the Optional Protocol applies to Australia as it has signed as a party.

When a member of the international community is a victim of a violation of their rights under the CRPD they can submit ‘Communications’ to the Committee on the Rights of Persons with Disabilities (the Committee). Responses to Communications are published as ‘Views Adopted’ by the Committee and they are useful resources for interpreting the CRPD and understanding the standards placed on states to fulfil their obligations. Views Adopted and the General Comments published by the Committee are authoritative as to how the CRPD is interpreted in International Law.

The Committee interprets the CRPD in line with the Vienna Convention on the Law of Treaties; reading the Convention as a whole, combining articles as they build on and facilitate one another,¹⁴ as well as considering external documents.¹⁵ Therefore it is arguably necessary, to understand Art 30 in conjunction with Art 8.¹⁶ These two Articles

¹¹ CRPD Art 8.2(a)(ii)

¹² CRPD Art 8.2(a)(iii)

¹³ CRPD Art 8.2(c)

¹⁴ Committee on the Rights of Persons with Disabilities, *Views: Communication* No. 3/2011, 7th sess, UN Doc CRPD/C/7/D/3/2011 (19 April 2012) 10 [7.3] (*H.M. v. Sweden*).

¹⁵ *Vienna Convention on the Law of Treaties*, opened for signature 23 May 1969, 1155 UNTS 331 (entered into force 27 January 1980) art 31.1, 31.2(b).

¹⁶ Committee on the Rights of Persons with Disabilities, *Views: Communication* No. 11/2013, 15th sess, UN Doc CRPD/C/15/D/11/2013 [8.6], [8.8] (*Gemma Beasley v. Australia*).

combine to formulate an obligation on Australia to provide structural adjustments to access cultural materials, and provide opportunities for persons with disabilities to contribute to the creation of cultural materials.¹⁷ They also impose an obligation to take immediate appropriate measures to ensure disability is portrayed positively in the media and popular culture to enable equal enjoyment and participation of persons with disabilities in Australian cultural life.

Article 9 Accessibility

There is a direct interaction between Art 30 and Art 9 to enable persons with disabilities to participate fully in the arts, compete in sports and visit restaurants and concerts.¹⁸ This art also demands that Australia take appropriate measures to develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public.¹⁹ Australia must also ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities²⁰ and provide training for stakeholders.²¹ Additionally, Australia must promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.²² The Committee held in its General Comment No. 2 (2014) on Art 9 that the obligation to implement accessibility is unconditional.²³ It was also determined that accessibility policy must necessarily change attitudes towards persons with disabilities 'in order to fight against stigma and discrimination, through ongoing education efforts, awareness-raising, cultural campaigns and communication.'²⁴ Therefore this further reinforces that Australia must not only facilitate access to physical environments that hold cultural materials, it also has an obligation to remove the artificial barriers to full participation in Australian culture.

Article 5 Equality and non-discrimination

The CRPD Committee has indicated its provisional position on the relationship between Arts 5 and 30 in its draft general comment on article 5. Reading Art 30 in conjunction with Art 5 indicates that Australia is required to take additional efforts to overcome attitudinal

¹⁷ CRPD art 30.1.

¹⁸ Committee on the Rights of Persons with Disabilities, *General Comment* No. 2/2014, 11th sess, UN Doc CRPD/C/GC/2 [44].

¹⁹ CRPD art 9.2(a)

²⁰ CRPD art 9.2(b).

²¹ CRPD art 9.2(c).

²² CRPD art 9.2(h).

²³ Committee on the Rights of Persons with Disabilities, *General Comment* No. 2/2014, 11th sess, UN Doc CRPD/C/GC/2 [25].

²⁴ *Ibid* [3].

barriers to disability. The Committee has suggested these have been insufficient thus far ‘as exemplified by the enduring stigma and humiliating stereotypes against persons with disabilities.’²⁵ The lasting and denigrating misconceptions about disability are a significant barrier for persons with disabilities to participate in social life on an equal basis with others due to the insufficient awareness of rights.²⁶ The Committee has held the right to equality and non-discrimination is at the heart of the Convention, it ‘runs like a golden thread’ through all the other articles, particularly emphasised by the phrase ‘on an equal basis with others’.²⁷ The Draft Comment on Art 5 has determined that states, including Australia, need to do more to overcome deeply entrenched disability-based discrimination. In order to implement systemic change, positive measures are necessary.²⁸ The discriminatory and negative portrayal of persons with disabilities in the media and cultural materials within Australian society must be addressed with specific measures to accelerate and achieve *de facto* equality.²⁹ As discussed above, most social and cultural rights are to be progressively realised, however non-discrimination and equality is a cross-cutting obligation that must be immediately realised and applies to all human rights and does not fall into the category of progressive realisation.³⁰ The prescribed rights and obligations under Art 30 are to be provided on ‘equal basis with others’ across the entire Article, therefore the opportunities and access to cultural materials provided to all Australians must be provided to Australians with disabilities equally. The obligation for a positive portrayal of persons with disabilities requires additional immediate action to attain substantive equality, as artificial barriers of prejudice and stigma prevent the realisation of these rights on the equal basis prescribed.

What are the parent rights of Article 30?

Article 30 of the CRPD provides for the right to participate in cultural life, recreation, leisure and sport. With reference to cultural life, sub-rights arise in Arts 30.1 and 30.4. The precursor to these rights may be found in the ICCPR and the ICESCR, which inform the nature and content of the Art 30 rights.

‘On an equal basis with others’

The wording of the Art 30.1 and 30.4 rights share the phrase ‘on an equal basis with others’ in common.³¹ The fundamental nature of the right to equality can be traced back to the

²⁵ Committee on the Rights of Persons with Disabilities, *First Draft General Comment on equality and non-discrimination (article 5)* (as at 31 August 2017) [2].

²⁶ *Ibid* [4].

²⁷ *Ibid* [5].

²⁸ *Ibid* [10].

²⁹ *CRPD* art 5(4); *Ibid* [30].

³⁰ *Ibid* [13].

³¹ See *CRPD* art 30.1; 30.4.

Universal Declaration of Human Rights (UDHR),³² in which the language of equality permeates the text. Article 1 states that “all human beings are born free and equal in dignity and rights”.³³ Every subsequent Art begins with the use of words such as “everyone” or “all”, that formally recognises the equality of all persons, and that rights apply equally to everyone.³⁴ Most relevantly, Art 27 of the UDHR states that *everyone* has the right freely to participate in the cultural life of the community.³⁵

This concept of equality is also enshrined in Art 3 of the International Covenant on Civil, and Political Rights, (ICCPR)³⁶ which promotes equal entitlement to all rights set forth. Art 26 makes clear that with equality and non-discrimination, one cannot be sought without the other. Art 26 notes that “all persons are equal before the law and are entitled without any discrimination to the equal protection of the law”.³⁷ Both fundamental concepts as found in the UDHR and ICCPR are explicitly imported into Art 5 of the CRPD, which ensures equality and non-discrimination. The thrust of these fundamental concepts also inform Art 30.

Defining ‘Cultural life’

The notion of ‘cultural life’ appearing in Art 30 of the CRPD was primarily adopted from the ‘right to take part in cultural life’ found in Art 15 of the ICESCR.³⁸ Roger O’Keefe notes that two definitions of cultural life are accommodated within the framework of the Art 15 (and, by extension, the Art. 30) right.³⁹ The narrower definition of cultural life draws upon the traditional definition of culture, which O’Keefe terms ‘high culture’.⁴⁰ The right to ‘high’ cultural life encompasses both the right to enjoy cultural, literary and artistic works and values,⁴¹ and the right to create such materials. The language of ‘enjoyment’ and a recognition of persons with disabilities right to create materials are preserved in Art 30.1 (‘enjoy access’) and Art 30.2 (‘opportunity to develop and utilize their creative, artistic and intellectual potential’).

³² *Universal Declaration on Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/801 (10 December 1948), (*UDHR*).

³³ *UDHR*, art 1.

³⁴ See generally *UDHR*.

³⁵ *UDHR*, art 27.

³⁶ *International Covenant on Civil and Political Rights*, opened for signature 19 December 1966, 999 UNTS 14668, art 3, (*ICCPR*).

³⁷ *ICCPR*, art 26.

³⁸ United Nations Enable, *International human rights conventions and other legal instruments (Draft Article 24)* <<http://www.un.org/esa/socdev/enable/rights/wghrefa24.htm>>.

³⁹ Roger O’Keefe, ‘The “Right to Take Part in Cultural Life” under Article 15 of the ICESCR’ (1998) 47 *International and Comparative Law Quarterly* 904.

⁴⁰ *Ibid* 906.

⁴¹ *Ibid*.

However, the ‘high culture’ definition has been accused of ‘highbrow bias’ - O’Keefe suggests that drafters of the ICESCR assumed that ‘culture’ referred to a “preordained canon” of work, to which persons may have access.⁴² Yet, a broader definition of cultural life has since been supplied by the discipline of anthropology, which defines culture as ‘way of life’ - in this definition, cultural life is not simply restricted to the products of creativity, but any form of self-expression.⁴³

This second definition of cultural life is much more subjective and reliant on the perspectives and identity of the particular person attempting to access it - everyone has the right to take part in cultural life in the way they consider to be relevant to them, not simply in ways that a small group of people from a particularly privileged background have determined to be relevant. The shift towards centrality of one’s identity, personal preferences and experiences to the notion of cultural life is echoed in Art. 30.4, which recognises a right of persons with disability to support of their specific cultural and linguistic identity.⁴⁴

Thus, Art. 30 of the CRPD incorporates both the ‘highbrow’ and ‘way of life’ definitions of cultural life into its right to participate in cultural life. This results in a broader range of rights that flow, including the right to enjoy, the right to create, and a right for persons with disabilities to participate in a manner that supports their own cultural identities.

Defining Art 15 rights

Art 15 of the ICESCR recognises three rights: the right to take part in cultural life, the right to enjoy the benefits of scientific progress and its applications, and the right to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.⁴⁵

The language of the Art 30 right (‘right to participation in cultural life’) is aligned most closely with the Art 15.1(a) right to take part in cultural life. While the language of participation is explicitly used by both articles, the UN General Comment No. 21 adopted by the Committee on Economic, Social and Cultural Rights (hereon ‘GC21’) noted that beyond participation, access to, and contribution to cultural life are also captured by the right to participate in cultural life.⁴⁶

⁴² Ibid 902.

⁴³ Ibid 913.

⁴⁴ CRPD art 30.4.

⁴⁵ ICESCR art 15.

⁴⁶ Committee on Economic, Social and Cultural Rights, *General Comment No. 21/2009*, 43rd sess, UN Doc E/C.12/GC/21 [4], (‘GC21’).

Participation in

The right to participate in cultural life in Art. 15 is elaborated on in GC21 as being the right of everyone to choose one's identity, engage in one's cultural practices and the right to seek and develop cultural knowledge and expressions and share them with others, as well as to act creatively and take part in creative activity.⁴⁷ This right is explicitly captured in Art. 30.1, which directly imports the language of taking part in cultural life. Parts (a) to (c) of Art. 30.1 may also be read as articulations of the right to seek and develop culture, through enjoyment of access to cultural life.⁴⁸ Art. 30.4 encompasses the right to recognition and support of the specific cultural and linguistic identity of a disabled person, including sign languages and deaf culture. The language of 'identity' explicitly imports the broad right to choose one's identity.

Access to

Another sub-component of the Art 15 ICESCR right is access to cultural life. GC21 notes that 'access' covers the right of everyone to know and understand cultures through education and information through any form of information communication; a right to quality education that pays due regard to cultural identity; to access specific cultural goods or institutions associated with following a particular way of life; and to *benefit* from the cultural heritage and the creation of other individuals and communities.⁴⁹ The language of access is captured in Art 30.1(a) to (c), in the context of ensuring that persons with disabilities enjoy access to cultural materials and places for cultural performances, services or cultural heritage.⁵⁰ This right to access appears thus far to have been interpreted narrowly, with concluding observations of the CRPD largely focusing on lack of physical/infrastructural access to cultural materials and places. Many of them focus on the failure of a state to ratify the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled (hereon 'Marrakesh Treaty'),⁵¹ or lack of infrastructure in place for accessibility to cultural places, such as museums or heritage buildings.⁵² However, the content of the access right could arguably be interpreted more broadly, in light of Art 15 of the ICESCR. Art 15 of the ICESCR and Art 30 of the CRPD respectively describe the right to access as one to be 'enjoyed' by persons with disabilities, which implies that both include a right of said persons to *benefit* from cultural heritage and the creation of other individuals and communities.⁵³ This right

⁴⁷ Ibid.

⁴⁸ CRPD art 30.1.

⁴⁹ GC21, [4].

⁵⁰ CRPD art 30.1.

⁵¹ International Disability Alliance, 'IDA's compilation of the CRPD Committee's Concluding Observations', see e.g. 'Luxembourg' discussion under art 30 on page 407.

⁵² Ibid, see e.g. 'Morocco' discussion under art 30 on page 408.

⁵³ ICESCR art 15, CRPD art 30.

is implied through the corresponding obligation set out in Art 30.2, through which states are expected to give persons with disabilities the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit but also for the enrichment of society.⁵⁴ Art 30.2's addition of 'also for the enrichment of society' potentially encompasses and then broadens the Art 15 definition of access, which incorporates benefit to the individual rights holder, but not the enrichment of society.⁵⁵

Contribution to

Contributions to cultural life refers to “the right of everyone to be involved in creating the spiritual, material, intellectual and emotional expressions of the community.”⁵⁶ This right is supported by an entitlement to take part in the development of the community in which one belongs, and to be a part of policy and decision-making in that community.⁵⁷ Both rights are implicitly acknowledged in Art 30.2.⁵⁸ The right to be involved and to participate in decision-making in a community is found in the Art 30.2 recognition of the obligation to support persons with disabilities to develop and utilise their creative, artistic and intellectual potential, not simply for their own benefit, but “for the enrichment of society”.⁵⁹ The language of 30.2 is couched in similar terms to the CRPD's preamble, which promotes full participation of persons with disabilities to the end of an enhanced sense of belonging, as well as development of society.⁶⁰ Including the enrichment of society as an outcome of contribution broadens the scope for persons with disability to participate more fully in decisions as to their own representations. This clearly supports an obligation to create positive representations of disability in the media and popular culture.

C. Are there other legal rights relating to accessing cultural materials that are implicated or potentially interfered with?

The Art 30 right to access cultural materials may potentially interfere with intellectual property rights in domestic settings. For example, allowing certain entities to reproduce cultural materials in more accessible formats may interfere with the original right to reproduction held by publishing houses. This potential interference is acknowledged by Art 30.3 of the CRPD, which attempts to prevent states from enforcing intellectual property rights to the extent to which it may be a barrier to access of cultural materials for persons with disabilities.⁶¹ When intellectual property rights may constitute barriers

⁵⁴ CRPD art 30.2.

⁵⁵ Ibid.

⁵⁶ GC21, 4.

⁵⁷ Ibid.

⁵⁸ CRPD art 30.2.

⁵⁹ Ibid.

⁶⁰ CRPD, Preamble [13].

⁶¹ CRPD art 30.3.

to access is outlined in the Marrakesh Treaty.⁶² This treaty requires contracting parties, of which Australia is one, to introduce a standard of limitations and exceptions to copyright rules,⁶³ with a view to facilitating access to cultural materials for persons with disabilities. As noted by Paul Harpur, real tension arises between intellectual property rights and the right to read.⁶⁴ Formal access to these materials may be denied, if intellectual property rights are violated.

Nevertheless, the obligation to make positive representations of persons with disabilities in popular culture hinges on a more substantive problem of access, of being able to see persons with disabilities in a certain manner on our television screens. Little tension is likely to arise between the protection of intellectual property rights and the obligation to provide positive representations. This is because intellectual property rights are more attendant to rights of formal access, for example the right of reproduction, distribution and making materials accessible to the public, and is less concerned with the content of the representation.

However, acknowledging the state obligation to ensure positive representations of disability may interfere with rights guaranteed under Art 19.2 of the ICCPR.⁶⁵ Art 19.2 states that everyone has the right to freedom of expression, and are allowed the freedom to seek, receive, or *impart* information and ideas of all kinds, in the form of art or through any other media.⁶⁶ An equivalent of this right is also found in Art 21 of the CRPD.⁶⁷ If the right to access cultural materials (and the corresponding obligation to ensure positive representations of disability in the media) is interpreted in light of the 'way of life' conception of cultural life, this may import an obligation in which states are called upon to monitor the impacts of popular culture.⁶⁸ In practice, this may amount to an endorsement of censorship, and if viewed as such by states, may chill the enthusiasm of states to accept a broader construction of the Art 30 right and accompanying obligation to positive representation of disability.

⁶² *Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled*, opened for signature 27 June 2013, WIPO (entered into force 30 September 2016).

⁶³ *Ibid* art 4

⁶⁴ Harpur, above n 9, 33.

⁶⁵ *ICCPR* art 19.2.

⁶⁶ *Ibid*.

⁶⁷ *CRPD* art 21.

⁶⁸ O'Keefe above n 39, 922.

PART II – THE IMPACT OF POSITIVE IMAGES OF DISABILITY IN MEDIA AND POPULAR CULTURE

Introduction

The impact of positive representations of persons with disability in popular culture and media can be examined through the lens of various disciplines, including that of critical disability studies, the humanities and education. Each can provide valuable insights into informing how States can promote positive representations, but only to the extent to which it does not contradict the philosophy of ‘nothing about us without us’,⁶⁹ which informs the core of the CRPD. This phrase promotes the centrality of persons with disability in any process they are involved in,⁷⁰ and has informed both the wider disability rights movement, as well as the drafting of the CRPD.⁷¹ Indeed, the Art 30 right is specifically a right of persons with disability to ‘enjoyment’ of access to cultural materials,⁷² placing their needs front and centre. As a result, much of the literature should be subject to the critical question of whether persons with disability are not only represented, but more significantly, enabled to participate in these representations.

Critical Disability Studies

The early disability studies literature has provided a framework through which one can better understand the need for positive representations of persons with disability. The literature begins with the starting point that negative conceptualisations of disability have pervaded the social consciousness, and are a key contributor to the marginalisation of persons with disabilities, but that these are all social constructs that can be shifted. Disability has been seen as “some terrible chance event which occurs at random to unfortunate individuals”,⁷³ and something that effectively “locates the “problem” of disability within the person”.⁷⁴ Such attitudes end up informing and determining one’s life chances and experiences.⁷⁵ If a person with disability is seen as a constant problem,

⁶⁹ See Charlton, J. I. (1998) *Nothing about us, without us: The dialectics of disability oppression and empowerment*, Ch 1, pp. ix – 17, Berkeley, CA. USA: University of California Press.

⁷⁰ Ibid.

⁷¹ Kayess and French, above n 2, 4.

⁷² CRPD art 30.1.

⁷³ Oliver M, 1990, ‘The individual and social models of disability’, paper presented at the Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals, 23 July 1990, 3.

⁷⁴ G Quinn and T Degener (eds.) 2002 *Human rights and disability: The current use and future potential of united nations human rights instruments in the context of disability*, United Nations, New York and Geneva, 14.

⁷⁵ Jenny Morris, ‘Impairment and Disability: Constructing an ethics of care that promotes human rights’ (2001), 16(4) *Hypatia* 1, 3.

then “the only things they can be offered are treatments and cures and services”.⁷⁶ In this perspective, persons with disability are prevented from having experiences of a non-disabled person, which ultimately leads to segregation and exclusion, and perpetuates the societal attitudes that a disabled person possesses a diminished self.

Michael Oliver⁷⁷ constructed an approach to disability discourse of a social consciousness about disablement of those that fall outside the ‘normal’ range of ability, referred to as the Social Model.⁷⁸ The Social Model is a conceptualisation of disability as ‘the product of interactions of persons with impairments with environmental barriers that hinder their full participation in society on an equal basis with others’.⁷⁹ This Model was adopted in the preamble of the CRPR and facilitates the CRPD’s approach in all articles (except art 25(b)) towards eliminating barriers and facilitating participation rather prevention or treatment of disability.⁸⁰

The area of critical disability studies has in later years developed in tandem with various disciplines of the social sciences and humanities,⁸¹ to focus on the cultural and linguistic critiques on discourses of disability, a topic intrinsically bound to questions of representation of persons with disabilities.⁸² A leading theorist in this field is Fiona Kumari Campbell, who analyses the way in which ableism manifests in society. Ableism is the attitude inherited by social institutions and relations that there exists a ‘corporeal standard’ of a perfect, species-typical body body that is equated with being fully human.⁸³ The following implication is that disabled bodies are ‘naturally’ cast as a diminished state of humanness,⁸⁴ a body confusing and unrecognisable, held hostage by its “recalcitrant corporeal matter”.⁸⁵ Such attitudes found a basis for negative representations of disability in cultural and societal discourse.

Various theorists have critiqued such discourse in various spheres of cultural life. Historian Douglas Baynton has critiqued how notions of ableism and a perfect body have been historically implicated in the American fight for racial and gender equality on both

⁷⁶ Ibid.

⁷⁷ Michael Oliver, *Understanding Disability: From Theory to Practise* (1996) Palgrave Macmillan, 37.

⁷⁸ Harpur, above n 64, 36.

⁷⁹ Kayess and French, above n 2, 148.

⁸⁰ Ibid.

⁸¹ Harpur, above n 64, 37.

⁸² Ibid.

⁸³ Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Aabledness* (Palgrave MacMillan, 2009) 5.

⁸⁴ Ibid.

⁸⁵ Ibid 11.

sides,⁸⁶ while Susan Schweik has done so in the context of American Indian rights.⁸⁷ Most relevantly, Jamie McDaniel has written on ableism in the context of popular culture, in particular the genre of horror movies.⁸⁸

Within the horror film genre, the discourse of ableism is widespread, apparent both in existing representations of persons with disability, and invisibly by way of metaphor. McDaniel asserts that existing representations of persons with disability relies on Mitchell and Snyder's notion of 'narrative prosthesis', whereby disability is used as a convenient characterisation tool as well as a metaphorical device.⁸⁹ Common representations of persons with disability in horror include the physically mutilated monster, as well as the morally superior disabled character, both of which are founded upon ableist views. McDaniel suggests that the concept of the zombie may potentially complicate these negative representations. The clear signs of impairment of a zombie readily lends itself to a metaphor for disability, but zombies may be characterised beyond their mere posture and stance - it has the potential to retain humanity and an ability to experience,⁹⁰ as depicted in movies such as Isaac Marion's 'Warm Bodies'. Yet, McDaniel is also aware of the limits of the metaphorical representation that zombies may afford persons with disability. 'Why are there no zombies with disabilities?' he asks.⁹¹ The absence of zombies with disabilities in television series such as 'The Walking Dead' shows that the use of zombies as a metaphor for disability, while ideologically powerful, cannot alone amount to adequate representation of persons with disabilities.

Zombies and their experiences are inherently fictional, while the realities of people with disabilities are not. Persons with disabilities have a right to be represented on screen in a plurality of ways that are an accurate reflection of their lives, some of which may involve metaphorical representations, but others which do not. Given the 'nothing about us without us' philosophy of the disability rights movement, the focus on actual representation (and particularly self-representation) is especially important for persons with disabilities, and this understanding should be reflected in the state obligation of positive representation.

⁸⁶ Douglas Baynton, 'Disability and the Justification of Inequality in American History' in Paul Longmore and Lauri Umansky (eds), *The New Disability History: American Perspectives*. (New York University Press, 2001), 39.

⁸⁷ Susan Schweik, 'Disability and the Normal Body of the (Native) Citizen' (2011) 78(2) *social research* 417, 420.

⁸⁸ Jamie McDaniel, "'You can point a finger at a zombie. Sometimes they fall off": Contemporary Zombie Films, Embedded Ableism and Disability as a Metaphor' (2016) 57(4) *Midwest Quarterly* 423.

⁸⁹ *Ibid* 433.

⁹⁰ *Ibid* 437.

⁹¹ *Ibid* 435.

Education

The field of education has outwardly recognised the importance of positive representations of persons with disability within classrooms. Exposure of both children and teachers to positive representations, particularly through literature, has numerous benefits. A study conducted by Marlowe and Maycock found that teacher candidates exposed to a special education course that incorporated literary texts held more positive attitudes towards children with disabilities than teacher candidates who were exposed to a traditional course based on professional texts such as textbooks.⁹² Stelle notes that children's literature in particular can help develop positive attitudes towards disability and encourage positive peer relationships among children of differing abilities.⁹³ It might cautiously be extrapolated to show that positive representations, facilitated on the wider platform of popular culture and media, could encourage positive relationships between non-disabled persons and persons with disability, as well as widely held positive attitudes toward disability. Such cultivation of positive relationships and attitudes would be in fulfilment of the Art 30 right of persons with disabilities to 'enjoy access' to culture and cultural materials.

The education literature may also assist in clarifying the content of the state obligation to provide 'positive' representations. Joan Blaska developed an 'Images & Encounters Profile', to assist parents and teachers in reviewing the representations of persons with disabilities in children's literature. This profile included ten criteria, some of which include: whether the text promoted empathy or pity, depicted acceptance or ridicule, and most relevantly, whether the text promoted positive representations of persons with disability.⁹⁴ Alicjia Rieger conducted a study in 2010, in which teacher candidates used Blaska's Profile to critique contemporary children's books that included persons of disabilities.⁹⁵ On the criteria of positive representations, a range of answers by teacher candidates were offered. Some labelled representations as positive on the basis that the character with a disability had positive personality traits, such as being happy,⁹⁶ while others stated that representations that portrayed normal interactions that moved beyond the character's disabilities were positive in themselves.⁹⁷ Two other

⁹² Marlowe, M, Maycock, G. A. 'Effects of literary texts and professional texts on preservice teachers' attitudes toward children with disabilities' (1989) *Appalachian State University*, Boone, North Carolina 28607, 3-4.

⁹³ Stelle, L. C.H. 'Review of children's literature: Children with disabilities as main characters' (1999) 35(2) *Intervention in School and Clinic* 123.

⁹⁴ Joan Blaska, 'Children's Literature That Includes Characters With Disabilities or Illnesses' (2004) 24(1) *Disability Studies Quarterly*. <<http://www.dsqsds.org/article/view/866/1041>>.

⁹⁵ Alicjia Rieger, 'Learning to critique Disability Children's Literature Available to Teacher Candidates in Their Local Communities' (2010) Winter *JAASEP* 78.

⁹⁶ *Ibid* 85.

⁹⁷ *Ibid* 86.

manifestations of positive representations arrive in the form of the portrayal of positive friendship relations between persons with and without disabilities, and portrayal of persons with disability as having a sense of humour.⁹⁸ This range of responses shows that there is no standard answer to what a positive representation of disabilities might look like; and that the concept of positive representation is a subjective one. Nonetheless, the applicability of this study's results in the context of understanding what positive representations mean to persons with a disability may be doubted; since this study appreciates the opinions of persons without disabilities.

Media and Communications

Media and Communications research frequently engage with the impact that media has on its audiences and its codification of modern day culture. Some research has considered the quantitative deficiency in representation.⁹⁹ Various media theories also focus on finding solutions based on the social model of disability.¹⁰⁰ Media consumption and production presents opportunities to alter society's understanding of disability and to enrich Australian media content through the inclusion of characters, writers and audiences with disabilities.

To answer the question of whether a television show can influence attitudes towards minority groups, Shiappa, Gregg and Hewes¹⁰¹ have developed an approach called the Parasocial Contact Hypothesis. The first aspect of this theory is that interpersonal contact is one of the most effective ways to reduce prejudice towards minority group members. However, this attitude change is stagnated by the lack of opportunity to develop these positive interactions with persons with disabilities if they are excluded from his or her social environment.¹⁰² This exclusion could be due to physical accessibility and the systematic exclusion of persons with disabilities while in institutional care. However, as Isaac Stern points out the permanency and unfamiliarity of impairments are met with "confusion, uncertainty and social awkwardness."¹⁰³ These negative attitudes can lead to further exclusion and avoidance by those who would benefit most from interacting with

⁹⁸ Ibid.

⁹⁹ Dennis Ganahl and Mark Arbuckle, 'The exclusion of Persons with Physical Disabilities from Prime Time television advertising: a two year quantitative analysis' (2001) *Disability Studies Quarterly* 21(2) 1.

¹⁰⁰ Barbara Hocking, 'Reducing mental illness stigma and discrimination – everybody's business' (2003) *Media Journal Australia* 178, S47; Joan Susman, 'Disability, Stigma and Deviance' (1994) *Social Science Medical* 38(1) 15; Heather Stuart (2006) 'Media Portrayals of Mental Illness and its Treatments: What effect does it have on People with Mental Illness?' (2006) *CNS Drugs* 20(2) 99.

¹⁰¹ Schiappa et al 'Can one TV show make a difference? *Will & Grace* and the Parasocial Contact Hypothesis' (2006) *Journal of Homosexuality* 51(4) 15.

¹⁰² Ibid 21.

¹⁰³ (2010) *Breaking a disabled limb: Social and Medical Construction of Legitimate and Illegitimate impairments*, 18.

persons with disabilities. The second aspect of the Parasocial Contact Hypothesis is that mass-media including television and movies, provide the illusion of face-to-face relationships with the performer and enables audiences to engage with persons with disabilities across a variety of social circumstances that a television series presents.¹⁰⁴ The benefit of television series, more so than movies, is that exposure is sustained over long periods of time which enables the evolution of emotional connections and the possibility of complex character development beyond the stereotypical inspirational narrative. According to Liesbet van Zoonen et al,¹⁰⁵ during this exposure characters with disabilities are giving both incidental and non-incidental representations that have different beneficial effects on audiences. From incidental representation characters that are portrayed positively and ordinarily allows an average viewer to align strong identification with them. Whereas non-incidental representation provides audiences an opportunity to engage is a process of social learning, importantly, showing how positive interactions are achieved between non-disabled persons and persons with disabilities they are unfamiliar with.¹⁰⁶ It is critical that exposure is positive, in that the medium provides enough information and enjoyment to reduce unease and discomfort, as negative exposure that does not meet these requirements can confirm a stereotype and cause negative sentiments to be reinforced.¹⁰⁷ It is through this multi-layered approach that demonstrates 'all facets of life with impairment'¹⁰⁸ (particularly physical impairment) that the realistic range and depth of identity and character can best be provided to challenge disabling perspectives of the public. It was concluded that reality TV offered the best avenue for this social learning process, rather than soap dramas (as they are not valued as realistic representations of life) or once off short documentaries (as they did not generally have multiple episodes or character to evince a wide range of interactions).¹⁰⁹

Media analysis requires consideration of both the encoding and decoding of content.¹¹⁰ Encoding is the process of producing media and cultural materials that innately reflects specific political and economic relationships within society. Persons with disabilities must be considered when content creators determine what and who is represented in the media and the symbols, narratives and context that surround. Decoding looks at the implications these 'legitimate' texts have on society and the effects they have on

¹⁰⁴ Schiappa et al, above n 97, 18.

¹⁰⁵ 'Disability, prejudice and reality TV: Disablism through media representations' (2012) *Telecommunications Journal of Australia* 62(2) 1, 3.

¹⁰⁶ Liesbet van Zoonen et al 'Disability, prejudice and reality TV: Disablism through media representations' (2012) *Telecommunications Journal of Australia* 62(2) 1, 3.

¹⁰⁷ Olan Farnall and Kim Smith 'Reactions to people with disabilities: personal contact versus viewing of specific media portrayals' (1999) *Journalism & Mass Communication Quarterly* 76(4) 659, 661.

¹⁰⁸ van Zoonen et al, above n 102, 10.

¹⁰⁹ Ibid 4.

¹¹⁰ Caroline Wang 'Culture, meaning and disability: injury prevention campaigns and the production of stigma' (1992) *Social Science Medical* 35(9) 1093, 1097.

individuals as they perceive the materials in relation to self and prejudices. In particular Caroline Wang has criticised government public health campaigns, for example prompting people to wear a seat belt and exercise other road safety behaviour.¹¹¹ These ads have codified the dangers of reckless driving but they also declare the the ultimate tragedy is the injuries that could be sustained. This portrayal of injury, that *becoming* disabled is an unacceptable risk in society ultimately contributes to the stigmatizing notion the *being* disabled is an unacceptable status in society. Cultural materials and media artefacts are critical reflections on how society perceives itself, in the case of public health campaigns cultural materials ‘pathologise individuals as helpless, defective and incapable of meeting their own needs.’¹¹²

Developments in the way society watches media content has change drastically with the introduction of online media. This is not only through practises of ‘binge watching’ television series, but fans can access numerous forums that provide behind the scenes insight, conversations with actors and writers, and social media sites where viewers can discuss the series, allowing characters and shows to develop and evolve in unprecedented ways.¹¹³ As audiences saturate themselves with entire seasons and commentary in a short amount of time, Metcalf¹¹⁴ has argued that producers have to meet the challenge; consumers are demanding more complex characters and extensive narratives instead of the regurgitation of familiar plots of tragedy or inspiration. An significant obstacle for content creators is that converting negative attitudes towards persons with disabilities requires exposing these positive portrayals to audiences who may not seek out these websites or choose to watch this content.¹¹⁵

Holmes and O’Loughlin¹¹⁶ have determined that social networking sites provide arenas for social and personal identity to be developed and empowered. An entire community can grow around a simple hashtag. For writers looking to promote conversations regarding disability #criplit has been established as a means to share their work and promote discussion of topics they want to collaborate upon.¹¹⁷ Additionally, for anyone with an interest, #criplit a resource pool of content that is both autobiographical and non-fictional. The wide range of styles and forms of writing appearing under this hashtag

¹¹¹ Ibid 1093.

¹¹² Ibid 1095.

¹¹³ Katie Ellis ‘Cripples, Bastards and Broken Things: disability in Game of Thrones’ (2014) *Media Culture Journal* 17(5).

¹¹⁴ Greg Metcalf, *The DVD Novel: How the way we watch television changed the television we watch* (2012) Praeger, California.

¹¹⁵ Farnall and Smith, above n 103, 661.

¹¹⁶ Holmes & O’Loughlin ‘The experiences of people with learning disabilities on social networking sites’ (2012) *British Journal of Learning Disabilities* 42(1), 1.

¹¹⁷ See Storify, *#criplit: Disabled Writers, Ableism & the Publishing Industry* (2016) < <https://storify.com/SFdirewolf/criplit-disabled-writers-ableism-the-publishing-in> >.

reaffirms the immense contribution content surrounding disability can provide to Australian cultural materials. Any person who engages with the #criplit conversation on publishing, ableism and disabled writers gains a sense that excluding disability from media representations, literature and denying acknowledgement of ableism actually deprives Australian culture of the multitude of voices and characters that enriches our media. An Australian online media source that assisted in the development original content on the conversation of disability is the Ramp Up website lead by Stella Young.¹¹⁸ Although this website is no longer active, it remains an archive of progressive media content and provides an example of successful online community engagement in Australia.

Case Studies:

Utilising a combination of the critical approaches discussed above the following are examples of contemporary media content portraying a positive representation of disability and promoting the rights and obligations referred to in Art 30.¹¹⁹ One particular framework for analysis is the Fries Test, formulated by author Kenny Fries, to critique representations of disability in fiction.¹²⁰ The test is as follows:

1. Does a work have more than one disabled character?
2. Do the disabled characters have their own narrative purpose other than the education and profit of a nondisabled character?
3. Is the character's disability not eradicated either by curing or killing?

While this test will not be explicitly adhered to in the case studies that follow, it is a useful guide for readers to keep in mind when critiquing such materials. In our research, it became apparent that in Australian made television shows and movies there is a severe lack of realistic, complex and central characters with disabilities.¹²¹ As a result, all of these examples are American. These case studies may serve as examples which Australia can emulate in fulfilment of their obligation to ensure positive representations of disability in the media.

¹¹⁸ See ABC, *Ramp Up* (2014) <<http://www.abc.net.au/rampup/>>.

¹¹⁹ CRPD art 30.

¹²⁰ Medium, *The Fries Test: On Disability Representation in Our Culture* (2017) <<https://medium.com/@kennyfries/the-fries-test-on-disability-representation-in-our-culture-9d1bad72cc00>>.

¹²¹ Screen Australia, *Milestone Study of Diversity on TV Released* (2016) <<https://www.screenaustralia.gov.au/sa/media-centre/news/2016/08-24-study-of-diversity-on-tv-released>>.

#TheDisabledLife comics

Two Canadian sisters have collated a series of comics about the ‘jerks and perks of living #thedisabledlife.’¹²² The humorous comics reflect scenarios the girls have found themselves in over the years and is a demonstration of how they react to accessibility barriers and the attitudinal impediments from people in the community. The artists are humorous and sarcastic in their responses to strangers’ negative attitudes towards them, and also emphasise some of the perks they have enjoyed such as skipping the cues to meet their celebrity crushes or creative Halloween costumes. Other comics focus on the ‘jerks’ of being a teenage girl with a wheelchair such as the choice between ‘high rise aka granny jeans’ or ‘low rise aka plumber jeans’, annoying tan lines from only sunbaking only the front of their bodies, and jiggling in their chair while the elevator is taking too long to get to the floor with the bathroom. The sisters have said they love to draw and have developed their sarcastic humour to help ‘take the edge off’ people who do not understand their abilities. Therefore, they felt it was natural to combine two things they loved, making jokes and drawing.¹²³ The benefit of posting these comics on Tumblr and Twitter is that others can reblog their comics and they are shared across thousands of users’ pages, spreading the talent of the sisters throughout the Tumblr and Twitter communities. As noted by Katie Dupere¹²⁴, conversations about disability both in the media and in person are often bound to serious, academic and somewhat stale approaches. However, the artwork created by these sisters shows difficult situations they have found themselves in (most commonly the awkward interactions with strangers) and how communicating the rights of persons with disabilities (and daily failures to realise them) can be approached through entertaining avenues. These Tumblr comics exemplify the rights under Art 30.2 as the artists are able to utilise their ‘creative, artistic and intellectual potential,’¹²⁵ in representing their experiences accurately and positively for the benefit of themselves and the online community.¹²⁶

Game of Thrones

It has been argued that Game of Thrones is inherently a show about power, those who possess it and those who do not.¹²⁷ After the deaths of the initial rulers in the show, new more ambiguous misfit leaders take their place; they are referred to by Ellis¹²⁸ as ‘cripples,

¹²² Tumblr, *The Disabled Life* < <http://thedisabledlife.tumblr.com/tagged/comics> >.

¹²³ Katie Dupere, ‘Comic series uses offbeat humor to give unfiltered look at life with a disability’, *Mashable* (online), 19 October 2016 < <http://mashable.com/2016/10/19/disability-comic-the-disabled-life/> > .

¹²⁴ *Ibid.*

¹²⁵ *CRPD* art 3.2.

¹²⁶ *CRPD* art 8.2(e).

¹²⁷ Ellis above n 109.

¹²⁸ *Ibid.*

bastards and broken things.’ To answer question one of the Fries test, there are a significant number of characters that have lifelong impairments as well as characters that acquire such impairments throughout the series. In particular, Tyrion Lannister, who has a visible disability and holds a significant position of power and leadership over the Lannister properties and armies. It is widely held that, set in a fictitious version of Medieval historic times, Game of Thrones has many violent, corrupt and morally deficient characters. Equally, characters with disabilities including Tyrion demonstrate these qualities just as any other character. It has also been noted that Tyrion (and others) is crucial to central narratives, occupies the screen in close-ups and is given a relatively significant amount of screen time.¹²⁹ Peter Dinklage has been awarded two Primetime Emmy Awards and a Golden Globe Award for his portrayal of Tyrion.

On an ordinary reading of ‘positive portrayal’ the character of Tyrion may not measure up, as he is depicted as a villain in many of the story arcs, he is discriminated against and threatened by some of the characters for his disability. Despite his portrayal as a violent villain in some episodes (no more so than other non-disabled characters) his character also demonstrates a high level of intellect, often getting him out of situations and capture when other characters understated his ability to escape. He also promotes a social model approach after another the character, Bran, becomes paraplegic, demanding adaptations to the environment and technology; such as a new saddle to be made so Bran can continue to ride his horse. The creation of the compelling character Tyrion as portrayal by Peter Dinklage is positively changing the nature of disability representation.¹³⁰

My Gimpy Life

‘My Gimpy Life’ is a Youtube web series starring Teal Sherer. Loosely based on Teal’s life, the series centres around her experiences as a disabled actress ‘trying to navigate Hollywood in a wheelchair’.¹³¹ The series documents both challenges that Teal faces as a person with a disability, as well as the normality of her experiences. For example, in an episode titled ‘Inspirational’, she faces the challenge of dealing with people in her everyday life who consider her ‘brave’ and ‘inspirational’ for things that are plainly ordinary, such as auditioning for roles, and showing up to social functions. In this episode she shows her frustrations at these challenges, and is thus a positive representation for persons with disability, showing that it’s natural to be frustrated by such comments, and that this is behaviour that persons with disability should not have to tolerate.

¹²⁹ Ibid.

¹³⁰ Ibid.

¹³¹ My Gimpy Life, *About* (2014) <<http://mygimpylife.com/about/>>.

The show is produced by Teal herself, under her own production company, 'Rolling Person Productions', and is a great example of persons with disability contributing to and being in charge of their own representations. Teal is also a part of the wider Youtube creator community, being more famously known for her role in 'The Guild', one of the first and most well-known series to be made for Youtube. She is also closely associated with Felicia Day, one of the pioneers of the Youtube creative community, who appears in 'My Gimpy Life' alongside Sherer. This means that people watching 'My Gimpy Life' often also watch 'The Guild', and this close association allows the show to be known as yet another good series to watch on Youtube, rather than a show to watch that is good because of the way it talks about disability. Positive representations such as 'My Gimpy Life' may fulfil Art 30 obligations in the same manner, as discussed above.¹³²

Switched at birth

Switched at Birth is a television drama about two girls, Daphne and Bay, who were accidentally taken home from the hospital by the wrong parents. The families do not discover the mistake until the girls are 15 years old and the series revolves around the two families raising the two teenagers together. Daphne is deaf, and is one of many central characters that have hearing impairments in the show. Meeting the Fries test, the *Switched at Birth* cast includes a multitude of deaf characters that have intricate friendships and romantic relationships with characters that do not have hearing impairments and have central narratives equal to non-deaf characters. The characters in both families develop their linguistic abilities as they, eventually, all learn American Sign Language (ASL) to be able to communicate with Daphne and her friends. Deafness is ultimately socially disabling due to the barriers created by a hearing society.¹³³ There are moments in the series, as well an entire episode, filmed from Daphne's perspective in which dialogue is muted and the only language spoken is ASL. The audience watch as she follows the expressions, lips and signing of those around her. In one scene Daphne sets off the fire alarm and looks out at her family in confusion as they panic and run through the house.¹³⁴ Unable to hear, the audience also have no idea what is happening. These muted episodes have subtitles for non-deaf viewers and provide a unique insight to navigating the hearing world.

¹³² See #thedisabledlife comics

¹³³ Seon-Kyoung et al 'Prominent Messages in Television Drama *Switched at Birth* Promote Attitude Change Towards Deafness' (2014) *Mass Communication and Society* 17 195.

¹³⁴ Jason Jughes 'Switched at Birth Goes Silent with Episode Almost Entirely in ASL, American Sign Language (VIDEO)' (2013) *Huffington Post (online)* [Accessed from: <
www.huffingtonpost.com.au/entry/switched-at-birth-asl-silent-video_n>].

A study by An, Paine and McNeil demonstrated that *Switched at Birth* improved attitudes towards deafness in viewers.¹³⁵ In particular the show's focus on the strong emotional relationships formed between a variety of characters, and an emphasis on the capabilities of the deaf characters (safely riding a motorbike, dancing with girlfriends, and taking cooking classes) were most influence in improved perspectives which persisted long after exposure.¹³⁶ The study also concluded narratives surrounding the main characters founded greater attitudinal changes.¹³⁷ This demonstrates the importance of persons with disabilities in central roles, not just supporting roles. The periodic viewing of episodes of *Switched at Birth* improved audience understanding and confidence interacting with persons with hearing impairments¹³⁸ and is a clear example of how the media can positively change attitudes towards persons with disabilities.

CONCLUSION

Australia has a state obligation to promote positive representations of persons with disabilities in the media and popular culture. Art 30 of the CRPD is the source of this state obligation. While at present, Art 30 is interpreted narrowly to found formal rights to access of cultural materials over substantive rights such as positive representations, an analysis of the CRPD, the ICESCR, the UDHR and the ICCPR show that there is scope for Art 30 to accommodate the obligation to positive representation. The disciplines of critical disability studies, education and media and communications studies further support the need for positive representations in popular culture. Critical disability studies provides frameworks to show the pervasiveness of negative attitudes that stem from current representations of persons with disability, founding a need to promote positive representations. Meanwhile, education and media and communication clarify the content of a positive representation, and affirm the positive impacts that stem from such representations in popular culture. Finally, evaluation of current representations of disability in popular culture in the form of case studies can show how Australia might promote positive representations in fulfilment of their obligations. The dearth of examples of positive representations in Australian media reflects how Australia has a long way to go to fulfilling this state obligation. The work of the Attitude Foundation in changing negative stereotypes in media will be integral to Australia's meeting of those obligations.

¹³⁵ Seon-Kyoung et al, above n 133, 207.

¹³⁶ Ibid 211.

¹³⁷ Ibid 210.

¹³⁸ Ibid 207-8.

GROUP 6 PROJECT

Research Ethics and Human Rights

Partner Organisation

Disability Human Rights Research Network

Group Members

Ruby Bell

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NO MORE TEA AND BISCUITS

I INTRODUCTION

“No more tea and biscuits” was the immediate reaction of Australian Human Rights Commissioner, Alastair McEwin when the concept of this paper was presented to him. He was referring to the traditional research practice where participants are invited to a ‘round table’ discussion over tea and biscuits. This approach is often used when conducting research that involves participants with a disability. This paper aims to determine how research practice can evolve from tea and biscuits, to emancipatory research that is in the control of people with a disability. This paper examines the history of approaches to ‘disability research’. This term refers to research that involves the participation of people with a disability, or research that is designed to examine the experience of people with a disability, be that cultural, social or biological. It is through this historical analysis that this paper hopes to situate the Disability Human Rights Research Network’s (DHRNN) new Research Protocol. This paper maps the development of research from positivist approaches in the industrial period, to the human rights based approach of the Protocol. This paper also examines the evolution of the models of disability that have informed disability research practice. Any discussion of the experience of disability throughout history would be incomplete without the considering the influence of the Social Model. This idea that disability is a social construct and people with impairments or differences have been ‘disabled’ by societal structures, not by their biological traits, is a key concept of this paper. This paper hopes to carry on the work of the Union of Physically Impaired Against Segregation (UPIAS), some of the original architects of the social model¹, by identifying barriers to conducting inclusive, emancipatory disability research.

II OVERVIEW

The history of research is not linear. Trying to create a timeline is like trying to unravel a knotted rope; you end up just pulling at threads. The history of research that involves people with a disability is one of those threads, inherently interconnected with the development of research practice. To attempt to unravel this ‘knot’ and find where disability research ties in, this section will attempt to establish a clear roadmap that briefly examines the various approaches to research throughout history.

¹Shakespeare, T. (2013). The social model of disability. In L. J. Davis (ed.). *The disability studies reader*. 4th ed. (Ch. 16, pp. 214-21). New York: Routledge, 2013.

Perhaps more pertinent to the issue of how to conduct CRPD compliant research, this section will look at developing approaches to research specific to the field of disability research. This analysis will help to locate the newly drafted protocol of the DHRRN within the evolving field of disability research methodologies and highlight the approaches that have informed this new research paradigm.

The structure of this section is inspired by Michael Oliver's early work, 'Changing the Social Relations of Research Production'². Oliver's paper, written in 1992, identifies three periods of research history; positivism in the industrial period, interpretivism in the enlightenment period and emancipatory research as result of periods of 'struggle'³. This framework⁴ is useful for comprehending both the history of research approaches and their interaction with disability research, as well as providing a thorough introduction to the more current approaches. This section will briefly outline Oliver's historical critique and update his framework by including human rights-based and participatory approaches to research. This update is important in understanding how the Networks new protocol is the next stage in the evolution of disability research.

III HISTORICAL APPROACHES

A Positivist and Interpretive

Any history of research text begins in much the same way with a review of the transition from 'positivist' approaches to 'interpretive'. That is, the shift from observing social groups in the same way that researchers study the 'natural world'⁵, to an 'enlightened' understanding that the outcomes of social research are particular to their context⁶. The result of the positivist approach for disability research was threefold. Firstly, people with a disability were the 'subjects' of research, a label that dehumanised participants and in some ways reinforced the practice of conducting research to satisfy curiosity or preconceived notions about the experience of 'disability'. There are numerous historical examples of this practice⁷ but it would be remiss to suggest this practice does not continue in the present day. Historically, positivism is easily recognised in medical studies where 'subjects' would be given trial drugs to 'cure' their impairment. This comes as the result of the observation that some biological condition was the cause of the impairment.

² Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 *Disability, Handicap & Society* 2

³ Ibid 106

⁴ Ibid 108

⁵ Ibid 106

⁶ Ibid

⁷ Emma Stone and Mark Priestly, 'Parasites, pawns and partners: disability research and the role of non-disabled researcher' (1996) 47 *British Journal of Sociology* 4, 700-702

As proponents of the social model attest⁸, the ‘impairment’ that many people with a disability experience can be constructed as a ‘medical problem’ in this way, or as a ‘social problem’, that is a result of inherent prejudices or assumption in the community. Today, positivism in research can have a more subtle influence. For example, many ethical guidelines categorise participants with a disability as ‘high risk’ which often means that these participants are excluded from studies due to the more ‘onerous’ requirements⁹. This is a reflection of the artificial separation of people into two groups; ‘disabled’ and ‘non-disabled’. This distinction is not ‘naturally occurring’, people with a disability do not live on their own private island, this division of participants is a social construct derived from the observation of a difference. Positivism as an approach is valuable when studying naturally occurring phenomenon, but the experience of disability is not solely biological nor does the experience occur in a vacuum.

This is perhaps why interpretivism is the next logical evolution in research approaches, as a paradigm that recognises our knowledge or observations are a result of contextual influences not naturally occurring as positivism would assert¹⁰. Interestingly, although this approach is more consistent with the concept of disability as a social construct it is still the subject of much criticism from a social model perspective¹¹. The interpretive approach goes beyond the scientific origins of positivism, however it maintains the basic research paradigm of researcher as expert observer and participant as ‘subject’. Oliver coins this relationship between researcher and participant as the ‘social relations of research production’ and argues that in disability research this power dynamic reinforces inherent assumptions about how to conduct studies on the experience of disability¹². Particularly, that persons with a disability are incapable of relaying their experience coherently and so research must be conducted by ‘experts’. This is problematic as it ignores the fact that people with a disability are the most informed when it comes to their

⁸ Mike Oliver, ‘Changing the Social Relations of Research Production?’ (1992) 7 *Disability, Handicap & Society* 2; Colin Barnes, ‘Disability and the Myth of the Independent Researcher’ (1996) 11 *Disability & Society* 1; Gerry Zarb, ‘On the Road to Damascus: first steps towards changing the relations of disability research production’ (1992) 7 *Disability, Handicap & Society* 2; Paul Abberley, ‘The Concept of Oppression and the Development of a Social Theory of Disability’ (1987) 2 *Disability, Handicap & Society* 1

⁹ National Health and Medical Research Council (2015) National Statement on Ethical Conduct in Human Research. Canberra: National Health and Medical Research Council. Accessed in <<https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>>

¹⁰ Mike Oliver, ‘Changing the Social Relations of Research Production?’ (1992) 7 *Disability, Handicap & Society* 2, 106-108; Emma Stone and Mark Priestly, ‘Parasites, pawns and partners: disability research and the role of non-disabled researcher’ (1996) 47 *British Journal of Sociology* 4 699-700

¹¹ Mike Oliver, ‘Changing the Social Relations of Research Production?’ (1992) 7 *Disability, Handicap & Society* 2, 108-109

¹² Mike Oliver, ‘Changing the Social Relations of Research Production?’ (1992) 7 *Disability, Handicap & Society* 2, 106-108; Emma Stone and Mark Priestly, ‘Parasites, pawns and partners: disability research and the role of non-disabled researcher’ (1996) 47 *British Journal of Sociology* 4 699-700

¹² Mike Oliver, ‘Changing the Social Relations of Research Production?’ (1992) 7 *Disability, Handicap & Society* 2, 108-109

own experiences. This may in turn skew outcomes of research which is often used to develop policy and public expenditure¹³.

It is now relevant to introduce some historical context to this discussion of research approaches as it is useful in understanding *why* these approaches were focused on methodology as opposed to research relationships. These approaches and more specifically their interaction with disability research, could arguably be considered a product of 'their time'. The industrial period in which positivism flourished, was centred on the able-bodied working-class man¹⁴. As a result, positivist research outcomes reflected this 'able' archetype and explained social practices by reference to this specific individual experience. In the disability sphere, this meant the experience of disability was understood as an 'outlier'¹⁵ specific to the individual, with little reference to the influence of social structures or context¹⁶.

The interpretive response to the experience of disability during the period of enlightenment again appears to be a natural evolution in approaches to research and disability research. This period shifted focus from the individual able-bodied man, to a more collective social consciousness centred on how society *should* be. In a disability context, this meant reframing disability as a social construct rather than a biological or natural 'condition'¹⁷, similar to Oliver's social model. However, as perhaps the somewhat bourgeois phrase 'enlightenment' suggests, the researcher/ participant relationship remained as expert, detached researcher and subject.

This history of positivism and interpretive approaches could be and is the content of volumes. This brief overview highlights the key concepts for understanding how these approaches inform disability research. This paper now departs from Oliver's framework in an attempt to update the timeline of disability research and the alternative approaches that have arisen in response to disability activism.

B Social Model Critique of Research Methods

Oliver's critical review of disability research throughout history is arguably now a part of that history, having been written almost 25 years ago. Although, as demonstrated by the

¹³ Gerry Zarb, 'On the Road to Damascus: first steps towards changing the relations of disability research production' (1992) 7 *Disability, Handicap & Society* 2, 131

¹⁴ Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 *Disability, Handicap & Society* 2

¹⁵ Ibid 106

¹⁶ Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 *Disability, Handicap & Society* 2, 106-108; Emma Stone and Mark Priestly, 'Parasites, pawns and partners: disability research and the role of non-disabled researcher' (1996) 47 *British Journal of Sociology* 4 699-700

¹⁷ Ibid

analysis above, many of Oliver's critiques to research approaches remain relevant, the 'social model' 703 (and subsequent or alternative formulations of it) has been the subject of heated debate since its first conception. This social model theory approach to research is designed to recognise disability as a social construct¹⁸ and the social barriers that inhibit people from participating in society and in this particular context, in meaningful research. 'Meaningful' in this instance, refers to research that is 'purpose aligned' with the emancipatory struggles of people with a disability¹⁹. Unfortunately, research practice remains relatively unchanged²⁰ since Oliver's critique, however theories about *how* research should change are abundant, which includes using a social model lens to restructure approaches. The model informs research practice by suggesting fundamental changes and requiring practical adjustments to the way research is conducted. Oliver argues for systematic overhaul by "...throw[ing] off the shackles of methodological individualism"²¹ in favour of an emancipatory research model. This model has been proposed as a way to implement social-model compliant research²². The emancipatory model is discussed further below, but one practical outcome might look like research design that includes the input or is under the control of people with a disability²³. This practically applies the social model conception of disability, that is people with a disability are not precluded from participating in discussion about their experience simply *because* of their disability. This is discussed further in the section addressing emancipatory and participatory research.

The Social Model is a theory imbued with the history of disability struggle and activism, which is why it is imperative to this discussion of historical bases of research and research involving people with a disability. However, as mentioned earlier in this paper, disability research theory is evolving and one part of that evolution is a critique of the Social Model. This critique is particularly relevant when examining the place of medical research in disability spheres. The Social Model has been critiqued for excluding or oversimplifying the experience of people who have an impairment. This model constructs 'disability' as a series of barriers created by societal norms. Some interpretations²⁴ of this construction find that it discounts the actual fact of some people's impairments and how these might require positive change, rather than the removal of barriers²⁵. Oliver himself has stated

¹⁸ Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35, 2

¹⁹ *Ibid*

²⁰ Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35, 1-3

²¹ Mike Oliver, 'Changing the Social Relations of Research Production?' (1992) 7 *Disability, Handicap & Society* 2, 113

²² Gerry Zarb, 'On the Road to Damascus: first steps towards changing the relations of disability research production' (1992) 7 *Disability, Handicap & Society* 2

²³ Jenny Morris, 'Impairment and Disability: Constructing an Ethics of Care that promotes Human Rights' (2001) 16 *Hypatia* 4

²⁴ Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35, 3

²⁵ *Ibid* 1-4

that the Social Model was intended to form a foundation for disability studies and is not immune to criticism.

What does this mean for disability research? The Social Model critique of research approaches alienates medical research as positivist in nature and therefore conforming to the emphasis on individualism disability studies is trying to avoid.

The Social Model reluctance to ‘medicalise’ a person’s impairment or experience of disability is a result of the assumptions underlying traditional Charity and Medical Model approaches namely; people with an impairment are inherently vulnerable and flawed²⁶ and ‘vulnerability’ has historically resulted in the loss of legal capacity and independent decision-making²⁷. This language has also generally contributed to negative stigma about disability and people with a disability. Medical research has played a big part in enabling Charity or ‘best interest’ approaches²⁸ to disability. Some examples of research that may have contributed to the ‘disabling’ of people with impairments are; the concept of a ‘mental age’ which has been used to categorise Intellectual Disability, attempts to cure physical impairment and medical models used to assess levels of disability based on ability²⁹. This research conflates two separate ideas, ‘disability’ and ‘impairment’³⁰. The Social Model approach helpfully identifies such research as problematic, but does not suggest an alternative that recognises that medical research can have a positive impact for people living with an impairment. Research must not simply fall back into the problematic aspects of traditional positivist research identified above.

C Emancipatory and Participatory Approaches

Participatory research has the dual goals of developing generalisable knowledge about a particular topic and benefitting the researched community, along with improving research protocols by incorporating community knowledge and expertise into research practices.³¹ Community expertise is often the key to successful research.³²

²⁶ Ibid 3

²⁷ Paul Abberley, ‘The Concept of Oppression and the Development of a Social Theory of Disability’ (1987) 2 *Disability, Handicap & Society* 1, 10-12

²⁸ See section below ‘Medical Research’ and section ‘Barriers: Top Down, Legal Capacity’

²⁹ Stella Young, ‘Not Disabled Enough for the Census’, *ABC* (Online), 10 August 2011 <<http://www.abc.net.au/news/2011-08-09/young-not-disabled-enough-for-the-census/2831560>>

³⁰ Jenny Morris, ‘Impairment and Disability: Constructing an Ethics of Care that promotes Human Rights’ (2001) 16 *Hypatia* 4

³¹ Ann C. MacAulay, Laura E. Commanda, William L. Freeman, Nancy Gibson, Melvina L. McCabe, Carolyn M. Robbins and Peter L. Twohig. 1999.

³² Ann C. MacAulay, Laura E. Commanda, William L. Freeman, Nancy Gibson, Melvina L. McCabe, Carolyn M. Robbins and Peter L. Twohig. 1999.

All research involves varying degrees of participation. Conventional research draws a clear distinction between ‘researchers’ and ‘subjects’. Such research often limits interaction between the two groups, with some research involving the ‘subjects’ more than others. In contrast, participatory research is grounded in mutually negotiated codes of ethics which prioritise shared leadership, decision making, and power. These agreements are in place for the entire duration of the research -- from the initial stages until the completion. Banks and colleagues outline four degrees of community participation in research: community controlled and managed research, with no professional involvement; community controlled research with professional researchers managed by and working within the community; equal partnerships between researchers and community, known as co-participation; and research controlled by professional researchers with varying degrees of community participation.³³ Some examples of this style of research include advisory groups being involved in the research design or dissemination; trained community researchers undertaking some or all of the data collection, analysis, and writing; or professional researchers incorporating participatory methods into their research (e.g. asking participants to help gather data).³⁴

There are several ethical issues which arise during the course of participatory research. Some such issues are informed consent; issues concerning protection of participants, and of the researcher’s responsibility for the wellbeing of participants; confidentiality; and potential for abuse.³⁵ These issues are present in all participatory research studies, but are more prevalent in research studies involving vulnerable participant groups. The history of exclusion and unethical inclusion of persons with disabilities in research may mean that things such as additional supports, ensuring accessible information, and consideration of wellbeing must be carefully considered.

Disabled and disability scholars assert that there is a need for research to be concerned with equity and social justice, and to reject neutrality and explicitly address political issues.³⁶ Emancipatory research prioritises research that is empowering and transformative.³⁷ Barton provides an outline of how he undertakes participatory research.

³³Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A. and Moore, N., 2013. Everyday ethics in community-based participatory research. *Contemporary Social Science*, 8(3), pp.263-277.

³⁴Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A. and Moore, N., 2013. Everyday ethics in community-based participatory research. *Contemporary Social Science*, 8(3), pp.263-277.

³⁵Thomas, N. and O’Kane, C., 1998. The ethics of participatory research with children. *Children & society*, 12(5), pp.336-348.

³⁶Barton, L., 2005. Emancipatory research and disabled people: Some observations and questions. *Educational review*, 57(3), pp.317-327.

³⁷Barton, L., 2005. Emancipatory research and disabled people: Some observations and questions. *Educational review*, 57(3), pp.317-327.

He identifies key questions which underpin all of his research: Who is the research for and who benefits from it? What right does he, a non-disabled researcher, have to undertake the research? What responsibilities arise from his privileges? Does the research challenge existing systems of oppression and domination, or adhere to them?³⁸

D The Role of the CRPD

In this next section regarding 'rights based approaches' to research, this paper makes reference to the Convention on the Rights of Persons with Disabilities (CRPD)³⁹. This section identifies the CRPD as the main source of authority in the human rights approach to disability research. The purpose of the CRPD is to enable the realisation of human rights for people with disabilities⁴⁰. The Convention guarantees the rights to respect for physical and mental integrity⁴¹, the right to legal capacity for all persons⁴², freedom from degrading treatment⁴³ and the right to the highest attainable standards of health⁴⁴. The rights contained in the Convention and its purpose are an intrinsic part of the development of the research approach discussed below.

E Rights Based

The next phase in research production is a Rights Based research approach. This approach is a relatively new paradigm that is informed by the Human Rights Model of disability. A Rights based research uses a 'universal rights' foundation and is generally the term used for research conducted on the realisation and application of human rights⁴⁵. However, this terminology has been used to describe a variety of approaches; as is common with *all* research approaches, there are many methods within rights based research. This section will touch on some of the previous conceptions of rights based research in an attempt to situate the Networks new protocol within research development. The protocol arose as a result of the DHRRN identifying the need for more guidance in this rights based field of research, particularly in applying this approach in disability studies. This discussion will attempt to highlight where rights based research has come from and how the protocol attempts to further develop one of the many strains of this human rights approach.

³⁸ Ibid.

³⁹ UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29*

⁴⁰ UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29, Article 1*

⁴¹ Ibid Article 17

⁴² Ibid Article 5

⁴³ Ibid Article 15

⁴⁴ Ibid Article 25

⁴⁵ Theresia Degener, 'Disability in a Human Rights Context' (2016) 5 *Laws* 35, 3

Rights based research is still developing, but this is not a concept in its infancy. Initially, this research approach was used in quantitative studies to help develop and inform policy. With the advent of ‘disability activism’ in the 1970s⁴⁶, there came a shift in policy focus from the economic standards implicit in certain positivist models, to a ‘social equity’ approach⁴⁷. This ‘shift’ manifested in research circles as a demand for data, specifically data that could inform and justify such social policy⁴⁸. For example, research that examines how subsidised healthcare affects GDP or data on how female employee quotas affects productivity. Human rights were used as one such ‘indicator’ in research as a method for measuring the what effect these social policies would have. From this history, rights based research has developed into an approach that at its core assumes that every person possesses a set of inalienable and universal human rights⁴⁹. Rights based research focuses on how or if, these rights are realised and how realisation of rights affects society more broadly⁵⁰.

The Networks protocol⁵¹ is derived from a more qualitative approach to research, however is designed to be applicable to all forms of disability research (and indeed *all* research). The protocol is informed by the human rights model of disability. Primarily, the Human Rights model is anchored in the premise that all people have ‘inherent self-worth’ that can be realised by ensuring their human rights⁵². This draws parallels with the Social Model idea that people are ‘disabled’ by societal structures and are not *inherently* different⁵³. The protocol uses this concept as a guiding principle and seeks to promote the realisation of this inherent equality for people with a disability, by ensuring research approaches are informed by and compliant with human rights.

This is similar to the arguments made by those who advocated for the Convention on the Rights of Persons with Disabilities (CRPD)⁵⁴. It is one thing to say that human rights are universal, but universal realisation of these rights is not straightforward. This is evidences

⁴⁶Shakespeare, T. (2013). The social model of disability. In L. J. Davis (ed.). *The disability studies reader*. 4th ed. (Ch. 16, pp. 214-21). New York: Routledge, 2013, 215-216

⁴⁷ Russel Barsh, ‘Measuring Human Rights: Problems of Methodology and Purpose’ (1992) 15 *Human Rights Quarterly*, 98

⁴⁸ Russel Barsh, ‘Measuring Human Rights: Problems of Methodology and Purpose’ (1992) 15 *Human Rights Quarterly*, 98-99

⁴⁹ Fons Coomans, Fred Gunfeld and Menno T. Kamminga, *Methods of Human Rights Research* (Intersentia, 2009), 11-13; Theresia Degener, ‘Disability in a Human Rights Context’ (2016) 5 *Laws* 35, 1-4

⁵⁰ Fons Coomans, Fred Gunfeld and Menno T. Kamminga, *Methods of Human Rights Research* (Intersentia, 2009), 24-26

⁵¹ Disability Human Rights Research Network Protocol for Rights- base Disability Research in All Fields

⁵² Theresia Degener, ‘Disability in a Human Rights Context’ (2016) 5 *Laws* 35, 3;

UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106. 1-29, Article 1

⁵³ See section ‘Social Model Critique’

⁵⁴ UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106. 1-29, Article 1

by the many different documents which attempt to ensure and elaborate on the content of specific rights and rights for specific people. For example, the Convention on the Elimination of all forms of discrimination against Women (CEDAW)⁵⁵ which recognises that Women experience particular challenges in realising their human rights and specific content and obligations are necessary. The CRPD fulfils a similar purpose, recognising that people with a disability experience many barriers in the realisation of their human rights. The DHRNN recognised the history, discussed earlier, of barriers that people with a disability face when it comes to research. The Network also recognised that these barriers prevent people with a disability from accessing and indeed utilising the many benefits of research. The protocol uses a rights based approach to attempt to remove some of these barriers and in many ways ‘emancipate’ disability research from the control of traditional research approaches. The protocol aims to encourage research that compliant with universal human rights, but also recognises the inherent need to realise those rights and take positive steps to achieve true emancipatory research. In this way, the DHRNN’s conception of a rights based approach is using a human rights framework to achieve emancipatory disability research.

F Medical Research

As mentioned earlier, the protocol is designed to apply to all facets of research. This paper has identified some of the difficulties people with a disability have encountered in the field of medical research. However, the protocol’s particular rights based approach may be able to resolve some of these tensions, specifically when navigating the issue of how to approach ‘impairment’ in research. Traditionally, medical research has been dominated by a positivist approach. As medicine is focussed on the improving the biological human experience, identifying illness or impairment and researching methods for ‘healing’ appears to be a practical approach. However, as discussed above, in a disability context, this ignores the *many* factors that inform a person’s experience of disability. Alternative conceptualisations of disability, such as the social model, have also had difficulty finding a way to include impairment without medicalising people and instead attempt to remove ‘impairment’ from the discussion. Impairment is stuck in this tension between social and medical approaches, making research that is both respectful, inclusive *and* useful for people with an impairment, very difficult.

The human right model, which informs this approach, does not distinguish between people with an impairment and people without; it is universal in application. This is where

⁵⁵ UN Committee on the Elimination of Discrimination Against Women (CEDAW), *CEDAW General Recommendations Nos. 19 and 20, adopted at the Eleventh Session, 1992 (contained in Document A/47/38)*, 1992, A/47/38, available at: <http://www.refworld.org/docid/453882a422.html> [accessed 11 December 2017]

the model resolves some of the tensions between positivism, medicalisation and disability activism. “Human Rights do not require the absence of impairment⁵⁶, rather this model does not avoid the term ‘impairment’ for fear of medicalisation or ‘vulnerability’ labels. In fact, the human rights model attempts to create disability policy that actively promotes action that realises the innate human rights of people with an impairment⁵⁷. Medical research, and the many positive outcomes of medical research, is one such action that can help to realise the rights of people with impairments. For example, research conducted on pain management for children with cerebral palsy, is medical research that supports the CRPD rights such as right to enjoyment of life⁵⁸ and the right to the highest attainable standard of health⁵⁹. In this way, the human rights model addresses many of the issues highlighted earlier in this paper by ‘levelling the playing field’ and assigning some innate characteristics to *all* people regardless of disability or impairment. This in turn informs research practice as it requires research to address the question of *how* to specifically realise these rights.

IV BARRIERS TO INCLUSIVE RESEARCH

Now that this paper has established the theoretical foundations of research and specifically the approach to research the Network’s protocol aims to foster, it is important to recognise and identify the barriers to this research. Barriers refers to practices that prevent or inhibit emancipatory disability research. This section looks at both ‘top down’ and ‘bottom up’ barriers to the inclusive research the protocol is directed at. ‘Top down’ refers to barriers at a structural level, like government policy and law, the allocation of resources within research and the ethical guidelines that currently govern research practice. ‘Bottom up’ refers to barriers at the grassroots level, like social stigma and attitudes towards people with disabilities pervasive in the research industry and the historical mistrust that has developed as a result of systemic mistreatment of people with a disability by researchers.

A Top Down Barriers

1) Legal Capacity

Consent is an essential part of research production and is the cornerstone of nearly all ethical guidelines. A person must be able to give ‘fully informed consent’

⁵⁶ Theresia Degener, ‘Disability in a Human Rights Context’ (2016) 5 *Laws* 35, 3

⁵⁷ *Ibid*;

UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29

⁵⁸ UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29, Article 10

⁵⁹ *Ibid* Article 25

to participate in research. Participants must demonstrate the capacity to understand what they are participating in⁶⁰. Traditionally, the definition of ‘capacity’ has meant that people with certain disabilities have not been able to consent to participate. This creates a significant barrier for inclusive research as it immediately excludes a large number of people for both participating and utilising research. The CRPD states that all persons with a disability enjoy the right to legal capacity⁶¹ and that States are under an obligation to help facilitate people exercising their capacity. However, in practice the right to ‘capacity’ is not often realised. Three examples of legal definitions from around the world illustrate the problem of ‘consent’.

In the UK, the Mental Capacity Act⁶² is the current legislative framework used for any determination of a person’s capacity to consent. In the USA, capacity to consent is determined by a series of factors that derive from both legislation and case law. Lastly, in Australia, the National Health and Medical Research Council (NHMRC) issues guidelines which inform ethical practice regarding capacity to consent⁶³. All three of these legal frameworks have some mechanism whereby a third party can act as a proxy for consent⁶⁴. All three frameworks have some version of a ‘best interest’ test which governs the decision making of the proxy. Not one of the frameworks contains a detailed provision on how consent might be achieved or understood for people who are unable to articulate consent in the traditional format, either verbally or in writing. For disability research this precludes people with a mental impairment that might prevent them from speaking, a physical impairment that prevents them from speaking or writing without an aid, or a cognitive disability that makes it more difficult to understand complex ideas, from participating in research and from enjoying the benefits of research.

⁶⁰ See for example National Health and Medical Research Council (2015) National Statement on Ethical Conduct in Human Research. Canberra: National Health and Medical Research Council. Ch 2.2, Accessed in <<https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>>

⁶¹ UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29, Article 5

⁶² *Mental Capacity Act 2005* (UK)

⁶³ National Health and Medical Research Council (2015) National Statement on Ethical Conduct in Human Research. Canberra: National Health and Medical Research Council. Accessed in <<https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>>

⁶⁴ *Ibid* Ch 2.2.12; *Mental Capacity Act 2005* (UK) s 2;

American Psychiatric Association. Guidelines for assessing the decision-making capacities of potential research subjects with cognitive impairment. *Am J Psychiatry* 1998;**155**:1649–1650

This very brief examination of some of the legislation regarding consent and capacity highlights the barrier traditional legal understanding of ‘capacity’ and ability to consent presents for disability research. Namely, persons with a disability are precluded from participating based on presumed inability to consent to research practice using the normal or standard protocols.

2) Resource Allocation

Research production is almost universally dependent on grants and bursaries for support. This presents numerous hurdles in the field of disability research, particularly regarding practical accessibility requirements and conditions attaching to funding. Practical accessibility was not discussed in the earlier historical overview section of this paper, mainly because the accessibility issue in research have been overshadowed by the critiques of foundational disability research theory. However, the issue of accessibility is another key barrier precluding the participation of people with disabilities in research production.

Accessibility is defined in the CRPD⁶⁵ as “...appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”⁶⁶ In a disability context this could require adjustment to physical research spaces and ensuring access to information and communications technologies and systems. The CRPD definition also states that accessibility means people should be enabled to “participate fully in all aspects of life”⁶⁷. If, as this paper does, we consider research an ‘aspect of life’, then accessibility might require some protocols to ensure independent participation. For example, facilitating people who have 24 hour care to participate independent of carers or parents. This is same idea is reiterated in the CRPD⁶⁸, under which States are obliged to ‘take all appropriate steps to ensure that reasonable accommodation is provided’. Reasonable accommodation refers to making adjustments specific to individual need, to ensure equality is realised⁶⁹.

⁶⁵UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29, Article 9

⁶⁶ Ibid

⁶⁷UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. 1-29, Article 9

⁶⁸ Ibid Article 5

⁶⁹ Nyusti, Takács, & Fazekas v. Hungary, Communication No. 1/2010, CRPD 9th session (15-19 April 2013), 1-15

This discussion highlights two things; firstly, there are numerous ways in which accessibility as a barrier can be addressed, secondly additional resources are required to facilitate disability research. The way research funding is allocated is often based on a very detailed budget plan listing all possible costs. An American sign language interpreter can charge \$125 per hour for a minimum of two hours⁷⁰, for a research project that runs days or possibly weeks long, this is a large additional cost.

Further, the way in which funding is allocated to research does not necessarily reflect on the participants but the researcher. For example, the Australian National Research Guidelines, allocate funding based on; time spent as a researcher, where the research is being conducted, relationships of trust that already exist between participant and researcher and research outputs by researcher⁷¹. There is no specific provision in the Australian Rules that provides for funding for accessibility. The decision about what research is funded and what is important to investigate is not determined by participants, but by power structures which have long prevented emancipatory and inclusive research.

3) Ethical Guidelines

Ethical guidelines are used to govern research practice. Some issues regarding the way these guidelines operate have been highlighted above, specifically issues of capacity. Another barrier to disability research, is the way guidelines ‘categorise’ people with a disability. This is inherently linked with ‘capacity to consent’ and allocation of funding, as the ‘category’ of participants informs both. The Australian National Guidelines⁷² are a good example of how these categories prevent inclusive research. Under these guidelines, ‘people in dependant or unequal relationships’⁷³, ‘people with a cognitive impairment, intellectual disability or mental illness’⁷⁴ and ‘people highly dependent on medical care’⁷⁵ are placed into categories because they increase the ‘risk’ of negligence on behalf of the

⁷⁰ Cost Helper, *Interpreter Cost* (2017) Small Business Cost Helper
<<http://smallbusiness.costhelper.com/interpreters.html>>

⁷¹ National Health and Medical Research Council (2016) Funding Rules. Canberra: National Health and Medical Research Council, section 6.2

⁷² National Health and Medical Research Council (2015) National Statement on Ethical Conduct in Human Research. Canberra: National Health and Medical Research Council. Accessed in
<<https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>>

⁷³ Ibid Ch 4.3

⁷⁴ Ibid Ch 4.5

⁷⁵ National Health and Medical Research Council (2015) National Statement on Ethical Conduct in Human Research. Canberra: National Health and Medical Research Council. Accessed in
<<https://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>> Ch 4.4

researcher⁷⁶. This is problematic for disability research as many people with a disability would fall into all three of these categories.

This kind of categorisation pervades all facets of research and plays a part in exacerbating many of the barriers identified in this paper. Having participants who are 'high risk' affect funding opportunities, which in turn affects the provision of accessible research production. This also affects ideas of 'capacity' and creates further regulation for 'determining' a person's capacity to consent. It also contributes to the stigma surrounding disability and attitudes of researchers in terms of willingness to include participants with a disability. Categorisation is not aligned with ideas of emancipatory research, people with a disability cannot utilise or control outcomes of research if participants are so heavily regulated that research becomes impossible. This issue also generalises the experience of people with a disability, by categorising people their individual experience is ignored and so is in turn their capacity to make decisions about how they participate.

B Bottom Up Barriers

1) Attitudes

Researchers cannot ignore the influence that societal attitudes towards disability and disabled people have on research.

Medical and individual models of disability place the onus of the disability on the disabled individual. Such attitudes in a research context can lead to ideas about 'curing' or 'fixing' disability. This can lead to researchers designing a research programme with a curative aim, rather than an exploratory one.

Ignorant or discriminatory attitudes towards disability and people with disability can also present as a barrier to disability-inclusive research. Article 9 of the CRPD states that appropriate measures should be taken to ensure that people with disability have equal access as non-disabled people. Of particular relevance in a research context is access to physical environments, information and communications, and other facilities and services.

2) Accessibility

⁷⁶ Ibid Ch 4.3

Banks and colleagues identify five ethical challenges in participatory research, along with three suggestions as to how researchers can address these issues.

The first challenge involves issues surrounding participation, collaboration, and power. It is necessary to observe how partnerships are established, how power is distributed, and how control is exerted. Existing literature identifies some issues in this area, including: a mismatch in understanding of timelines and expectations between the community and the researchers;⁷⁷ understanding that a closer research relationship can lead to a greater potential for exploitation;⁷⁸ and accounting for the fact that community members may fluctuate between feeling included in and excluded from the research.⁷⁹

The second challenge involves blurred boundaries between researcher and researched, and academic and activist. This can cause difficulty for people who are researching their own communities, or who are engaged in dual roles as researchers and community activists.⁸⁰

The third challenge concerns ownership and dissemination of data, findings, and publications. If multiple authors or parties are involved in research, issues may arise regarding who is credited for the work and how the research is distributed.⁸¹ These issues may arise in decisions about co-authorship, publicity, and research impact claims. This issue is also relevant due to the increasing pressure on academics to publish work -- i.e. the 'publish or perish' mentality that is prevalent in the academy.

The fourth challenge involves anonymity, privacy, and confidentiality. Participatory research has a much greater potential to develop relationships between researchers and participants than other research methods. This raises issues for confidentiality and concealment of participants' identities. Such issues are particularly prevalent when researchers engage with participants in their own homes.

⁷⁷Love, P.E., Edwards, D.J., Irani, Z. and Sharif, A., 2011. Participatory action research approach to public sector procurement selection. *Journal of Construction Engineering and Management*, 138(3), pp.311-322.

⁷⁸Dodson, L., Piatelli, D. and Schmalzbauer, L., 2007. Researching inequality through interpretive collaborations: Shifting power and the unspoken contract. *Qualitative Inquiry*, 13(6), pp.821-843.

⁷⁹Ponic, P., Reid, C. and Frisby, W., 2010. Cultivating the power of partnerships in feminist participatory action research in women's health. *Nursing inquiry*, 17(4), pp.324-335.

⁸⁰Horn, K., McCracken, L., Dino, G., & Braybot, M. 2008. Applying community-based participatory research principles to the development of a smoking-cessation program for American Indian teens: 'Telling our story'. *Health Education and Behaviour*, 44, 44-69.

⁸¹Love, 2011; Maddocks, I. 1992. Ethics in Aboriginal research: A model for minorities or for all? *The Medical Journal of Australia*, 157, 553-555.; Quigley, D. 2006. A review of improved ethical practices in environmental and public health research: Case examples from native communities. *Health Education and Behavior*, 33(2), 130-147.

The fifth challenge concerns institutional ethical review procedures. Participatory research does not fit easily into traditional research ethics review procedures. Ethical guidelines are often grounded in an understanding of a dichotomy between ‘researchers’ and ‘subjects’, and assume that an academic or professional researcher (i.e. ‘principal research investigator’) has primary control over and responsibility for the research.

The authors suggest three ways in which to address these issues. The first is to reconceptualise research ethics, with the authors asserting that relationship based ethics should be understood as equally important as principle based ethics. Participatory research also has a greater focus on social justice outcomes than traditional research. The second suggestion is to reframe research governance questions in order to take into account participatory research. Such guidelines are often framed around more traditional forms of research. The third suggestion involves researcher reflexivity, education, and training, with the authors suggesting that research methods, education, and training in universities and community research needs to engage more with critical reflection.

C Historical Experience

1) Mistrust of Research

People with disabilities, along with other marginalised groups, have a long standing and well-founded mistrust of academia and research. There is also a long standing perception, both among people with and without disabilities, that research does not understand ethical issues or uphold human rights. The traditional research dichotomy of ‘researchers’ and ‘subjects’ and its resulting power relations further ingrained this mistrust. Historically, people with disabilities have been excluded from academic and institutional research. Disability discourse has been, instead, largely dominated by non disabled people.⁸²

Hunt describes his experience as a participant in disability research, describing himself as a ‘victim of research’.⁸³ He further discussed how he and other residents where he lived felt disillusioned with the researchers who purported to be engaging in unbiased research whilst, during the course of research, prioritising the voices of non-disabled staff over disabled residents.⁸⁴

⁸² Kitchin, R., 2000. The researched opinions on research: Disabled people and disability research. *Disability & Society*, 15(1), pp.25-47.

⁸³ Hunt, P., 1981. Settling accounts with the parasite people: a critique of ‘A Life Apart’ by EJ Miller and GV Gwynne. *Disability Challenge*, 1(5), pp.37-50.

⁸⁴ Ibid

Iacono and Carling-Jenkins assert that the onus of disproving these assumption lies with researchers.⁸⁵ It is researchers and the academy which created the current situation. Furthermore, the existing power imbalance and exploitation make it difficult for people with disabilities to assert themselves.

V CONCLUSIONS

This paper has attempted to deliver a cohesive framework for examining the many factors that influence research that involves people with a disability. This discussion has demonstrated that the current production of research is inextricably linked with the history of approaches to research. Positivism and Interpretivist approaches are not remnants of the past, but inform approaches to disability research today. Reformers and researcher alike ignore this influence at the expense of true development. The Social Model also exerts influence over disability research production and is still the foundation of disability activism, even in the field of research development.

Today, human rights are the new lens through which research can attempt to reform traditional practices to include and empower people with a disability. The DHRNN's new protocol attempts to use universal human rights to guide research production towards true emancipatory research. Research that is initiated and led by voices from the disability community and research that responds to a rights need in that community⁸⁶. Research that begins and ends with people with a disability.

⁸⁵Iacono, T. and Carling-Jenkins, R., 2012. The human rights context for ethical requirements for involving people with intellectual disability in medical research. *Journal of Intellectual Disability Research*, 56(11), pp.1122-1132.

⁸⁶Disability Human Rights Research Network Protocol for Rights- base Disability Research in All Fields

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