Review of the Guardianship and Property Management Act 1991 (ACT)

Women With Disabilities ACT
July 2015
Women and girls with disabilities: ACT Guardianship Review

Women With Disabilities ACT
Women with Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation for women with disabilities in the ACT. WWDACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of Discrimination against Women (CEDAW). WWDACT supports and encourages women with disabilities in the ACT to fully partake in every aspect of community life. WWDACT envisages a day when barriers for women with disabilities no longer exist.

Introduction
This submission examines the compliance of the Guardianship and Management of Property Act 1991 (ACT) with the Convention on the Rights of Persons with Disabilities from the viewpoint of WWDACT constituents: viz. women and girls with disabilities. It focuses on the issue of forced sterilization to exemplify where this legislation fails to comply with Australia’s CRPD obligations.

Based on the experience of our constituents, WWDACT strongly believes that a radical cultural change will be necessary before an effective change from substituted to supported decision making can become a reality within the law regulating guardianship and the consent to medical treatment in our jurisdiction. Such radical change must include the determination of guidelines; training and safeguards which are adequately resourced and updated. In this regard, WWDACT’s submission supports (but will not reiterate) the views in relation to this reference expressed by Advocacy For Inclusion, ADACAS and the community disability sector generally.
Obligations Under the CRPD

Through its General Comment No 1 (2014) Article 12: Equal recognition before the Law, the Committee on the Rights of Persons with with Disabilities (the Committee) has clarified that under the CRPD, an individual has the right to make a supported rather than substituted decision. The Committee has clarified, in fact, that (i) substituted decision making is discriminatory and that (ii) governments have an immediate obligation at international law to take steps to provide support for people with disabilities to make decisions that respect the rights, will and preference of each person.

The Committee clearly states the right to equal recognition before the law is an absolute right and cannot be modified in any way, by anyone or at any time - even in a public emergency. The Committee expressly states people with intellectual and psychosocial disabilities - as well as people with physical and or sensory impairment - must never be deprived of this right. It is the right to legal capacity. The Committee states:

ALL PRACTICES THAT IN PURPOSE OR EFFECT VIOLATE ARTICLE 12 MUST BE ABOLISHED IN ORDER TO ENSURE THAT FULL LEGAL CAPACITY IS RESTORED TO PERSONS WITH DISABILITIES ON AN EQUAL BASIS WITH OTHERS;¹

In General Comment No 1, the Committee clarifies that legal capacity consists of two strands. The first strand is to be recognised as a legal person before the law, as someone who has legal rights. The second strand is the legal agency to act on those rights, and to have those rights recognised by the law. These two strands are indivisible: they cannot be separated.² The Committee emphasises that:

LEGAL CAPACITY IS ENTIRELY SEPARATE FROM THE CONCEPT OF MENTAL CAPACITY. THE LATTER IS A HIGHLY CONTROVERSIAL AND SOCIALLY-CONSTRUCTED CONCEPT THAT HAS NO BEARING ON THE LEGAL CAPACITY OF A PERSON. SUPPORT IN THE EXERCISE OF LEGAL CAPACITY MUST RESPECT

¹ General comment No 1 (2014) Article 12: Equal recognition before the law para 9
² ibid. para 12bis
**THE RIGHTS, WILL AND PREFERENCE OF PERSONS WITH DISABILITIES AND SHOULD NEVER AMOUNT TO SUBSTITUTE DECISION-MAKING.**

The right to equal recognition before the law impacts on our ability to enjoy many other human rights: for example, in relation to finance and economic affairs; our right to health care; freedom from torture, violence, exploitation or abuse; the right to marry and found a family; to live independently in the community; and participate in public life. It impacts on our privacy, autonomy, bodily integrity and citizenship.

General comment No 1 clarifies that the Federal and ACT Governments have immediate obligations at international law:

- to refrain from actions that deprive persons with disabilities of the right to equal protection before the law;
- to prevent non-government actors and private persons from interfering in the ability of persons with disabilities to realise and enjoy their human rights; and
- to support each person to exercise their legal capacity in a way that is based on the will and preference of the person, not on what is perceived to be in her or his best interest.

The Committee has taken a very practical approach to this topic. General Comment No 1 states government support in the exercise of legal capacity must be in the person’s usual mode of communication, even if not conventional; support must be available at nominal or no cost to those who lack financial resources; and that the existence of supports must not be used to deny that person other rights such as the right to vote, parental rights or choice to accept or refuse medical treatment.

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3 ibid. para 15
4 ibid. para 26
5 ibid. para 25
The Relevant Law in the ACT

In the ACT, the involuntary use of contraceptives by women and girls with disabilities for the purpose of menstrual management or to avoid pregnancy must be sanctioned by an independent authority. This sanctioning procedure has been designed to protect the interests of the woman or female child.

The relevant law in the ACT is split. Young women and girls who are coerced into taking contraceptive measures are regulated by the Family Court under Rule 4.09(2) of the Family Law Rules 2004 (Cth). Women above the age of 18 years who are coerced into taking contraceptive measures are regulated by the ACT Civil and Administrative Tribunal (ACAT) under section 27(d) of the Guardianship and Management of Property Act 1991.

The relevant parts of the relevant legislation are set out below:

Rule 4.09(2) of the Family Law Rules 2004 (Cth)

(1) If a Medical Procedure Application is filed, evidence must be given to satisfy the court that the proposed medical procedure is in the best interests of the child.

(2) The evidence must include evidence from a medical, psychological or other relevant expert witness that establishes the following:

(a) the exact nature and purpose of the proposed medical procedure;
(b) the particular condition of the child for which the procedure is required;
(c) the likely long-term physical, social and psychological effects on the child:
   (i) if the procedure is carried out; and
   (ii) if the procedure is not carried out;
(d) the nature and degree of any risk to the child from the procedure;
(e) if alternative and less invasive treatment is available—the reason the procedure is recommended instead of the alternative treatments;
(f) that the procedure is necessary for the welfare of the child;
(g) if the child is capable of making an informed decision about the procedure—whether the child agrees to the procedure;
(h) if the child is incapable of making an informed decision about the procedure—that the child:
   (i) is currently incapable of making an informed decision; and
(ii) is unlikely to develop sufficiently to be able to make an informed decision within the time in which the procedure should be carried out, or within the foreseeable future;

(i) whether the child's parents or carer agree to the procedure.

Section 4 of the Guardianship and Management of Property Act 1991

4(2) The decision-making principles to be followed by the decision-maker are the following;

(a) the protected person’s wishes, as far as they can be worked out, must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect the protected person’s interests;

(b) if giving effect to the protected person’s wishes is likely to significantly adversely effect the person’s interests – the decision-maker must give effect to the protected person’s wishes as far as possible without significantly adversely affecting the protected person’s interests;

(c) if the protected person’s interests cannot be given effect to at all – the interests of the protected person must be promoted;

(d) the protected person’s life (including the person’s lifestyle) must be interfered with to the smallest extent possible;

(e) the protected person must be encouraged to look after himself or herself as far as possible;

(f) the protected person must be encouraged to live in the general community, and take part in community activities, as far as possible.

4(3) Before making a decision, the decision-maker must consult with each carer of the protected person.

Proposed Principles and Presumptions

In our view, the involuntary use of contraceptives on women and girls with disabilities in order to manage their menstruation and to avoid unwanted pregnancy must adhere to the following principles:
• The presumption that a woman or female child has the capacity to consent or refuse medical treatment, including the right to be assisted to consent or refuse medical treatment. (Principle of equality)

• The presumption that best medical practice is identical for any woman or female child irrespective of the presence of disability. (Principle of non-discrimination)

• The presumption that a woman or female child does not consent, of her own free will, to non-therapeutic medical or medicinal interventions which amount to trespass to person. (Principle of bodily integrity)

• The principal that a woman or female child who is capable of forming her own views has the right to express those views freely in all matters affecting them, the views of the female child being given due weight in accordance with the age and maturity of the individual. (Principle of self-determination)

These presumptions - if they can be rebutted - may only be rebutted in the most restrictive and exceptional circumstances and only as a last resort. If these presumptions can be rebutted, they can only be rebutted in a manner that is reasonable, proportionate and necessary for the well-being of the woman or female child involved.

Non-Compliance Under Current Laws Operating in the ACT

The mandated requirement under s4(2)(a)(b) of the Guardianship and Management of Property Act 1991 above to place the “best interests” of a protected person above their right to make a wrong decision (often referred to as “the dignity of risk”) violates the Article 12 CRPD rights of an individual. It begs the question of how to identify another’s “best interests”; it disregards the right of any individual to made and learn from a poor decision; and therefore these legislative provisions fail to respond in a nuanced manner to the complex realities of life.
Recommendations for Reform

The laws in the ACT that regulate the forced use of contraception by women and girls must be harmonised. There is a definite need to create an effective and uniform approach to this area of law in the ACT. This approach should not be contingent on their age; but rather on the evolving capacity of women and girls to make decisions about their bodies, their health and all aspects of their life.

Model legislation must allow health professionals, parents, carers and children to apply to a non-adversarial tribunal for a determination whether an individual is competent to give a binding consent or refusal of contraceptive treatment. The presumption is one of competence.

Reform must:

- Expressly confirm that contraceptive procedures are included as the concept of medical procedures under the legislation
- Clarify that the legislation covers both the right to consent to medical treatment and the right to refuse medical treatment
- Include the principles of equality, non-discrimination, bodily integrity and self-determination in the preamble of the legislation
- Provide a statutory right to an independent representative to assist a woman or girl put her views directly before the determining body or, if she is unwilling or unable to express a view, to call evidence and make submissions based on the best interests of the individual. An individual’s views must be taken into account whether or not she has sufficient understanding and intelligence to enable her to fully understand what is proposed
- Establish a graduated regime of decision-making that ranges from (i) decisions made with minimal support; through (ii) supported decisions; to (iii) facilitated decisions when one’s will and preferences are not known. This model has been proposed under the Essential Principles of Irish Legal Capacity Law⁶.

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Background
In the past, women and girls with disabilities have been both involuntarily sterilised and forced to use contraceptives to manage their menstruation and to avoid unwanted pregnancy. These past practices are on-going. They are a form of torture, cruel, inhuman and degrading treatment. These practices violate, *inter alia*, the right of every woman and girl to equal recognition before the law; to bodily integrity and their right to found a family.

There has been a contemporary revolution in the range of contraception available to women and girls – including long-acting reversible contraceptives (LARCS) and etonogestrel implants. This contraceptive revolution has now totally eliminated the need or justification to perform involuntary, non-therapeutic sterilisation procedures on women and girls with or without disabilities. WWDACT opposes and condemns all forced sterilisation interventions in all circumstances: both as a matter of principle and as a matter of practice.

This submission is therefore limited to a discussion of the forced use of contraceptives on women and girls with disabilities for the purpose of menstrual management or to avoid pregnancy.

Contemporary Contraceptive Options
Contraceptive choice includes a number of social, cultural and economic considerations. Contraception is a way to either express or constrain sexual expression. Women and girls with disabilities may experience multiple barriers to forming healthy, equal sexual relationships. These include a hesitancy to broach matters of sexual health; a lack of sexual knowledge and limited opportunities for sex education; higher prevalence of sexual abuse and assault; under treatment of menstrual disorders; societal, legal and environmental barriers; and a lack of dialogue around our human right to consensual sexual expression.7

Today contraceptive choices span a continuum of non-permanent options that can be used to manage menstruation and/or prevent pregnancy. These range

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from implants that last for up to three years; injections administered every 12 to 14 weeks; intrauterine devices (IUDs), including hormonal IUDs; emergency contraception; pills and vaginal rings; barrier methods of contraception; and natural methods of contraception. Not all methods of contraception are suitable for all individuals.\(^8\) The fundamental determinants are choice and reliability.

Families who have a daughter with a significant disability - either physical or developmental - who has reached menses are reminded that their daughter is at risk of sexual abuse and pregnancy. Parents and carers of these daughters have concern about the practicalities of how to manage menstruation – both the hygiene aspects of menses and the potential side effects of fluid retention, headaches, fatigue, mood alteration, pain or heavy menstrual flow. Contraception is generally considered the best option by parents and carers in these circumstances.\(^9\) Choices, however, need to be made in conjunction with information about the role and importance of reproductive hormones for preventing cardiac disease and osteoporosis. A number of other medical problems may be related to long term alteration of reproductive hormone levels – such as cyclic seizures.

Medical practitioners, parents, carers and independent advocates - amongst others - have the potential to influence opportunities for normative life experiences in the area of sexuality for individuals with intellectual disability. Frighteningly, recent findings\(^10\) suggest that a surprisingly large number of doctors still believed that sterilisation is a desirable practice to solve menstruation and pregnancy concerns. Only 12% of surveyed doctors believed they had received sufficient training in the area of disability and sexuality.\(^11\)

\(^8\) In an article of the *Australian Nursing Journal* of October 2012\(^8\) a thorough review of contemporary contraceptive methods was undertaken. The authors adopted the Medical Eligibility Criteria (MEC) system as a useful tool that allows health professionals to safely match a woman’s medical and personal history with their preferred methods of contraception. Australian guidance on MEC uses both the Faculty of Sexual and Reproductive Health (FSRH) and World Health Organisation (WHO) standards. The results are detailed in table form at Appendix One not included in current document.

\(^9\) Grover, S R. “Gynaecological issues in adolescents with disability” 47(9) *Journal of Paediatric and Child Health* 610 (2011)

\(^10\) Gilmore, L and Malcolm, L “Best for everyone concerned” or “Only as a last resort”? Views of Australian doctors about sterilisation of men and women with intellectual disability. 39 *Journal of Intellectual and Developmental Disability* 2014

\(^11\) Ibid.
Conclusion
Forced contraception, recognised as a form of torture, is commonly used on women and girls with disabilities to suppress menstruation or sexual expression for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse). Its use must be regulated and constrained in such a way that the right to equality before the law of the woman and female child are never violated. In its current form, s4(2)(a)(b) of the Guardianship and Management of Property Act 1991 violates an individual’s CPRD rights. In order to comply with our CRPD obligations and introduce a system of supported decision-making into the ACT, amendments to the Guardianship and Management of Property Act 1991 (ACT) will result in necessary, radical cultural and legal change in this jurisdiction.

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28/7/15

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