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The Involuntary or Coerced Sterilisation of People with Disabilities in Australia

Centre for Disability Research and Policy Submission to the Senate Community Affairs References Committee

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Introduction

1. The Centre for Disability Research and Policy, University of Sydney makes this submission to the Senate Community Affairs References Committee in its inquiry into voluntary or coerced sterilisation of people with disabilities in Australia.

The Centre for Disability Research and Policy (the Centre) aims to create a greater understanding of disability and improve disability services and programs by increasing the use of evidence and research in policy decisions in Australia and the Asia Pacific Region.

The vision of the Centre is a better life for people with disabilities in Australia and abroad. The Centre endeavours to achieve this vision by focusing on the social and economic participation of people with disabilities and their health and well-being over the life course. The Centre organises its work through five work streams, information about which can be found by visiting its website, located at http://sydney.edu.au/health-sciences/cdrp/[1]

The foundation for the Centre's work comes from the United Nations Convention on the Rights of Persons with Disabilities - the purpose of which is: to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The Centre strongly endorses the view of the Australian Human Rights Commission, in its submission to the Committee: 'urging the Committee to adopt a human rights framework in its inquiry and to consider the promotion and protection of the rights of people with disability, particularly women and girls, first and foremost in the development of each recommendation'.[2]

This submission prepared by Professor Gwynnyth Llewellyn with input from Centre members is restricted to addressing two Terms of Reference only:

(e) the impacts of sterilisation of people with disabilities and

(g) the factors that lead to sterilisation procedures being sought by others for people with disabilities.

This results from the particular expertise in parents and parenting with disability, specifically for women with intellectual and developmental disability.(see Australian Family and Disability Studies Research Collaboration, http://sydney.edu.au/health-sciences/afdsrc/). The reason for this submission which focuses on parenting is the relationship between sterilisation and removal of right to parenthood. The recommendations address policy and practice initiatives to educate, inform and support people with disabilities, in particular intellectual disability, their families, carers or legal guardians and service providers.

2. Why sterilisation and why people with disability?

Eugenic movement

An often cited reason for sterilisation of people with disability, particularly women and girls, is to prevent pregnancy. In the early 20th century in Australia and elsewhere the belief that people with disability would produce offspring that were burdensome to society (the eugenics movement) resulted in many women – and men – with disability being sterilised. In the United States for example where over 30 states legalised involuntary sterilisation, it has been estimated that by 1970 well over 65,000 Americans had been involuntarily sterilised based on this eugenic belief.[3]

In the much criticised judgement of Justice Oliver Wendell Holmes in Virginia in 1927 he upheld that state's sterilisation statute on the premise that it served the 'best interests of the patient and of society' concluding that 'three generations of imbeciles (sic) are enough'[4] . This now outmoded belief that all disability is inheritable occurred within the context of creating a 'purer' society. That said the belief that the children of parents with disability will be burdensome to society remains strong in the 21st century.

Negative stereotypes

Inaccurate and /or stereotypical knowledge about disability in the community for example leaves many community members still believing that disability is inherited. Thus if the parent or parents have a disability so too will their children[5]. Only a small minority of health conditions are hereditary or present at birth. Stereotypes about disability frame persons with disability only by their disability denying any individuality in circumstance or context. This is true of both women and men with disability and particularly intellectual disability. This submission primarily addresses women with intellectual disability, with less attention in the literature to sterilisation of men with intellectual disability (however see Carlson, Taylor and Wilson, 2000[6] for research on this in the Australian context)

International research about the children of parents with intellectual disability[7] including a longitudinal study of children of parents with intellectual disability over a 12-14 year span, demonstrates strength and resilience in families where parents are supported by family and/or friends[8] [9]. Practice evidence suggests that, as with other non-disabled parents in the community, parents with intellectual disabilities, living in unsafe neighbourhoods and with few familial, social or financial resources struggle with child rearing responsibilities.

Similarly, our work with mothers with intellectual disability talking about their own childhoods demonstrated diverse experiences, ranging from positive to more negative[10]. Not surprisingly, this diversity is also found in talking with other mothers in the community about their own childhoods. Stereotypical thinking based on *perceived* attributes of particular groups of people, in this case persons with disability, is *false* thinking. Stereotypical thinking about parenting and disability completely obscures the diversity and

variety of family life, support available and economic and neighbourhood resources. In such complex matters as the best interests of any one individual, systematic and evidence based supported decision making procedures have been found to be helpful (see below),

Beliefs about 'unfit' parents

Another belief that remains strong is that having a disability renders an individual unfit for being a parent. In September 2012, the National Council on Disability, an independent US federal agency which makes recommendations to the President and Congress to enhance the quality of life of all Americans with disabilities and their families, released a landmark report - *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children.*[11]

This report notes that, in the US, "the familial rights of people with disabilities appear to be declining rapidly. In 1989, 29 states restricted the rights of people with disabilities to marry. Ten years later, this number has increased to 33. Further, in 1989, 23 states restricted the parenting rights of people with psychiatric disabilities; by 1999, 27 states had enacted restrictions" (p.45)[12].

A similar detailed analysis of legal restrictions to marriage and parenting for persons with disability remains to be done across Australian jurisdictions. There is however considerable evidence from Australia and other higher income countries that persons with disability especially although not exclusively intellectual disability, face discriminatory attitudes and practices in relation to parenting[13][14][15]. Most telling are the consistently high figures of child removal from parents with intellectual disability across high income countries, typically reported as between 40%-60%, proportionally higher than for other parent groups including those with mental illness and those from indigenous populations[16][17][18]
.

There are other barriers in addition to legislation, and attitudinal and policy related practices that affect reproduction and creating a family for people with disability.

Social disadvantage and exclusion

There is for example ample evidence of social (and economic) disadvantage experienced by Australians with disabilities. At a quite foundational level of social participation the recent COAG Reform Council Report *Disability 2010-2011: Comparing performance across Australia*[19] documented that there has been no increase in rates of social participation of people with a disability between 2003 and 2009. This report also notes based on Australian Bureau of Statistics data[20] that "people with disability are also more likely to live alone – in 2009 around 16.2% of people with disability lived alone compared to 6.6% of people without disability aged 15 to 59 years".

This significant difference is likely not to be due primarily to choice. We have analysed data extracted from the survey of Household Income and Labour Dynamics in Australia (HILDA) to compare the well-being and aspirations of Australian adolescents and young adults (15-29) with long term health conditions, disabilities or impairments and their nondisabled peers. This analysis showed that overall, young people with long-term health condition, disability or impairment have very similar aspirations (now and when they are 35) to their peers[21]. They are, however, significantly more likely than their peers to be:

- socially isolated
- excluded from the labour force and to have fewer educational qualifications
- experience poverty and hardship
- live in poorer neighbourhoods
- have poorer health (including mental health)
- less satisfied with their lives

All of these factors may interfere with a young person's aspirations to be in a long term relationship, form a family or become a parent.

The desire to prevent pregnancy may come from parents, caregivers, service providers and medical professionals – all who believe, together with many others in the community, - that a person with disability is not capable of being a parent. This belief may stem from concern that their offspring will be burdensome or maltreated; lack of fitness for the role of parent; or that they lack economic or social stability to support a family and children as we have detailed briefly above. Whatever may be the driver, beliefs about incapacity to parent deny persons with disabilities the fundamental right to enjoy sexual relationships, to form families and to parenthood.

3. Impacts of sterilisation of people with disabilities

Our experience in this matter primarily relates to persons with disabilities who have already become parents. Our experience concurs with the observations offered by Women with Disabilities Australia that 'the practice of forced sterilisation is itself part of a broader pattern of denial of human and reproductive rights of disabled women and girls ..... framed within traditional social attitudes that characterise disability as a personal tragedy, a burden and/or a matter for medical management and rehabilitation"[22].

Thus for the mother with disability who has fallen foul of child protection authorities – and as the evidence demonstrates most likely due to prejudicial beliefs or systemic shortcomings rather than substantiated abuse or neglect[23] [24] – it is highly likely that social services and health professionals will seek to 'control' the likelihood of further pregnancies.

The difficulty is that, faced with one's child being taken away and no or little attempt on the part of professionals to help resolve the grief and loss that inevitably occurs, mothers may

well seek some comfort, and understandably so, by having another child.[25] [26] This speaks to the critical importance of providing appropriate counselling services when children are removed and information and advice about contraception and family planning in a helpful, respectful and non-coercive manner. Supported decision making procedures for individuals with intellectual disability have been found to be helpful for women and men with intellectual disabilities in the United Kingdom. However as noted by Mc Gaw and Candy[27] 'supporting women with intellectual disabilities to participate in decisions that affect their lives needs to begin in childhood" (p.146).

Regrettably there is an absence of specific programs and resources for teaching children, adolescents and adults with intellectual disabilities about the requirements and responsibilities of parenting and indeed how to protect themselves from harm including abusive relationships. It appears from research and practitioners' evidence that many women with intellectual disability become pregnant not through choice but rather through ignorance, or being vulnerable to predatory behaviours or sexual assault[8] [9] [24] [25].

4. Applying a human rights framework to matters affecting persons with disability

Again, we would urge the Committee to apply a human rights framework to their deliberations. First and foremost the Committee can do so by ensuring that in all their considerations they actively seek out and take into account the views of people with disabilities and their organisations. In line with CRPD Article 4 General Obligations, point 4, and the principle of 'nothing about us, without us', it is fundamental that the views of persons with disability are privileged on this critical matter of involuntary or coerced sterilisation.

By way of informing the Committee, members may wish to review material from a British organisation *Disability, Pregnancy and Parenthood International* - *http://www.dppi.org.uk/*. This excellent website and accompanying journal for persons with disability, their families and professionals includes many articles written by parents with disability, their partners and also their children. This provides one point of entry into understanding the lives of persons with disabilities as they seek to realise their aspirations – and their reproductive rights under Article 23 to found and maintain a family.

Despite the international conventions ratified by Australia that affect people with disability and in particular the *Convention on the Rights of Persons with Disabilities* persons with disabilities remain – entirely unjustly in our view - required to 'prove' their abilities.

There is now a substantive body of literature about the capacity of people with disability, including intellectual disability, to be capable parents. The premier scientific organisation in the field of intellectual and developmental disability, the International Association for the Scientific Study of Intellectual and Developmental Disability (IASIDD) has endorsed a

position statement, *Parents Labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities*[28]. This statement recognises the UN Convention Articles that affirm the right of persons with disabilities to marry and found a family (Article 23, (1)(a)), and to 'take effective action and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships…' (Article 23 (1)). Importantly the Convention also noted that states are bound to …render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities' (Article 23 (2)). If the Committee so desires, we would be willing to present the evidence about parenting capability and relevant parenting programs and supports.

5. Moving forward to address discriminatory attitudes and provide an educational and support framework

Article 23 of CRPD affirms the right of persons with disabilities to found and maintain a family and to retain their fertility on an equal basis with others. Article 25 recognises that persons with disabilities should have access to sexual and reproductive health services which include voluntary sterilisation and any other method of contraception, on an equal basis with others. Article 25 also articulates that free and informed consent is required for the provision of health care to persons with disabilities.

Scientific evidence internationally has demonstrated that there remains a gap between the intent and realisation of Articles 23 and 25, however there are promising initiatives in Australia and elsewhere aiming to close this gap.

The *Audit of Disability Research in Australia*[29] is a research project being conducted by the Centre in 2013 in collaboration with persons with disabilities and their organisations and national disability service organisations. This work is funded by the Disability Policy and Research Working Group under the National Disability Agreement, and will identify where there is sufficient evidence to inform new policy and practice initiatives and research gaps where further investment needs to be made. One specific emphasis of this audit is to examine research on the profile, experiences and issues affecting disadvantaged groups of people with disability including women with disability.

Findings from this audit will contribute to the work that needs to be undertaken across Australia to address discriminatory attitudes towards persons with disabilities in relation to their sexuality, forming a family and parenthood. To expand the assessment made by WWDA previously referred to that:

> The practice of forced sterilisation is itself part of a broader patter of denial of human and reproductive rights of disabled women and girls which also includes systematic exclusion from appropriate reproductive health care and sexual health

> screening, limited contraceptive choices, a focus on menstrual suppression, poorly managed pregnancy and birth, selective or coerced abortion and the denial of the rights to parenting. These practices are framed within traditional social attitudes that characterise disability as a personal tragedy, a burden and/ or a matter for medical management and rehabilitation[30].

The submission by the Australian Human Rights Commission to the Committee makes thoughtful and useful recommendations in relation to the need for a broad educational and support framework to address the underlying reasons why involuntary or coerced sterilisation occurs in Australia[31]. These recommendations include supports, services and information, all of which in our view are necessary to ensure full implementation of Australia's obligations under CRPD. We strongly endorse these recommendations.

6. Support, education and resources

Specific recommendations to support persons with disability when they become parents (with a focus on intellectual disability) are found in a publication funded by the then National Disability Administrators in the International Year of Disabled Persons[32]. These drew attention to the critical importance of building capacity in mainstream family support and children's agencies to provide evidence based support and programs for parents with intellectual disability.

An ongoing Australian national program, *Healthy Start,* which is funded by the Commonwealth Government under FAHCSIA, addresses the urgent need to build capacity in the human and social services sector to appropriately support parents with intellectual disability, their children and their families. Details about this strategy can be accessed at http://www.healthystart.net.au/. This strategy is regarded internationally as best practice and is now being replicated in Sweden and the Netherlands.

Again, by way of informing the Committee, members may wish to turn to an easily accessible internet resource produced in The Netherlands for persons with intellectual disability, their families and professionals available at www.asvz.nl/supportingfutureparents. This quality resource -*Toolkit Talking about Children* - is one example of the type of resources that could be made available to support persons with disability, their families and professionals to educate and inform and above all to 'make the right real' in relation to forming a family and parenthood. This educational toolkit aims to provide a balanced view of the right to and the responsibilitiesof being a parent, and in this way supports informed decision making by individuals with intellectual disabilities in the context of their personal, familial and social situations.

Following on from these few of many practical examples of education and support to persons with disabilities, their families and professionals we urge the Committee to:

Carefully focus in their deliberations on the reasons why involuntary or coerced sterilisation of people with disability is still occurring in Australia. Regrettably, there remain family, professional and societal attitudes and beliefs stemming from now outdated notions of disability as a medical condition requiring medical – and in the case of involuntary or coerced sterilisation – permanent solutions.

There is no sound evidentiary reason to deny persons with disability their right to reproduction, it is morally unjust to do so, and it contravenes Australia's obligations under international human rights conventions. We offer the following recommendations with a specific focus on individuals with intellectual disability and parenting to prevent the current situation concerning involuntary or coerced sterilisation continuing.

7. Recommendations

We recommend that:

1. Children and young people with intellectual disability receive evidence based programs on supported decision making as well as evidence based programs promoting respect, choice and responsibility in sexuality, relationships **and** parenting.

2 Mainstream family planning services are required to enhance their capacity to respond appropriately to women and men with intellectual disability including referral to specialist disability family planning services as needed. Fundamental to the exercise of free and informed choice is the provision of comprehensive and accessible information, counselling and support.

3. Current specialised family planning services are expanded throughout the country and made accessible to women and men with disabilities of child bearing age utilising social media and e-health or mhealth applications, and with outreach education to family members and service providers.

4. Funded services are required to provide evidence based programs in supported decision making for people with cognitive impairments including intellectual disability.

5. Further that funded services are required to engage with family members and legal guardians with regard to programs and support around sexuality, relationships and parenting to ensure the individual's right to choice is respected and not violated.

6. Media organisations take responsibility to avoid promoting misleading and non-factual information about the capacity of people with intellectual disabilities in relation to marriage and parenthood.

7. Pre-service programs for medical, health and social services personnel be required to include a module on (i) the UN Nations Convention on the Rights of Persons with Disabilities, (ii) Australia's legislative and regulatory framework in disability, (iii) evidence based information on supported decision making and programs for people with intellectual disability, and (iv) programs and tools on sexuality and parenting which promote respect, choice and responsibility in sexuality, relationship and parenting.

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[1] http://sydney.edu.au/health-sciences/cdrp/

[2] Australian Human Rights Commission Submission to the Senate Community Affairs References Committee, 20th November 2012

[3] National Council on Disability. *Rocking the Cradle: Ensuring the rights of parents with disabilities and their children.* September 27,2012, p,43.

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