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national council on intellectual disability

Becoming and Being a Woman

The involuntary or coerced sterilization of girls and women with intellectual disability - a response to the submission by Women with Disabilities Australian (WwDA) to the Senate Community Affairs Committee

Version 1.0

April 2013

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends, in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

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Statement of Principles

- All people have inherent dignity and worth and equal and inalienable rights.
- All people are valued members of the Australian Community.
- People with intellectual disability as equal participating members of the Australian Community have the same rights:
    - to respect for their individual autonomy and independence
    - to make their own choices
    - to participate in decisions which affect their lives
    - to pursue any grievance which affects their lives
    - to diversity of choice for housing, education, work, recreation and leisure
    - to equity and justice
    - to be empowered to take their full place in the Australian Community
    - to dignity and privacy in all aspects of their lives

National Council on Intellectual Disability will:

- ✓ work to make the Australian Community one in which people with intellectual disability have full and equal enjoyment of all human rights and fundamental freedoms and are involved and accepted as equal participating members.
- ✓ promote and protect the human rights of all persons with intellectual disability, including those who require more intensive support.

Consultation Statement

National Council on Intellectual Disability consults people with intellectual disability and family members through our State and Territory Agency Members. In particular we:

- ➡ conduct an annual survey of members and stakeholders
- ➡ hold two meetings a year, rotating through all States and Territories
- ➡ present at the Having a Say Conference each year, attended by over a 1,000 delegates the majority of whom have a disability
- ➡ hold forums on specific issues
- ➡ sponsor actions and representations on issues of importance to people with disability

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Introduction

Sterilization of a girl or woman (and boy or man) with an intellectual disability should not be undertaken as a means of birth control but only where medical conditions exist which require such actions as would be recommended for a women without a disability. When making decisions about contraception and therapeutic interventions, women need to be the decision maker and where they are not able to do so decisions must be made strictly in their best interest.

On the issue of involuntary or coerced sterilization of girls and women (and men) as a form of menstruation management National Council on Intellectual Disability supports the position that menstruation is a normal stage or development for a young woman, thus the same education and support systems that are available to girls and young women must be available to young women with intellectual disability in a form that is appropriate to them.

Broad support of WwDA's Submission

Firstly we wish to congratulate WwDA for many decades of advocacy demanding the betterment of lives of women with a disability in Australia. The work WwDA have undertaken to highlight the day to day reality of living with a disability in Australia for women and girls is to be commended and celebrated. Women have benefited from the strength of their advocacy, clarity of vision to live good lives, and the depth of their knowledge and research, specialising in areas of sexuality, abuse, neglect and violence against women living with a disability.

WwDA's submission provided to the Senate Community Affairs committee is well researched and provides important background and evidence on the involuntary and coercive sterilisation of women and girls with a disability. NCID supports the advocacy of WwDA, and agree, that it is a girl and woman's right to be in control of her body and to be the decision maker in regard to issues of menstruation, contraception and sterilisation. Today there is a growing literature and models of practice that assist girls and women to understand and make decisions relating to their health, body, relationships and lifestyle, which have historically been denied to them. **Hence in our advocacy, NCID promotes, the developmental model, meaning that people defined as having an intellectual disability are seen as people first, who with appropriate support and education do live full and meaningful lives, as students, workers, partners and friends.**

The focus of WwDA's submission is appropriately upon girls and women, however as an organisation that supports men, women and children with intellectual disabilities, NCID acknowledges that there is a small number of boys and men who have been or continue to be sterilised without their consent or without their knowledge. This was a common event during days of institutionalisation and the picture of current practice is unclear. As with girls and women with an intellectual disability we would advocate that the person is the decision maker and they are provided with all and every support they need, in the way they understand, so that they control their lives, relating to health, body, relationships and lifestyle.

NCID does not support the sterilisation of a young women as a generalised response to menstruation management and rather would advocate that precise intervention and support be put in place for them, and their families, to empower and assist them to celebrate and manage the changes from a girl to a woman which occur in a young woman's body. It is a normal change and one to be celebrated. The social response should be no different to that given to any girl moving into adulthood, it would be our view that girls are provided education and supports, in a way that this individual needs for them to understand and develop toward independence and competence in managing menstruation. Where decisions relating to sterilisation are made by a woman, we advocate that they are the primary decision maker, who is fully informed by a medical practitioner, with an appropriate support system who provide her with plain English information, and time to be fully informed, to be empowered. As would be typical for a woman without a disability.

In considering WwDA's submission, NCID agrees with the analysis that underpins the report, that the practices of involuntary or coerced sterilisation for girls and women with a disability have tentacles that reach deeply into our social history. Enmeshed in this practice, is the intersection of what it means to be a 'woman' 'a good mother' and what it means to be 'human', or 'disabled'. These are complex and highly nuanced debates that need to be considered in deep and conscious ways by policy makers who are working in the area of disability policy. Women living with intellectual disability are captured within these dominant and ongoing constructions, and typically live in situations where they are not considered equal decision makers on issues that will affect and shape their entire lives. The junction of the complex constructs, that operate to make up disability in our Australian culture, need to be at the forefront of thinking when policy makers examines issues like sterilisation of girls and women with a disability.

Highlighted Issues

Abuse

It is problematic to locate sterilisations simplistically within a legal paradigm, when the unspoken core of this action is societal responses to the sexuality of women with intellectual disability. For most people sex is a part of relationship, and people with a disability are often impoverished in their access to relationships. What is also underpinning this discussion is abuse, as WWDA states, and we believe that sterilisation is not a developmentally appropriate response to the sexual abuse of women and girls with an intellectual disability. Rather we would advocate for services like WWILD to be funded around Australia to educate girls and women on protection against violence, education on sex and relationships. Adding to this NCID notes, that many men are also victims of abuse and therefore a service based on the model of WWLD needs to respond to the issues of abuse of boys and men. There is a great deal of work that needs to be undertaken around Australia responding to the education needs of children and adults relating to the information they are able to access on relationships, sex and sexuality. Furthermore this information also needs to be available to families to empower and support them to build their capacity in assisting children with creating healthy relationships. Abuse is common among children and adults with a disability and it is the lack of education on what sex is and isn't, that leaves a woman vulnerable to exploitation.

WWDA discusses the link between sterilisation and abuse, and the notions of sterilisation to prevent a woman becoming a mother. The importance of these issues cannot be understated. Sterilisation may stop an unwanted pregnancy but it will not stop abuse nor will it prevent girls and women being exposed to sexually transmitted diseases.

Parenting

At some levels society has made progress to understand the rights of people with intellectual disability to engage in sex and relationship yet, this has not followed on to considering the support that needs to be wrapped around men, women and children in families where there is the presence of intellectual disability. This of itself is an important area of social policy and women and men with intellectual disability have their children removed at a much higher rate, which should be a focus of research and policy review. We would argue alongside WWDA that these of themselves are not valid reasons to impose sterilisation upon girls and women, rather that society needs to change its response to providing what is typical education on relationships and sex, in ways that are adapted to meed individual need and difference.

While medical sterilisation was a common practice during the era of institutionalisation, the picture of the number of women, adolescents and children with intellectual disabilities who are forcibly or coerced into being medically sterilised is difficult to attain, in contemporary Australia. As covered in WWDA's submission there are several high profile cases that continue to influence contemporary practices in this area. What is also difficult to establish is the number of women who experience chemical sterilisation with the administration of Depo-Provera and other medications that offer birth control to women with and without disabilities. Women with intellectual disability should be able to avail themselves of these contraceptives in the same ways, for the same reasons as women without a disability do. This is a normative developmental approach women take to prevent pregnancy. Contraception is another decision where they become the primary decider not the person who has this decision imposed upon them, but also needs to be available and accessible to women who choose it.

Access to mainstream medical management

Where we would differ in our position from that of WWDA is that we believe that all current developments in the field of medical research and treatment should be available to people with a disability in the same ways as is available to people without a disability. This would include genetic screening for predisposition to heart disease, breast cancer and prostate cancer and other health concerns that affect them during their lives. **Again we are advocating that what is best practice for a person without a disability, should be available to a person with a disability. This means that there are times when hysterectomy is required to manage fibroids, endometriosis and long periods of heavy menstruation that lead to poor health for a girl or woman, as with girls or women without a disability, the evidence based practice response should be available.** What would need to differ is how the information is present and that a person is given the time that they need to fully understand what the options are so that they can give fully informed consent. For a person who is unable to consent we would advocate that it is their 'best interest' that is the core principle for the decision making.[i]

Access to counselling

WWDA refers to counselling as part of a redress system to girls and women who have been forcibly sterilised. While we do not disagree with this recommendation NCID would advocate that access to skilled counselling services for people with a disability is limited across the nation. People with a disability experience all and many times more of the traumas and trials of life, however there is a dearth of skilled professionals who are able to assist them work towards developing their emotional literacy to empower them to live a good life.

NCID's current view and experience

Our consultations with men, women and children with intellectual disability tells us that they want to live a full and meaningful life, one of their own choosing, not one imposed upon them. Their dreams are no different to any other person. They want to be loved and to love. They want to be challenged by work and education where there are high expectations for their success. In our conversations we know that they want to be deeply submerged in all that life has to offer and not be separated out based on the difference of their ability.

While the past has been one of restraint and limitation of the lives of people with intellectual disability NCID strongly advocates for a move to having high expectations for them to succeed, as students and workers, partners and friends. To make this a reality will require a social response. For this to be achieved governments need to draw on evidence based practice when making decisions that impact on the lives of people with a disability, opening up inclusive options rather than simply providing a segregated option. Some states around Australia are moving more quickly to this model of service delivery with self-managed services and individual funding packages. The detail of what service delivery will look like under the National Disability Insurance Scheme (NDIS) remains unclear at this point in time, however it purports to be a systems that enabled a person to direct the service to meet their individual need .

NCID believes in a developmental model, which means having high expectations for each person. To achieve this we must provide support and education based on the individual needs and learning style of each person. We know that people with intellectual disability can and do grow and develop through live ages and stages when given access the powerful, potent and precise intervention when appropriate in their lives. The WWDA submission refers to (87 p 41) legal cases where a person is defined as having the mental capacity no greater than a one year old. This is a vexed issue. While the intellectual processing of a person may be at a one year old level, we would argue with the appropriate support it will not remain at that level, and even if it did, that person has the social and emotional intelligence of their chronological age. A 40 year old has 40 years of knowledge based on their life experience. Simply to focus on this IQ score diminishes and delimits the skill, knowledge and capacity of this individual. If the person is limited by low expectations it is unlikely they will be challenged and exposed to learning opportunity to promote their development.

In considering the issue of forces or coerced sterilisation of girls and women, NCID would like to normalise this discussion in a sense by locating sexuality into the context of relationship. It is our experience that all people desire relationship, it could be said that relationships are a primary driver for humans. In the past people with intellectual disability have been locked out of community and denied access to freely given loving relationships. Therefore they need some powerful teaching in what defines a relationship – intimate and friendship, and when sex and sexuality is a part of this relationship. Walker Hirsch (2007) provides an excellent resource to education people with intellectual disabilities on the 'Facts of Life and More'.

Around Australia there is a move to creating education programs to enable and empower girls and women with intellectual disability to live safe sex lives. It would be our view that when we move towards teaching parents, girls and women that menstruation is normal, and that they are provided with the knowledge and skill to manage their own bodies, rather than being made afraid or given a negative message about menstruation, we can empower them to become safe and sexually healthy.

Thus NCID would advocate for an investment in programs that inform girls and women about relationships, and within this context what is sex and sexuality, so that they are empowered to live safer sex lives and have full and meaningful relationships.

Family perspectives

Nationally, there is little evidence currently regarding the rate and incidence of application for and completion of sterilisation procedures of young people with an intellectual disability by families to Guardianship Boards or the Family Law Court. Anecdotally, NCID has been advised that the number of families applying to the Guardianship Board and Family Court for leave to have the medical procedure of sterilisation approved for their child is extremely small. Typically, the small number of families who do apply through the current extensive process do so as a last resort for they and their child who has been unable to manage their menstruation. This may well be due to the lack of specialist services available to girls woman and families that provide practical support and information on who to deal with menstruation and the associated health effects. . From the information available it would appear that families in regional centre often have little or no access to expert support service that can assist them with managing the day to day menstruation needs of their child.

The capacity a family has to respond to the growth and development of a daughter will be central to the successful transition. The majority of families in Australian make these transitions with success. Family attitudes to sex, menstruation and relationship will all play a part in how this developmental stage is managed. It is problematic when there are insufficient specialist services around Australia to enable to successful progress for a girl to manage her menses be the decision maker on her personal health and wellbeing. For families living in regional and remote areas often the first point of call will be the general practitioner, therefore it is important to develop information in Easy English, that is available to GP's to pass on to these families. Additionally an area of need is the education of medical professionals in appropriate ways to provide education to families and girls and women on menstruation, contraception and where relevant sterilisation.

Without the necessary information and resources it can be difficult for families to know the best ways of supporting their daughter through this developmental stage and change. This can be an emotional and psychologically distressful time for everyone involved. Where families face extreme behavioural responses to the stage of menses they can be propelled into times of social isolation and rejection, particularly in the school environment. Without the necessary support and information these families can enter long periods of disharmony and distress. Where these continue without positive intervention and assistance it can lead to the breakdown of a family.

For many families the issues around managing their daughter's menstruation and fertility can be highly emotional, fraught and very distressing. For many families there is can be an endless medical round trying to find the best way to manage their daughter's monthly menses. There is often also associated emotional and psychological distress which also needs to be managed. This can lead to increased social isolation, difficulties with school and other support services. This on top of what can already be a very demanding, stressful and exhausting life for all concerned. For some this may just be the straw that finally breaks the camel's back.

Making any decisions about one's child's life is always a difficult and emotional process, weighing up the pros and cons, seeking all available information and opinions of experts, always worrying about whether one is doing "the right thing". It is highly unlikely that any parent is going to make a decision about their child's future fertility or life options lightly. It is the experience of most families that significant decisions about the their child's future is done after much thought and agonising.

The case of Marion (1992) held that

- court or tribunal authority is required before any child can lawfully be sterilised unless the sterilisation occurs as a by-product of surgery appropriately carried out to treat some malfunction or disease; and
- authorisation may be given only if sterilisation is in the child's best interests after alternative and less invasive procedures have all failed or it is certain that no other procedure or treatment will work.

Advocacy groups and legal aid services continue to argue that girls and women are being forced or coerced into sterilisation. The difficulty remains the dearth of statistics which reveal the extent of the current practice. The Marion determination has set out a clear legal pathway that we would argue is well understood by medical professionals and families. Typically families act in the best interest of their children and strive to ensure that they are treated with dignity and provided their human rights. Family members have been at the forefront of standing alongside people with a disability and calling for their inclusion in community, education and employment. It is our position that families typically act in the best interests of their children and do so following a long process of thoughtful contemplation and decision making.

As with a daughter without a disability families provide support and information on menstruation and how to manage, this will also be the case for girls with an intellectual disability.

What is helpful to families is information in easy English and access to specialist information and services where they can talk through any difficulties and find appropriate strategies for their daughters. Education of families and children on relationships and education is an important part of this developmental stage, and with the appropriate skill acquisition and practical knowledge then both parties are enabled to look forward to a life of their choosing.

The opportunity to access good reproductive health services is often critical to the decision-making process regarding management of fertility and menstruation. Medical procedures to assist with menstruation management has improved immensely in recent years since the Marion Ruling took effect. It would be expected that the effect of both the ruling and improved medial management would have impacted on the rate of sterilisation procedures on young women with disability. However, access to reproductive health services across Australia as with all services for people with disability is at best patchy and worst non-existent. There are centres of excellence providing outstanding service such as through the Melbourne Children's Hospital. However, for many people living in regional centres and in some States in particular access to quality information and services are very poor.

Conclusion

NCID believes that the current mechanisms relating to the decision making process for accessing sterilisation provides enough protection for girls and women. Where it becomes apparent that there is a failure to comply with the legislation the appropriate penalties need to be rigorously applied.

Family Planning agencies around Australia have developed some excellent resources for girls, women and families and professionals and these are available through websites to the community.

In considering this issue it has become apparent that the areas of deficit are in access to information for girls, women and families that enables and empowers them to succeed in the transition from girl to woman. While there is some good information in states around Australia it is typically located in metropolitan based services that have funding restrictions which inhibit their capacity to provide this information to regional and remote communities.

For regional and remote families, girls and women the local General Practitioner would typically be the first port of call when menstruation becomes difficult to manage. While there is some information being presented in journals relating to managing menstruation for girls and women with an intellectual disability, there doesn't seem to be an easily accessed Easy English resource kit available that can provide information to the GP, the family and the girls and women. This resource should also be available to Obstetrician & Gynaecologists, sexual health nurses and any other appropriate health professionals. What research is available shows that will the appropriate information and support girls with intellectual disability can and do manage this transition well.

Sterilisation of girls and women with a disability if and where it is required would need to be undertake for an evidenced based reason and the individual should be provided with all the information they need to give fully informed consent. We would caution against making this a criminal act because of the unintended consequences that it may have to decrease a woman's range of choice in managing their bodies in the sam way and on the same basis as a women without a disability. Where this cannot occur the current legislation acts to maintain the best interest of the individual. However as the WwDA submission highlights there are historic stereotypes that continue perception of medical practitioners and legal professionals on the capacity of a person with an intellectual disability to live a full and meaningful life.   Both professions need education to expand their expectation and understanding of peoples capacity.

Recommended Resources

Managing Menstration (2010) Queensland Centre for Intellectual and Developmental Disability in the School of Medicine at the University of Queensland:

Family Planning New South Wales, South Australia, Queensland and Victoria: Have a range of fact sheets and plain English information on sex, menstruation and relationships available in the library and resources to professionals, organisations and parents

Sex Education

Walker- Hirsch L 2007. The Facts of Life and More: sexuality and intellectual disability, Brooks Publishing, USA

http://www.me-and-us.co.uk/ - Me and Us provides easy English information for people with intellectual disability on relationships and sexuality.

Peer Education Program – Dr Patsie Frawley 2011, (La Trobe Universtiy) a program designed to train people with intellectual disabilities to act a peer educators on relationships, sex and sexuality.

Women working alongside Women with and Intellectual or Learning Disability – QLD a services funded to provided education to girls and women on sex relationships and violence. http://www.wwild.org.au/

Parenting

While it is beyond the scope of this inquiry the issue of discrimination against parents with an intellectual disability is an important social issue and where children are removed there are negative impacts on parents and children. Below are links to two organisation who have developed and evidenced based practice in working alongside families.

Healthy Start NSW. http://www.nswfamilyservices.asn.au/component/content/article/80-recent-projects/500-healthy-start-supporting-parents-with-intellectual-disabilities.html

Norah Fry Centre. http://www.bristol.ac.uk/norahfry/

[i] Comments have been made about the decision making processes and outcomes by Guardianship Boards and the Family Court. From NCID's perspective these concerns must be addressed in relation to all decisions that these bodies make on behalf of people with intellectual disability. These concerns must not be addressed only in relation to interventions which result in sterilisation.