Moving Forward

Sterilisation and Reproductive Health of Women and Girls with Disabilities

A Report on The National Project
conducted by Women With Disabilities
Australia (WWDA)

July 2001

By Leanne Dowse
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Section Eight: **Appendices**

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Section One: Introduction

Women With Disabilities Australia (WWDA) is the national peak organisation for women with all types of disabilities in Australia. Through its membership, WWDA identifies issues that are important to women with disabilities and undertakes work to advance the interests of women with disabilities on those issues. Sterilisation and reproductive health have been identified by WWDA members over several years as areas of concern. In response to this, the organisation sought funding through the Commonwealth Office of the Status of Women to conduct a national project which would review the current status and developments in the area, both nationally and internationally, and integrate this, for the first time, with the perspectives and experiences of women with disabilities themselves. This report is the result of that project.

Structure of the Report

The report provides a context for the discussion of sterilisation and reproductive health of women and girls with disabilities. It:

- explores the assumptions made in discussing the issues and examines how they come to manifest themselves in the denial of human rights to bodily integrity and rights to reproductive choice and parenting;
- examines the major issues in the debate around sterilisation of girls and women with disabilities and reports on developments both in Australian and internationally;
- outlines significant issues in reproductive health for women with disabilities.

The report reflects the experiences and perspectives of women and girls with disabilities in reporting on the National Forum on Sterilisation and Reproductive Health for Women and Girls with Disabilities held in Sydney in February 2001. It also contains the personal stories of women who have experienced sterilisation and other denials of their rights to reproductive choice and parenting. Issues of advocacy, policy, and practice for service providers, academics and people with disabilities are discussed in a report on the Sterilisation and Reproductive Health Special Interest Group convened at the Disability with Attitude International Conference in Sydney in February 2001. The establishment of a National Reproductive Rights for Women With Disabilities Network (outlined in this report) was an outcome of this meeting.

Professor Adrienne Asch, Henry R. Luce Professor in Biology, Ethics and the Politics of Human Reproduction, Wellesley College, Massachusetts, USA, delivered the Elizabeth Hasting Memorial address at the Disability with Attitude Conference. In this address, sponsored by WWDA, Professor Asch argues for a broader understanding of"Sterilisation, Reproduction and Parenthood for Women and Girls With Disabilities."

Finally the report outlines WWDA's recommendations in seven key areas aimed at redressing the past and creating a co-ordinated and consultative process for progressing the issue into the future in a way that holds the human rights of women and girls with disabilities as paramount.

Section Two: Executive Summary and Recommendations

Women With Disabilities Australia (WWDA), the national peak organisation for women with disabilities identified the need, through its membership, to address the issues of Sterilisation and Reproductive Health as they affect women with disabilities. As an advocacy organisation for women with disabilities it is WWDA's responsibility to ensure the voices of women with disabilities are heard on issues that affect their lives. This report provides an analysis of the current debate around sterilisation and reproductive health informed by the experiences and perspectives of women with disabilities.

The limited debate that has occurred in the area of sterilisation and reproductive health has seldom included or involved women with disabilities. They, particularly women with intellectual disabilities, have had little opportunity to speak about their experiences, or participate in legislative, policy and/or program development. The National Project on the Sterilisation and Reproductive Health of Women and Girls with Disabilities aimed to redress this imbalance. The project's main components were:

- a background research phase to examine international and national developments;
- the staging of a National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities, to provide women and girls with disabilities a safe and secure environment to speak out about their experiences;
- providing an opportunity for women with disabilities to come together with academics, researchers and service providers to critically analyse the issue and develop strategies to advance debate and action. This occurred in conjunction with the International Conference *Disability with Attitude: Critical Issues 20 Years After International Year of Disabled Persons* held in Sydney in February 2001.

The right to bodily integrity and the right of a woman to make choices about her reproduction are enshrined in the United Nations Declaration on Human Rights. In Australia in the 21st century there are numbers of women and girls with disabilities who have been and are currently being denied their human rights to make informed choices about their bodies and their reproductive lives (Brady, Briton & Grover 2001). There are many reasons for this and in exploring them we must look to the broader context of society's understanding of disability as a personal tragedy, as a medical problem to be treated with medical intervention and as a gendered issue within which we make decisions about who can be parents. Sterilisation and reproductive rights for women and girls with disabilities are human rights issues.

There has been a paucity of research conducted on the issue of forced sterilisation, and more broadly, on the issue of reproductive health of women with disabilities. A literature review conducted on behalf of WWDA in 1999 concluded that the majority of research conducted in the area has focused on the incidence and issues surrounding sterilisation of girls (those under 18 years) with intellectual disability with high support needs (Spicer 1999). While this research has very usefully explored the legal mechanisms involved and identified many of the issues that come to bear on the decision to sterilise, there is little acknowledgment in the literature that the lives of many women and girls with physical, psychiatric and other disabilities have been adversely affected. A focus on sterilisation by hysterectomy and tubal ligation in research and statistics gathering has continued to ignore the many other discriminatory and often coercive practices that have been used to deny women and girls with disabilities their human rights in reproduction and parenting.

In considering the sterilisation of women and girls with disabilities many issues remain problematic in the Australian context. The conditions under which sterilisation is sought include the prevention of disabled women producing disabled children and the resulting 'burden' on society, the inability of the girl or women to 'cope with' menstruation and the prevention of unwanted pregnancy which may occur in some instances from sexual abuse. While decisions about whether sterilisation should be sought are often made on the basis of the presumed 'best interests' of the disabled girl or woman, clarification of whose 'best interest' is really at stake is necessary when the consequences are lifelong and irreversible. The issue of who decides whether a girl or woman is unable to consent, and the age at which this decision is made is also critical. The unintended consequences such as increased vulnerability to sexual abuse need to also be considered. Sterilisation, an irreversible medical procedure with lifelong physical, mental and social consequences, if performed without consent, is a violation of a woman's human rights.

In Australia, the debates about sterilisation have focused on the legal issue of who can authorise a sterilisation. There has been little national debate about the human rights of the women and girls affected. Women with disabilities are now speaking out demanding action to address the human rights violations and calling for support services and compensation. The Australian government has taken little action in the area, despite the efforts of organisations such as the Human Rights and Equal Opportunity Commission (HREOC) and other non-government organisations in calling for reform. Internationally, many countries continue to grapple with the issue. Notably in Canada, the Alberta government has recently awarded more than $80 million to 703 people who were forcibly sterilised.

For women with disabilities, issues of reproductive health also continue to be problematic. Support for choices and services in menstrual management, contraception, abortion, sexual health management, pregnancy, birth and menopause remain inappropriate, absent or inaccessible. Women with disabilities have spoken out at the first National Forum on Sterilisation and Reproductive Health about the impact of all these issues on their lives. They have spoken about sterilisation as a life sentence, the loss and betrayal and the health effects they can anticipate. Their message is to listen to women and learn from them so that healing can take place for those already affected and safeguards can be put in place to prevent others being denied their human rights.

Recommendations

1. Reconciliation

1.1. The Federal Government act immediately to redress the human rights violations against women and girls with disabilities who have been sterilised without their consent. In the process of reconciliation, financial compensation and an official apology for discrimination should be provided.

1.2. The Commonwealth Department of Health & Aged Care, through the National Women's Health Program, act immediately to establish support and counselling for survivors of forced sterilisation. The establishment of any support and counselling services must be done in consultation with women with disabilities.

2. Co-ordinated Approach to Legislative and Policy Development

2.1. The Federal Attorney General's Department co-ordinate the establishment of a National Working Party to develop and implement a five year Action Plan based on the recommendations of this report, and the recommendations of the report by Brady, Briton & Grover (2001) *The Sterilisation of Girls and Young Women in Australia – Issues & Progress.* The National Working Party should encompass membership, which demonstrates a whole-of-government approach. Membership should include representatives from:

- Women With Disabilities Australia (WWDA);
- National Women's Justice Coalition (NWJC);
- Commonwealth Office of the Status of Women (OSW);
- FPA Health NSW;
- Aboriginal & Torres Strait Islander Commission (ATSIC);
- National Ethnic Disability Alliance (NEDA);
- Federal Attorney General's Department;
- Human Rights and Equal Opportunity Commission (HREOC);
- Commonwealth Department of Health & Aged Care;
- Commonwealth Department of Family & Community Services (FACS);
- Commonwealth Department of Education, Training & Youth Affairs (DETYA);
- Australian Medical Association (AMA);
- Royal College of Obstetricians & Gynaecologists;
- Royal Australian College of General Practice (RACGP);
- Law Society of Australia (or a nominated legal representative);
- National Reproductive Rights for Women With Disabilities Network (as described in this report).

2.2. This National Working Party should be funded and appropriately resourced.

2.3. The National Working Party review all current protocols and legal avenues dealing with the issue of sterilisation and recommend uniform measures which can be enacted by all States and Territories. Those recommendations can then be enacted through Commonwealth/State funding agreements such as: the Commonwealth/State Medicare Agreement and/or the Commonwealth/State Disability Agreement.

2.4. Any reforms must be based on the premise that the forced sterilisation of girls and women with disabilities is a human rights issue. Reforms must reflect that any sterilisation carried out without the informed consent of a person is a *forced* sterilisation and that applications to sterilise must be seen as procedures *done to* women with disabilities not procedures *done for* them.

2.5. Any reforms must address the issue of forced sterilisation for all women and girls with disabilities, including those with psychiatric, physical, cognitive, and sensory disabilities.

2.6. The Federal Government establish mechanisms to ensure that any action or progress on the issue of sterilisation of girls and women with disabilities undertaken by Government is reported back to Women With Disabilities Australia (WWDA).

3. Information, Support and Service Models

3.1. The Commonwealth Department of Health & Aged Care fund a fulltime Project Officer position for Women With Disabilities Australia (WWDA) for a period of three years to:

- research and develop accessible information resources for girls and women with disabilities regarding sterilisation and the implications of such procedures;
- research and develop best practice service models to support women and girls with disabilities who have undergone forced sterilisation, as well as those seeking information and support regarding the decision to undergo sterilisation and broader reproductive health issues.

3.2. The Commonwealth Department of Health & Aged Care fund FPA Health (NSW) to establish and operate the National Reproductive Rights for Women With Disabilities Network (as described in this report). The Network would consist of women with disabilities, service providers, policy makers and other interested individuals to progress reproductive rights issues for women with disabilities. This would include but not be limited to addressing the issue of forced sterilisation of women with disabilities.

4. Consent

4.1. The Federal Government act immediately to ban all sterilisations of girls under the age of 18 years, unless the sterilisation is being performed as a life saving measure or medical emergency. Implicit in this should be the recognition that girls under the age of 18 years cannot be expected to provide informed consent to sterilisation. Sterilisations should never occur until an age where the ability to give informed consent can be determined.

4.2. The Federal Attorney General's Department undertake an investigation into the issue of 'consent' as it applies to sterilisation and other reproductive health issues for women and girls with disabilities of all ages.

4.3. The Federal Attorney General's Department undertake an immediate review of procedures and processes currently in place for sterilisations occurring to girls and women with disabilities who are deemed 'incapable of giving informed consent.' Any review must address the following issues:

- who should determine that a person is incapable of giving informed consent; and,
- what processes and mechanisms should be used to determine that a person is incapable of giving informed consent.

4.4. The Federal Attorney General's Department develop and establish an independent mechanism to establish whether informed consent can or cannot be given.

5. Reproductive Health Care

5.1. The Commonwealth Department of Health & Aged Care fund a national project on reproductive health care for girls and women with disabilities which:

- addresses the process, concerns, and issues identified in this report, along with the incidence of forced sterilisation for ALL women with disabilities, including those with psychiatric, cognitive, sensory and physical disabilities;
- researches the long-term physical and mental health and social effects of sterilisation;
- researches the practice of menstrual suppression of girls and women with disabilities, including those in group homes and other forms of institutional care. Research into menstrual suppression practices must include:
  - an investigation into the use of Depo-Provera and other injectable contraceptives, the contraceptive pill, and other forms of contraception;
  - an investigation into the use of contraception as a form of social control of girls and women with disabilities;
  - an investigation into the process of Substitute Decision Making;
  - an investigation into the long term physical and mental health and social effects of menstrual suppression practices.

5.2. The Australian Division of General Practice fund a national project to educate and inform general practitioners on:

- their obligations under the *Disability Discrimination Act (DDA) 1992;*
- sexual health issues (contraception, sexual health, fertility management, pregnancy, menopause, breast and cervical cancer screening) for women with disabilities;
- sterilisation as a human rights issue;
- options for menstrual management;
- services that are available for general practitioners to refer women and girls with disabilities.

5.3. The Australian Medical Association (AMA) in conjunction with the Royal College of Obstetricians & Gynaecologists undertake responsibility for the development of an Information Package on the legal, medical, and social implications of forced sterilisation and menstrual suppression practices.

5.4. The Commonwealth Department of Health & Aged Care fund the development of national sexual health protocols for women with disabilities which incorporate options for menstrual management and contraception.

6. Data Collection

6.1. The Australian Institute of Health & Welfare (AIHW) be responsible for the co-ordination, collation and analysis of reliable statistics on forced sterilisation, including those currently being performed and those that have been performed in the past. Any data collection system developed must incorporate provision for an independent means of checking the database for accuracy and comprehensiveness of records.

6.2. The Commonwealth Department for Health & Aged Care examine how data on sterilisation of women with disabilities is currently collected, and investigate the possibility of developing coding information which provides more accurate and reliable statistics on sterilisations of women and girls with disabilities, including those with psychiatric, cognitive, sensory and physical disabilities.

7. Education

7.1. The Federal Government, through the Department of Education, Training and Youth Affairs (DETYA) develop national protocols for health education curriculum (beginning at primary school level) which incorporate models of diversity that portray positive images of people with disabilities as parents and as sexual beings.

7.2. The Commonwealth Department of Education, Training and Youth Affairs (DETYA) fund a fulltime Project Officer position for Women With Disabilities Australia (WWDA) for a period of two years to:

- conduct a national project, which educates and informs women with disabilities of their reproductive health rights, including their right to sexuality and their right to parent.

Section Three: About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is the national peak organisation for women with all types of disabilities in Australia. It is a federating body of individuals and networks in each State and Territory of Australia and is made up of women with disabilities and associated organisations. WWDA is run by women with disabilities, *for* women with disabilities. It is the only organisation of its kind in Australia and one of only a very small number internationally.

WWDA is inclusive and does not discriminate against any disability. WWDA seeks to ensure opportunities in all walks of life for all women with disabilities. In this it aims to increase awareness of, and address issues faced by, women with disabilities in the community. It links women with disabilities from around Australia, providing opportunities for them to identify and discuss issues of common concern. WWDA works in partnership with other disability organisations and women's organisations and generates and disseminates information to women with disabilities, their families, carers, service providers, government and the media.

WWDA has national and international membership, from both individuals and organisations. Women With Disabilities Australia (WWDA) is a proactive organisation that works hard to effect systemic change for women with disabilities at all levels of society. Development of WWDA policies and programs is based on the identified needs and concerns of women with disabilities in Australia. WWDA is a non-party political organisation that cuts across political, economic, social and ethnic barriers.

WWDA seeks to ensure the advancement of education of society to the status and needs of women with disabilities in order to promote equity, reduce suffering, poverty, discrimination and exploitation of women with disabilities.

AIM

The main aim of Women With Disabilities Australia (WWDA) is to improve the status of women with disabilities through education; support, information; and systemic and individual advocacy.

The **objectives** of Women With Disabilities Australia (WWDA) are:

- to develop a network of women with disabilities throughout Australia to work together for the mutual benefits of all women with disabilities;
- to provide information, education, support, practical assistance, referral, counselling and other forms of service provision to promote equity for women with disabilities;
- to change social attitudes, practices, and power relationships which discriminate against women with disabilities;

- to advocate for the implementation of procedures and enactment of legislation which will advance and benefit women with disabilities and combat sexism;
- to inform and educate the public with a view to advancing the opportunities for conditions of women with disabilities in the political, creative, civil and social fields as well as in industry, commerce, the professions and in the community generally;
- to continue advocacy work in the government system for the interests of women with disabilities;
- to advocate for women with disabilities true involvement in all levels of society;
- to ensure women with disabilities have sufficient information to enable them to make an informed choice about matters which concern their lives;
- to support national and local work of members;
- to develop leadership and sharing of responsibilities to enable women with disabilities to take their place in whatever section of society they choose;
- to promote the feminist goals of achieving social, economic, educational and sexual equality for women with disabilities.

More information about Women With Disabilities Australia (WWDA) is provided in Appendix 1.

Section Four: Background to the National Project on Sterilisation and Reproductive Health of Women and Girls with Disabilities

In 1992 the High Court, in what has come to be known as 'Marion's Case,' decided that the non-therapeutic sterilisation of an intellectually disabled minor could not be authorised without a court order. Despite this decision, it has become clear that these authorisations have not been occurring. On March 15, 2000, a resolution was passed in the Senate which called for the Australian Government to conduct a review of the legal, ethical and human rights mechanisms in place, or needed, to protect the rights and interests of the reproductive health of women with intellectual and other disabilities; and, commission research on the practice, effects and implications of the sterilisation of women with intellectual and other disabilities (Ref: Senate Journal No. 104, 24). This Senate Resolution was endorsed by the Liberal Party, the Australian Labor Party and the Australian Democrats. Women With Disabilities Australia (WWDA) has been advocating for several years for the need for this work to occur, and the Senate Resolution is a reflection of this work.

In mid 2000, WWDA applied for and received project funding from the Commonwealth Office of the Status of Women, to conduct a National Project on the issue of Sterilisation and Reproductive Health of Women and Girls with Disabilities. While developments in the legislation have been ongoing since the early 1990s, WWDA saw the need for a project to address the issues for women whose lives had been affected. It had become clear that the voices of women with disabilities were absent in the limited debate, research and literature that had occurred in Australia on the issue of sterilisation and reproductive health of women with disabilities. For far too long women with disabilities have had 'experts' speak on their behalf, and/or make decisions that affect them – WWDA's national project aimed to redress this by empowering women with disabilities to reclaim their issue, and in doing so, reclaim some control over their lives. Therefore, WWDA's major commitment in its national project was to women with disabilities. The Project brief was very clear in its intention to enable women with disabilities to express their issues, concerns, stories, suggestions and ideas around the issues of sterilisation and reproductive health. In this context, WWDA was committed to ensuring that women with disabilities were afforded a safe, supportive environment in which to tell their stories, and work on strategies to redress an issue that has been neglected for far too long.

The National Project on the issue of Sterilisation and Reproductive Health of Women and Girls with Disabilities comprised two main components: a background research phase to examine international and national developments; and a National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities, to provide women and girls with disabilities a safe and secure environment to speak out about their experiences and, in conjunction with the International Conference *Disability with Attitude: Critical Issues 20 Years After International Year of Disabled Persons* held in Sydney in February 2001, an opportunity for those women with disabilities to come together with academics, researchers and service providers to critically analyse the issue and develop strategies to advance debate and action. This document reports on the outcomes of the project. In keeping with WWDA's commitment to women with disabilities, the project frames issues of sterilisation and reproductive health of women with disabilities in the context of human rights.

Project Objectives

The objectives of the Project were:

- to undertake background research on the issue of Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- to develop a national and international perspective of the range of activities regarding Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- to develop and provide a national collection point for materials relating to the issues of Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- to conduct a National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- to develop a National Plan of action for WWDA and other key stakeholders around the issues of Sterilisation and Reproductive Health of Women and Girls with Disabilities.

The anticipated **outcomes** of the Project included:

- a national and international perspective of the range of activities regarding Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- development of a national database of materials and activities relating to the issues of Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- promotion of collaborative working relationships between women with disabilities, researchers, service providers and policy makers;
- a National Plan of action for WWDA and other key stakeholders around the issues of Sterilisation and Reproductive Health of Women and Girls with Disabilities;
- representation of women with disabilities at the International Disability Conference: 'Disability with Attitude: Critical Issues 20 Years After IYDP;'
- increased recognition nationally and internationally of Women With Disabilities Australia (WWDA).

Section Five: Sterilisation and Reproductive Health of Women and Girls with Disabilities – The Context

The issue of unlawful sterilisation of women and girls with disabilities, set in the broader context of reproductive health issues for women with disabilities, has received little attention in Australia. There has been a dearth of research on the issue, and women with disabilities have not been involved in the limited debate and research that has occurred. The enormity of the issue and the tasks that must be undertaken to redress those wrongs and ensure that they do not continue to occur have emerged as a result of listening to the voices and views of women with disabilities whose lives have been affected by a wide range of practices that have infringed their reproductive rights.

5.1. The Scope of the Issue

The issue of reproductive rights for women with disabilities encompasses far more than sterilisation. Preconceptions and presumptions about the experience of disability as personal tragedy or a medical problem, and about the sexuality of women with disabilities, frame social attitudes to reproduction. Assumptions abound about who has the right to parent and whether future populations will encompass a diversity of human beings. These assumptions have real life implications for women and girls with disabilities. To understand the issues as they affect women and girls with disabilities we need to look carefully at the assumptions that are made and see how they come to manifest themselves in the denial of human rights to bodily integrity and rights to reproductive choice and parenting. Specifically we can see the results in forced sterilisation, systematic denial of appropriate reproductive health care and sexual health screening, limited contraceptive choices, a focus on menstrual control, poorly managed pregnancy and birth, selective or coerced abortion and the denial of rights to be a parent based solely on the fact of disability.

Discriminatory practices are not only still occurring in the Australia of 2001 but have affected the lives of countless women with disabilities over the past many decades. This report seeks to redress the issues raised by practices in the past that have sentenced many women with disabilities to lifelong alienation, loss, betrayal and health problems and to mobilise action to prevent further infringements of the human rights of women with disabilities in the form of inaccessible or absent reproductive health and support services, forced sterilisations, forced contraception, abortion and parental custody.

The need for action in this area was highlighted at the First Public Tribunal on Women's Human Rights auspiced by the Women's Rights Action Network, and held in Melbourne in May 1999. WWDA was invited to give a presentation at this Tribunal which was attended by over 300 people and broadcast live via the Internet. Ms Vicki Toovey, who gave the presentation, stated:

> *Women with disabilities have a right to bodily integrity, to make informed choices about their health and reproductive activity. The issue of sterilisation is seen by many as violence against women. It reflects society's continuing inability to deal with the issue of sexuality and people with disabilities. It also reflects the need for support and care for people with disabilities and those who care for them. Support should be provided to*

> *enable independence in daily activities, to enable the management of menstruation, education to protect against unwanted sexual advances and to provide both proper support and respite care for parents and carers. At the centre of all these issues is the continued need for action and awareness of people with disabilities in our community and our rights to full citizenship and participation in our society without discrimination."*

5.1.1. Terminology

It is often true that the way we can talk about something can limit the way we think about it. The practices that law makers and health care providers call 'unlawful,' 'unauthorised,' 'non-consensual,' 'involuntary', or 'non-therapeutic' sanitises the picture of what really happens to women with disabilities in their reproductive choices. For many women with disabilities the experience is about being denied access to suitable services, forced against their will, coerced, intimidated, pressurised, compelled, raped and even unknowingly deprived of their human rights to bodily integrity and control over their reproductive health. Using the language of violence is an alternative way of talking about these particular experiences of reproductive rights. In the case of sterilisation, the fact that a procedure may be 'authorised' or 'lawful' does not in any way obviate the reality that a woman with a disability, often a very young woman, undergoes a medical procedure to remove non-diseased parts of her body which are essential to her ongoing health. The long-term negative social and psychological effects on women with disabilities are somehow deemed insignificant. In considering issues of sterilisation it is important to be clear that any sterilisation carried out without the informed consent of a person is a *forced* sterilisation and that applications to sterilise must be seen as procedures *done to* women with disabilities not procedures *done for* them.

5.1.2. Research

The limited research that has occurred has not included or involved women with disabilities. One notable exception is *On the Record: A Report on the 1990 Conference on Sterilisation – My Body, My Mind, My Choice* conducted by STAR Victoria, the first opportunity for women with intellectual disabilities to talk about and explore the issue of sterilisation. For the most part, the research that has occurred has concentrated on legal issues to do with who can be forcibly sterilised. There is little medical research specifically focused on reproductive health issues for women with disabilities and the research that has been done is limited to identifying possible short and long term health risks rather than identifying how these risks can be managed. Women with disabilities themselves have had little opportunity to speak about their experiences or to participate in legislative, policy and program development. It is impossible to address the subject of sterilisation and reproductive health for women with disabilities without addressing the broader social context of disability and without listening to what women with disabilities have to say about how these issues affect their lives.

5.2. Sterilisation – The Issues

The sterilisation of women with disabilities is a complex issue with numerous grey areas, which have remained unexplored in the debates in Australia in recent years. This report aims to present some of the broader issues which need to be considered if we are to go beyond the legal wrangling about how we decide who should be sterilised and consider the human rights of disabled women and girls. It presents the issues in a way that reflects what disabled women whose lives have been affected by sterilisation have said.

Forced sterilisation is an act of unnecessary and dehumanising violence, which denies a woman's right to bodily integrity and her right to bear children. Sterilisation of disabled women is a form of social control in which a woman's right to bodily integrity is denied often at the behest of parents and medical or other professionals, who deem this bodily violation 'in her best interests.' By way of balance it is also important to protect the rights of women with disabilities to choose sterilisation as a means of contraception.

Justifications for forced sterilisation generally fall into three broad categories:

- *Genetic* – the fear that women with disabilities will produce children with 'genetic defects.' This reasoning is grounded in eugenic thinking and in the broad views that society holds of disability as a personal tragedy or medical problem. There are very few instances in which disability is caused genetically and in fact much evidence suggests that the causes are more likely to be environmental or social such as pollution, poverty or war.
- *For the good of the state, community or family* – the burden of caring for any 'defective' child that may result from a pregnancy, or the burden of caring for the disabled woman and her reproductive functions, especially menstruation. Burden of care is a complex argument that encompasses both social and economic factors. The burden on the State or community in providing disability services is essentially a financial argument in which the issue of dollar cost is used to justify a denial of human rights. The question to be answered here is whether the respecting of fundamental human rights depends on the potential expense involved. In terms of the burden on families of the care of girls and women with disabilities, lack of resources and appropriate education and support services, appropriate respite care, school and post-school options, sees many families already struggling to manage the care of their girl or young woman with disabilities. Faced with the prospect of added personal care tasks in dealing with menstruation and in the limited availability or accessibility of specific reproductive health and training services including those for menstrual management, families may well see sterilisation as the only option open to them. The denial of a young woman's human rights through the performance of an irreversible medical intervention with long term physical and mental health risks is wrongly seen as the most appropriate solution to the social problem of lack of services and support.
- *Incapacity for parenthood on the part of the women with a disability* – there is a widely held view that women with disabilities cannot be parents, even in the face of the evidence that many disabled women successfully parent happy children within our communities. There are few clear criteria for judging or determining competence and incompetence in parents. There is also a tendency to go beyond the competence argument in this emotive area and use subjective ideas of 'good' and 'bad.' There is no clear relationship between competence or intelligence and good parenting and we need to keep in mind that parenting judgements are value judgements.

5.2.1. Best Interest

The reason used to justify forced sterilisation is that it will be in the 'best interest' of the girls or women involved. To unpack the term 'best interests' reveals a complex interplay of factors that have very little to do with the young woman's rights and more to do with social factors and the 'burden of caring.' In making judgements about best interests it is crucial that we are clear about whose best interests are really at stake. We need to be clear about whether 'best interest' is judged according to human rights principles or whether the judgement is about the 'best compromise between the competing interests' of parents, carers, service providers and policy makers. To really determine 'best interest' for women and girls with disabilities it is crucial to focus on the fact that a person will be subjected to an irreversible medical procedure with life long consequences without informed consent.

It is important also to take into account the fact that women (including disabled women) *do* choose sterilisation for social purposes such as contraception. It may be beneficial to look at the reasons why women do choose sterilisation and see if they are relevant to the best interests of someone unable to consent.

There will be some cases where sterilisation may be in the best interests of women with disabilities, just as is the case for all women. However this decision can only be made after exhaustive procedures that clarify how this comes to be the case and differentiated from the interests of parents and the interests of society. The debates must be openly had and they must be within a rights framework that maintains the right to bodily integrity and the right to informed consent.

5.2.2. Who Decides

There can be little debate that parents of children with disabilities may well be acting in good faith in seeking a sterilisation for their child, but parents can only make decisions on the basis of the information and support available to them. The lack of research into the long term effects of sterilisation coupled with the lack of viable support within communities for families and people with disabilities mean that parents could be making a crucial and irreversible decision without knowing all the 'facts.' In the daily struggle to care for their child, and without adequate support services, it is often assumed that the best interests of a child will coincide with the wishes of her parents. This may not always be the case. When parents make decisions in a vacuum of information and services, it is the human rights of the person with a disability that will be violated.

Medical professionals are often very influential in the decision to sterilise. The propensity of parents and courts to value medical opinion above all else has the effect of reducing the 'best interests' of women or girls with disabilities to the 'best ways' of controlling/managing their bodies. These judgements are made from a particular perspective which must be questioned – that the woman or girl with a disability is essentially the sum of her biology or her psychology and her rights to bodily integrity are less important than controlling her body and her behaviour.

5.2.3. The Issue of Age

Currently in Australia the Family Court and Guardianship Tribunals of New South Wales and South Australia can authorise the sterilisation for girls under 18 years. Guardianship Tribunals in all States can authorise sterilisation for women over 18 years with 'decision making disabilities.' Applications have been made for sterilisation of girls as young as 10 years old (Brady 2001).

Several areas warrant careful consideration here. Firstly an application for sterilisation of a girl before she begins to menstruate is based on the assumption that the girl will not be able to manage her own menstruation, before she has had the opportunity to try. Added to this, the little medical research that has been done in this area has raised the likelihood that grave health risks such as early onset menopause, osteoporosis and cardio-vascular disease can result from sterilisation of girls before they begin to menstruate. Secondly there is an important legal contradiction. In seeking forced sterilisation of a young women before she is of full legal age (ie 18 years) a violation of standard legal procedure when dealing with juveniles occurs. Someone under 18 years cannot consent. When a juvenile commits a crime he or she is immune from the full punishment that would be given to an adult who committed the same crime. The 'crime' for a girl or young women in the consideration of forced sterilisation is her disability, her 'uncontrollable' body. Moreover this violation is likely to be authorised due to the fact that the girl or young woman is judged incompetent (at the age of perhaps 12 or 16) to give informed consent to the procedure, and thought likely to be incapable of managing her own menstruation and contraception and to be a parent.

5.2.4. Consent, Capacity and Competence

Consent is a contentious issue. In the cases of very young women with intellectual disability who undergo sterilisation, the issue of obtaining consent to the procedure is compounded both by the girl's age and the fact that there is an expectation that due to her disability the young woman is unlikely to ever be able to understand what is being asked and therefore will not be able to provide consent even in the future. The fact that a girl is not competent in her teenage years does not mean that she will never be. It is possible that with appropriate education and support and further development and maturation, she may become 'competent' to give consent. It may be that competence to consent will never be achieved, but as long as the possibility remains, forced sterilisation is an extreme and irreversible step that should not be considered.

In determining when lasting decisions about competence to consent can be made it is important to bear in mind that there are many instances in which women, judged incapable or incompetent to consent and forcibly sterilised under the age of 18, have later married or had relationships and discovered that they have been sterilised only when they failed to fall pregnant. We need to consider the question of who decides this competence or capacity to consent and on what basis or evidence. There is very little independent research into how these decisions should be made. There is also a real need to be aware of the possibility of a girl or woman being subject to coercion to consent. The opinion of parents that their daughter is unable to consent may be taken at face value in these circumstances and although parents may feel they know their child best, they do not necessarily provide an independent opinion. The opinion of medical professionals, including psychiatrists, may be seen as independent but their expertise lies in medical rather than social or communication matters. These opinions may deserve some weight but should not make up the entire picture, either in a court or tribunal setting. The involvement of a trained advocate is one measure that may help to ensure that the rights of women and girls in decisions about their bodily integrity are protected.

Capacity or competence to consent is also closely related to the ways in which information is provided. There are very few specific materials available that describe sterilisation and its consequences using Plain English and pictures and few support workers trained to use them. From anecdotal reports it seems that information about sterilisation and its consequences is either not given at all or is given by parents or medical professionals who may either have vested interests or have few skills in communicating with women or girls with specific communication support needs. Until appropriate resources have been developed we are unable to say with any certainty that a girl or young woman cannot or will not be able to understand the issues and can or cannot give informed consent. Capacity to consent must then be judged on a case by case basis with respect to the specific circumstances in which the consent is sought. It must be seen as an interactive developmental process not an isolated event in time.

5.2.5. Unintended Consequences

Forced sterilisation can increase a disabled woman's vulnerability to sexual abuse (Sobsey & Doe 1991). We already know that sexual abuse of women with disabilities is occurring at very high rates in our communities. A young woman who has been sterilised is less likely to be taught about sexuality or sexual abuse because she cannot become pregnant. Sterilisation is quicker, easier and cheaper than sex education. Sterilisation can also inadvertently serve to cover up the sexual abuse of women with disabilities, since pregnancy is often the only clear evidence that sexual abuse has occurred. Others may know she has been sterilised and she may be seen as a safe target. On the other hand women who have been sterilised may also be assumed to be non-sexual and therefore will be more easily passed over for sexual and reproductive health screening.

5.3. Sterilisation – The Picture in Australia

In Australia the issue of sterilisation has been the subject of debate since the early 1980s when it became clear that many women with disabilities had been and were being sterilised without their consent and in some cases without their knowledge. It was clear this was happening with the informal consent of family, carers or doctors and without public scrutiny or accountability (Cooke, Topp & Webster 1994). This was in keeping with the legacy of the coercive and government sanctioned mass sterilisation of women with disabilities in pre-war Australia (Goldhar 1991). Responses to these concerns at the time focused overwhelmingly on the legal issues involved in 'authorising' the procedure and not on the human rights of women and girls with disabilities. This focus has continued up until the present day and has resulted in the main thrust of public policy in the area being focused on reactive legislation to prevent further abuse and piecemeal development of appropriate protocols and support services. Fundamentally, the debate has focused on *who can* be forcibly sterilised and how this is done in a way that does not break the current laws. While legislation constitutes part of any public policy it is not the whole picture. In the Australia of 2001, many of the broader debates about forced sterilisation of disabled women and girls, from a human rights perspective, have not taken place.

Additionally, the legal question essentially addressed in the debates around forced sterilisation of women and girls with disabilities has been constructed as a decision about whether to sanction a 'medical procedure.' This has resulted in the narrow conception of forced sterilisation as a legal and medical matter when in fact it is essentially one of human rights grounded in a social context that devalues the lives of women and girls with disabilities. Crucially the voices of the disabled women who have been the subject of these laws have not been heard. This silence has been in some measure due to the fact that the majority of women affected are those with intellectual disability – a group whose voices are seldom heard on any issue. But this is not the only sub-group of disabled people affected. Women with physical and psychiatric disabilities are now coming forward to speak out about their experiences. Little is known also about the incidence of sterilisation of men and boys with disability.

The growth of human rights and disability rights movement since the early 1980s and the appearance of disability advocacy and lobby organisations such as WWDA, has begun to redress this imbalance by calling for a broadening of the way we talk and think about sterilisation to focus on the human rights of those at risk. Importantly women with disabilities who have been sterilised are now beginning to speak publicly about their experiences. The important message is that broader society must ensure the rights of young women and girls are upheld to ensure that forced sterilisation does not continue to happen. They are also telling us that their needs as survivors are not being met. There has been little action, from either the human service professions or non-government organisations that has been targeted at redressing the human rights violations that have already occurred. The provision of support and counselling for survivors, the commissioning of research into the health and social effects and compensation for discrimination and the life long consequences of forced sterilisation must now be addressed.

5.3.1. The Human Rights and Equal Opportunity Commission (HREOC)

The Human Rights and Equal Opportunity Commission (HREOC) has shown an ongoing commitment to further the debate on the issue of sterilisation. In 1997, Elizabeth Hastings (the then Disability Discrimination Commissioner), commissioned a report: *The Sterilisation of Girls and Young Women in Australia: a legal, medical and social context* by Susan Brady & Sonia Grover. The report described the legal framework, the reasons that are commonly given in support of sterilisation, and the medical procedures by which it is done. It also analysed the data available and found that the numbers of sterilisations far exceeded the number of authorisations issued by the courts and tribunals. The report concluded that:

> *the law failed to protect significant numbers of children from abuse of their fundamental right to bodily integrity.*

The Human Rights and Equal Opportunity Commission (HREOC) succeeded in having the Medicare Benefits Schedule Notes for Guidance amended to include a declaration that sterilisation of a minor is unlawful if not related to a disease state and could not be consented to by parents. It reminded practitioners that they would be liable to criminal and civil action if they conducted sterilisation procedures without the authority of a court or tribunal. Additionally, HREOC attempted to impose more stringent accountability in the conduct of procedures by seeking Medicare Benefits Schedule to require clinical notes justifying the necessity of the procedure before Medicare payment is made. This was unsuccessful.

HREOC remains committed to change in the area as evidenced by a follow up to the 1997 report – *The Sterilisation of Girls and Young Women In Australia: issues and progress* (Brady, Briton & Grover) published in April 2001, jointly commissioned by the Sex Discrimination and the Disability Discrimination Commissioners. This report summarises developments since the 1997 report, provides up-to-date information on the numbers of applications to the Family Court and Guardianship Tribunals, outlines the national profile of 'lawful' sterilisation, and discusses the rules, guidelines and protocols currently in place. The report also identifies key areas for reform which include:

- *increased accountability of medical practitioners by requiring a court order or full clinical notes justifying a claim for Medicare for sterilisation procedures on children;*
- *legislative reform which gives Guardianship Boards in all States jurisdiction over applications for the sterilisation of children;*

- *development of specific criteria and uniform national standards which prescribe the circumstances in which children may or may not be sterilised;*
- *improving co-ordination of policies and procedures and access to appropriate resources for service providers in assisting families in managing their daughter's menstruation and fertility.*

These steps are particularly aimed at halting the unlawful practices still happening to girls and young women with intellectual disabilities. They are important elements of a broader picture of reform that must address the implications and effects of sterilisation for all women and girls with disabilities who are at risk or who have been sterilised.

5.3.2. The Legal Framework

The response to early concerns about sterilisation of disabled women in Australia centred on who can lawfully give consent to the medical procedure. This line of thinking has continued to determine the legislative framework and its reform. Since 1992, as a result of what is known as 'Marion's Case' (Secretary, Department of Health and Community Services (NT) v. JWB and SMB), the forced sterilisation of girls with disabilities under the age of 18 years can only be authorised by the Family Court of Australia and by Guardianship Tribunals in NSW and South Australia. For women over 18 years who have 'decision making disabilities' Guardianship Boards in all States have the authority to sanction a sterilisation.

These reforms have been seen by many as a significant step in protecting young women and girls with disabilities from being 'unlawfully' sterilised. However there is no co-ordinated national legislative/regulatory approach to the issue and this seems unlikely while responsibility for the decisions can be taken in either a State based tribunal or a Federal court. There is considerable debate about which legal forum is best placed to consider the issue. Criticisms of the court as being too adversarial in its approach and requiring expensive legal representation reflect the traditional inaccessibility problems inherent in court proceedings. State Guardianship Boards, being more closely linked to the service system and the community, are considered by some legal experts to be vulnerable to 'giving in to popular pressure' and thus, not working in the interests of disabled women. However, there is some evidence to suggest that Guardianship Boards have more flexibility to tailor their interventions through a process of consultation, co-operation and coalition building with families, advocates and service providers. This enables them to more effectively address issues of reproductive health for women with disabilities including menstrual management when faced with decisions to authorise sterilisation. Boards may also be able to address the issue of obtaining consent as an ongoing developmental process rather than one event in time. Arguments about which legal process is best placed to authorise 'lawful' sterilisation are important given the fractured responsibilities at both the State and Federal levels, but they may stand in the way of more pressing debates about the nature of forced sterilisation as an infringement of basic human rights.

There is a plethora of guiding principles, protocols and practice guidelines which have been developed within the different jurisdictions to ensure that decisions by the court or a tribunal are made in the 'best interests' of the girl or young woman and that sterilisation is a 'step of last resort.' There is no one coherent national prescriptive approach against which all processes must be measured. This has resulted in replication and the inevitable waste of scarce resources. *The Sterilisation of Girls and Young Women In Australia: issues and progress* (Brady, Briton & Grover 2001) contains a detailed analysis of the current rules, protocols and practice guidelines for both the Family Court and Guardianship Boards.

Sterilisation has been located in the legal framework as an issue about who can authorise a medical procedure. Illegality focuses on 'unlawful sterilisation,' that is, procedures carried out without the authorisation of a court or tribunal. Since the early 1980s, in keeping with United Nations Charters and Conventions, Australia has seen the introduction of rights based legislation prohibiting discrimination of the grounds of disability. The HREOC has tested the usefulness of UN Declarations on the Rights of the Child, the Rights of Mentally Retarded Persons and the Rights of Disabled Persons in several Family Court cases with limited success. The rights of women with disabilities are protected under the *Disability Discrimination Act (1992)* and various State based anti-discrimination legislation. The usefulness of these legal avenues for women who are at risk or who have been forcibly sterilised are currently unexplored and untested. Moreover, individualised, case by case approaches have limited applicability. If a case using discrimination legislation is upheld and the woman is found to have been discriminated against, there is no feasible way for her to have the damage reversed.

5.3.3. Government Action or Inaction?

The practice of unlawful sterilisation of girls and women with disabilities in Australia has been recognised by Commonwealth and State Governments (Law Reform Commission of Western Australia 1994; Human Rights & Equal Opportunity Commission 1997; Family Law Council 1994). Despite legislation that is meant to ensure that all sterilisations conducted on girls and young women with disabilities be authorised by a court or tribunal, it is clear that these authorisations have not been occurring and that the practice of unlawful sterilisation of women and girls with disabilities continues in Australia (Brady, Briton & Grover 2001; Hastings 1999; Brady & Grover 1997; Toovey 1999).

WWDA has lobbied the government for some time to take action in addressing these concerns (Spicer 1999; Toovey 1999). In response to this effort on the part of WWDA and other community organisations, a resolution was passed in the Senate, on March 15th, 2000, calling for the Australian Government to:

> *conduct a review of the legal, ethical and human rights mechanisms in place, or needed, to protect the rights and interests of the reproductive health of women with intellectual and other disabilities, and, commission research on the practice, effects and implications of the sterilisation of women with intellectual and other disabilities.*
> (Senate Journal No.104, 24. Human Rights – Women with Intellectual Disabilities – Sterilisation)

This Senate Resolution was endorsed by the Liberal Party, the Australian Labor Party and the Australian Democrats. Thus the political representatives of the Australian community have signalled that there should be a consensus approach to this issue.

The Commonwealth Department of Family and Community Services co-ordinated a cross-departmental response to the motion involving Health and Aged Care, Attorney General's Department and the Office of the Status of Women which culminated in a report entitled *Sterilisation of Women and Young Girls with an Intellectual Disability*, tabled by the Minister on 6 December 2000 (See Appendix 2). Contrary to WWDA's and the Senate motion's specific requests, the report addressed the issues relating to women and girls with intellectual disabilities only and did not consider any issues that may more broadly affect women with other disabilities.

The report undertook a review of available national data to ascertain the incidence of sterilisation of women and young girls with intellectual disabilities. It concludes that:

> *it is not possible to ascertain the precise number of unauthorised sterilisation procedures that may be being performed on women with intellectual disabilities... It is possible that there are unrecorded and unauthorised non-therapeutic sterilisations of young women with intellectual disability being undertaken in Australia.*

In its review of the legal, ethical and human rights mechanisms, the report outlined the very limited efforts that have been made in Australia to prevent unauthorised sterilisations of young women with intellectual disabilities since the 1997 publication of *Sterilisation of Girls and Young Women, A Legal, Medical and Social Context* commissioned by the Human Rights and Equal Opportunity Commission (HREOC). These included:

- letters from the Attorney General to Australian medical colleges and associations reminding them of the law;
- amendments to the Legal Aid guidelines to provide for representation of the child in any Family Court cases (although still requiring the means test to be applied to parents, thus not addressing the issue of accessibility to the legal system for those who should be encouraged to use it);
- changes to the Medicare Benefits schedule (see HREOC above);
- verification with the practitioner of Medicare claims for procedures on girls under 17 years. The aim of this is to 'safeguard the integrity of the Medicare claims data.' Verification does not extend to whether the service was authorised by the relevant court or tribunal;
- gathering of information from Family Planning Organisations on the types of resources available for professionals and parents about the sexuality of young people with disabilities.

In reviewing research on the practice, effects and implications of the sterilisation of women with intellectual and other disabilities, the report highlights the WWDA Sterilisation and Reproductive Health of Women and Girls with Disabilities project as the only notable development. The report was understandably greeted by those working to progress the debate related to the sterilisation of disabled women and girls with a great deal of disappointment. The words of the late Elizabeth Hastings, former Disability Discrimination Commissioner of the HREOC in a keynote speech delivered in 1998 still hold true:

> *A world in which government cannot be bothered to investigate potential illegal medical assault on nearly 200 of its citizens, in which those with no authority feel free to make decisions which are blatantly against the law and to carry out serious and irreversible procedures on those with little or no capacity to give or withhold consent, is a world in which people with disabilities can have no certainty or confidence about their human being or their future...*
> (Elizabeth Hastings, *The right to right treatment*. The keynote speech for the launch of "A Question of Right Treatment" University of Melbourne March 28 1998, p4)

5.4. Sterilisation – The International Context

Involuntary or forced sterilisation has been acknowledged as a critical human rights issue facing women with disabilities in a variety of international contexts including the United Nations and within international disability and women's right's forums. The United Nations Standard Rules state:

> *"persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood." These rights are commonly denied to both men and women with disabilities worldwide. Both the sterilisation of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2).*

There is a historical precedent in several countries including the US (until the 1950s), in Canada and Sweden (until the 1970s) and Japan (until 1996) indicating that abuse of disabled women by sterilisation occurred on a collective scale – that is, mass forced sterilisation. This policy was rationalised by a pseudo-scientific theory called eugenics – the aim being the eradication of a wide range of social problems by preventing those with 'physical, mental or social problems' from reproducing. Although eugenic policies have never overtly existed in Australia and have now been erased from legal statutes in most countries, vestiges still remain within the attitudes of some sectors of the community, and in some areas of the legal and medical establishments.

In the United States involuntary sterilisation affected women with disabilities and women from black and other ethnic backgrounds from the turn of the century in many States until the 1950s when proactive policies were removed from the statute books of most States. As a result of lobbying by community groups, forced sterilisation came to be seen as institutional violence and the Federal government became involved in the 1970s (Reilly 1991). In 1979 Sterilisation Regulations were introduced which were aimed at standardising consent forms (they are to be voluntary and completed in the person's preferred language), required explanation of contraception measures and the irreversibility of sterilisation procedures, imposed a waiting period of 30 days after consent was signed and prohibiting the use of hysterectomy for sterilisation alone. The I979 Federal regulations were passed to reduce the frequency of non-consensual sterilisation, however they apply only to operations subsidised by federal funding. Most cases of non-consensual sterilisation fall within the jurisdiction of the States. While most States have followed the recent trend prohibiting involuntary sterilisation and requiring consent, each state has inconsistent and often contradictory regulations, which allow the abuse of forced sterilisation to continue (Elkins & Anderson 1992). At least 14 States still have laws authorising involuntary sterilisation of 'mentally incompetent persons.' *The Americans With Disabilities Act* has been successfully used in challenging involuntary sterilisation procedures.

Eugenic policies also operated in several European countries including Denmark, Germany, Sweden, Norway and Finland in the early part of the last century (Macklin & Gaylin, 1981). There are claims that these policies still operate in Austria and some parts of Switzerland. In Sweden in 1997 the involuntary sterilisation of people with disabilities was widely reported in the media resulting in a government apology and moves by those affected to seek compensation.

In England the legal position advocated by the courts recognises that sterilisation for adults with learning disabilities is generally non-consensual. The courts cannot consent on behalf of the adult but can rule on the lawfulness of the operation *(Re B 1987)*. Cases need not be brought before the court when the operation is to be carried out to treat a specific menstrual malady and where sterilisation is an incidental result. However, the Law Commission has set guidelines which recommend that such operations require a certificate from an independent medical practitioner. In operations where the sole purpose is contraception the courts will always need to be involved. Their decision on the lawfulness of the operation will be based on what is in the person's best interests, which in turn will be determined by reference to standards set by a responsible body of medical practitioners (British Law Commission 1993).

In New Zealand the issue is similarly contentious. Current legislation allows for a woman under 20 years of age who is incapable of consent to undergo a hysterectomy by the consent of her parents or guardian. This decision can be made without the specific authorisation of a Court. Medical advisers must ensure that the informed consent of parents or guardians is given, there are valid medical or therapeutic reasons for the procedure and consent is in the best interests of the young woman. For women over the age of 20 who are incapable of consent the procedure must be authorised by the Family Court (*In re X, 1990*). Caregiver convenience is not considered a valid reason for sterilisation. Disability advocacy organisations are engaged in an ongoing dialogue with law-makers over their concerns that the legislation does not provide sufficient protection of the rights of women with disabilities.

South Africa introduced legislation in 1998 to provide the right to sterilisation; to determine the circumstances under which sterilisation may be performed and, in particular, the circumstances under which sterilisation may be performed on persons incapable of consenting or incompetent to consent due to mental disability. It states that two medical practitioners must certify that the woman suffers a hereditary condition which would cause the child to suffer serious disability, or that the woman cannot comprehend or manage parental responsibilities. The woman's guardian or a magistrate must consent and the Minister of Health or authorised medical officer of the Department of Health must provide written authority *(Sterilisation Act 1998).*

In China many provinces enforce mandatory sterilisation and abortion for people with hereditary mental illness and genetic physical disability. India also currently has a requirement for involuntary sterilisation of some categories of women with disabilities (Reilly 1991).

In Japan a eugenic law permitted involuntary sterilisation of up to 16 500 people with intellectual, psychiatric and physical disability from 1948 to 1996 (Tsuchiya, 1997). Since 1997 civic groups representing those affected and people with disabilities themselves have demanded an investigation into the practice and an apology combined with compensation for those affected, with no success. The campaign is ongoing.

Currently in France (April 2001) there is move to introduce legislation that is worth considering in some depth because it has parallels with the Australian situation. The French Senate is currently set to legalise the sterilisation of women who choose to have their fallopian tubes tied as a means of contraception, which up to now has been altogether illegal. There is an addendum to this law, about the case of women with 'mental handicaps' which seeks to regulate the occurrences of sterilisation of mentally disabled women so that they no longer occur undercover, in secrecy, but rather after official approval. Disabled women campaigners are concerned that if the law is passed, requests made for the sterilisation of 'mentally disabled women' will have to be submitted to the approval of a special commission. This commission will include a judge, a doctor and a representative of an organisation of disabled people. It will grant permission to perform the sterilisation only in the case of disabled women who don't seem to be have the ability to use another means of contraception and for whom pregnancy is medically proven to be a risk, provided the women have formulated the request themselves or given their consent. If they are unable to, the request is formulated by a legal representative, (Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé. 1999).

Campaigners against this law are concerned that attempting to provide a legal framework for the sterilisation of this population might, in the long run, make the recourse to an irreversible form of birth control for disabled people a totally accepted phenomenon. Specific concerns centre on the validity of what is meant by the necessity for these women having to give their 'consent,' given that consent can easily be forced upon people with developmental disabilities. They question how the commission will verify how the women's consent was obtained. They also question the assumption that if a woman is unable to formulate consent or refusal, it can be considered acceptable that a legal representative makes a request for sterilisation in her place. Additionally, French research has confirmed the negative psychological consequences that sterilisation has had upon disabled women, with testimonies reporting that sterilisation was experienced as a physical violation, which often resulted in symptoms of regression, and occasionally, self-destructive acts. They argue that while using sterilisation as a means of birth control might appear a simpler solution to some parents and staff responsible for institutionalised disabled women, it increases the risk of spreading STDs and HIV among the population of institutionalised people. "The sterilisation of women who are unable to defend themselves against (or denounce) sexual abusers is a way for institutions and families to avoid facing the fact that many mentally disabled women are victims of rape, and to avoid protecting such women from abusers. Removing the risk of pregnancies resulting from sexual abuse might actually be an indirect encouragement to abusers, who have less to fear" (Diederich & Moyse 2001).

The experience in Canada is also of particular interest to the Australian context, if only for its very different approach to the issue. Women with disabilities were subject to eugenic sterilisation policies in several Canadian States until the 1970s. In a radical turn around in 1986 the Canadian Supreme Court ruled in *Re Eve (E(MRS) v Eve 1986)* that a sterilisation could not be performed on someone who cannot give consent – that no one (not even the Court) can consent on their behalf. This resulted in a blanket prohibition of non-voluntary sterilisation. The court reasoned that it can never "safely be determined that a procedure such as sterilisation is for the benefit of the person considering the grave intrusion on their rights and the physical damage that ensues from the non-voluntary sterilisation without consent, when compared to the highly questionable advantages that can result."

The Canadian authorities, as a consequence of this decision, have considered several important issues in greater depth than in the Australian process. The underlying assumptions and conclusions that have resulted include:

- any sterilisation carried out without the informed consent of a person is a forced sterilisation;
- applications to sterilise must be seen as procedures *done to* women with disabilities not procedures *done for* them;
- the legislative process should provide protection against any potential abuse of legally incompetent people by forced sterilisation;
- blanket prohibitions on sterilisation are in the interests of collective rights and justice;
- the issue of consent – that not all adults with intellectual disabilities are automatically incapable of legal consent. A person might be legally competent in some areas but legally incompetent in others, that a person's mental ability to consent to treatment or a procedure must not be assumed from her status within either the health care system or the legal system and that the person's legal competence must be judged in relation to specific choices that must be made;
- non-therapeutic sterilisations are those conducted for social purposes alone, that is, sterilisation for contraception and hysterectomy for menstrual management;
- the notion of best interest – in considering this issue it is important to be clear about the underlying reasons for seeking sterilisation and to understand that social reasons are not reasons enough – that social reasons arise due to social factors such as resources and other variables;
- importance of acknowledging that women *do* choose sterilisation for social purposes like contraception and that it is necessary to look at the reasons why women do choose sterilisation and see if they are relevant to the best wishes of someone unable to consent.

To the degree that it is one of the first instances in which women who have been forcibly sterilised have successfully sought compensation, the Canadian experience is also salutary. Last year, the Alberta government offered an $82 million compensation package and an apology to the 703 people who were forcibly sterilised under that province's Sexual Sterilisation Act. In British Columbia, fourteen women with mental disabilities who were sterilised at a provincial mental hospital are currently suing the government on a similar basis.

It is clear from even this brief overview of international legislative and policy contexts that forced sterilisation remains a vexed issue worldwide. What is also clear is that there are many different approaches to regulating such sterilisations and that in several countries women who have been affected have been able to take action to obtain compensation. The Canadian and French examples point to the need for careful consideration of notions of consent, best interests and the broader and less obvious implications of legislation aimed at 'protecting' women with disabilities.

5.5. Reproductive Health

Women with disabilities have the same basic reproductive health care needs as women in general yet these have been fundamentally ignored by service providers, health care professionals and families. Often women with disabilities themselves neglect getting routine primary health care (especially reproductive health care) because of physical barriers to access clinics and the lack of knowledge within the health care system of their unique needs (Jackson, 1996). There is some research focused on reproductive health issues for women with physical disability and little investigation of issues for women with intellectual, cognitive, psychiatric, sensory and other disabilities. In general medical research focuses on rehabilitation and treatment without taking into account the whole of the lives of women with disabilities. There is little focus on psychological and social issues such as sense of self, relationships, parenting, sexual orientation, abuse, gaining access to the health care system and the politics surrounding the sexuality of women with disabilities (Nosek, 1996).

5.5.1. Contraception

Women with disabilities need safe and effective contraception. The myth that women with disabilities are asexual may mean that doctors or gynaecologists often do not ask disabled women about their contraceptive needs. This can make getting accurate information about contraceptive options very difficult. There is a lack of information regarding the most appropriate way to manage contraception for women with different types of impairments, and limited research into the specific interactions of oral contraceptives with medications used in the treatment of spasticity, epilepsy, diabetes and other chronic illnesses (Welner, 1996). The impact of some oral contraceptives on bone density is also a critical issue for women with mobility impairments who are at risk from osteoporosis due to lack of weight bearing. With further basic research needed in this area, women with disabilities are being denied the potentially beneficial effects of new developments in low-dose oral contraceptives such as prevention of ovarian and endometrial cancer and decreasing blood cholesterol levels. Abuses of women with disabilities have been linked to the unsafe promotion of new contraceptive devices such as Norplant or Depo-Provera. Little is known about the effective use of barrier methods of contraception by women with disabilities beyond the obvious limitations of use for some women with physical disabilities.

For many women with disabilities forced contraception can become a means of denying basic reproductive rights. For women with intellectual disability it has been established that sterilisation is often sought by families as a means of contraception (Family Law Council 1994). This is often justified on the basis that although the girl or woman may not even be thought to be able to choose to enter into a sexual relationship, her vulnerability to sexual assault makes pregnancy a possibility. This issue is obviously not one of contraception but of the rights of women with intellectual disabilities to live in a safe environment free from the threat of sexual violence. Additionally, parents seek sterilisation as a form of contraception on the grounds that if their daughter were to become pregnant she would not be able to understand or to care for a child. Again this issue is not one of contraception but a social issue. Also important is the misguided belief that disabled women will produce disabled children which goes to the core of our values as a society in which disability is seen as an unmitigated tragedy.

5.5.2. Menstrual Management

There have been few investigations in this area. One study into menstrual management issues for women with physical disabilities, who receive assistance with menstrual tasks, related to the lack of information available to staff who were assisting them (Duffy 1981). Others have noted inadequacies in professional literature and training in menstrual management for women with intellectual disability (Brantlinger, 1992; and Elkins et al, 1897).

Within the medical literature there appears to be an assumption that menstruation for women with intellectual disabilities is a problem that should be overcome by menstrual suppression or elimination of the cycle. Carlson & Wilson (1994), in looking at menstrual management issues for women with intellectual disability noted that frequent access to medical advice and an apparent lack of access to advice about educational and environmental management approaches and to practical support, may be reinforcing a perception that managing menstruation is a medical matter. At the same time there have been no long-term studies into the health effects of surgical elimination or long-term hormonal suppression of menstruation on young women although risk factors such as dysfunction of the ovaries and the cardiovascular system have been identified.

Importantly, this issue is one often cited by parents and medical professionals as a reason to sterilise. The literature suggests that there are many possibilities for teaching menstrual management skills to women and girls with intellectual disability which remain undeveloped and unexplored. The consequence of this failure to develop training and support services results in medical strategies where sterilisation appears to parents and carers as the only management option.

5.5.3. Sexually Transmitted Diseases

For sexually active women with disabilities, detection and treatment of sexually transmitted diseases (STDs) are important issues often neglected. Given that women with disabilities experience barriers in many areas of health service delivery, they are at greater risk of STDs. Women with physical or sensory impairments may have limited capacity for self-diagnosis. Conditions that may occur as a result of impairment can make diagnosis difficult, especially for untrained health care providers. Other barriers to effective diagnosis and treatment may include limited physical access to trained STD health professionals – women with disabilities may rely for transport on community services or family members to whom they may not want to disclose such a problem. The lack of accessible treatment rooms and equipment is also a barrier to effective treatment.

For some women with disabilities STDs may be an indication of an abusive sexual relationship. This requires specialist intervention and support services and the provision of safe spaces for women with disabilities in these situations to go. Most women's refuges do not cater to the needs of disabled women. Sex and protective behaviour education, especially for women with intellectual disability and support for safe-sex practices are a critical part of the picture, especially for women with disabilities who are living in institutions.

5.5.5. Pregnancy and Birth

Very little research has been conducted into the issues surrounding pregnancy and birth for women with disabilities. The research that does exist focuses on women with physical disabilities, particularly those with spinal cord injury. Women with disabilities have little confidence that there are health care professionals appropriately trained to deal with their specific needs throughout pregnancy, labour and delivery.

The attitudes of health service providers has been reported in the research literature to have a major impact on the experiences of women with disabilities during pregnancy and birth. Many professionals question the decision of a woman with a disability to become pregnant, making access to effective consultation about options for pregnancy, birth and parenting fraught for many women with disabilities. Potentially, for women with disabilities access to fertility treatment is affected by similar attitudes. Evidence also suggests that women with disabilities are more likely to be pressured into sterilisation procedures when presenting with complications during birth, often in contravention of the law (Rogers 1996).

Other issues that may arise for women with physical disabilities during pregnancy and birth centre on a lack of communication between and education of medical specialists in managing anaesthesia, circulatory, respiratory, urinary and neuromuscular problems and hormonal changes. For all women with disabilities, research suggests a higher incidence of caesarean section attributed to an unsubstantiated belief that this is inherently safer and easier for women with disabilities. Little is known about the recovery of women with disabilities from this procedure or from natural birth experiences. The lack of accessible medical equipment also presents problems for women with disabilities. Examination tables, scales, birthing stools and tables are generally not adaptable for use by women with disabilities.

5.5.6. Menopause

Little is known about the impact of disability on menopause. The risk of osteoporosis for women with long-term physical disabilities who have had many years of decreased weight bearing has been identified and menopause is known to compound this risk. Little research has been undertaken into the risks and benefits for bone density and cardiovascular health from hormone replacement therapies for these women and others with chronic illnesses.

Similarly, the lack of research examining the interaction of sterilisation and menopause, particularly for those women who had hysterectomy prior to beginning menstruation, suggests that women have no way of knowing when they are undergoing menopause. Research on non-disabled women has found there may be major health effects, including early onset menopause, osteoporosis, cardiovascular disease and thyroid dysfunction as a result of sterilisation.

5.5.7. Abortion

The impact of prenatal testing and selective abortion on the reproductive rights of women with disabilities is complex. The reproductive rights movement has argued for the right of women to choose whether or not to continue with a pregnancy. On the other hand, the aim of the disability rights movement is to establish the same rights for disabled women – particularly the right to continue with a pregnancy (Saxton, 1999). The mounting pressure in contemporary society on women to undergo prenatal testing is intensified for women with disabilities, due to the often erroneous assumption that disabled women produce disabled children. Disabled women have the right to bear children and be mothers and all women have the right to *resist* prenatal diagnosis and abortion when the foetus is identified as potentially becoming a child with a disability.

In the Australian legislative context there is an issue of concern in the provisions of South Australia and the Northern Territory, specifically in relation to one of the criteria for the lawful performance of abortion – the opinion of two doctors that if born, the child would "suffer from such physical or mental abnormalities as to be seriously handicapped." Pringle (2001) argues that these provisions support government policies that view that life with disabilities as intrinsically less valuable than other lives.

Section Six: Report on the WWDA National Forum on Sterilisation and Reproductive Health for Women and Girls with Disabilities

Sydney 15 February 2001

6.1. Background

In mid 2000, Women With Disabilities Australia (WWDA) applied for, and received project funding from the Commonwealth Office of the Status of Women, to conduct a National Project on the issue of Sterilisation and Reproductive Health of Women and Girls with Disabilities. This National Project comprised two main components: a background research phase to examine international and national developments (discussed earlier in this report); and a National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities – to provide women and girls with disabilities a safe and secure environment to speak out about their experiences.

6.1.1. Process

A Project Officer (Ms Leanne Dowse) was employed by WWDA to co-ordinate the Project. A Steering Committee, made up of women with disabilities, was established to oversee the Project. The Project was advertised and promoted through a range of mechanisms which included:

- email and electronic discussion forums;
- articles in newsletters and journals;
- development of fliers and newsletters;
- phone calls, word of mouth, TTY;
- existing networks already established by WWDA.

Materials advertising and explaining the Project were developed in Plain English format and widely distributed. An Expression of Interest Form was developed, and a more detailed Application Process was developed once WWDA established the level of interest in the project. There was a high level of interest in the Forum, from women with disabilities; service providers; researchers; policy makers; and more (a copy of the Expression of Interest Forms is provided in Appendices 5 and 6).

Due to the high level of interest in the Forum by a wide range of key stakeholders, WWDA decided to conduct two Forums – one for women with disabilities, and one for other key stakeholders. The 'Special Interest Group on Sterilisation and Reproductive Health for Women and Girls with Disabilities' was conducted during the International Disability with Attitude Conference and was facilitated by Susan Halliday, Federal Sex Discrimination Commissioner (and previous Acting Disability Discrimination Commissioner). Over 60 academics, government policy advisers, service providers, disability advocates and people with disabilities who have an interest in the area, together with women with disabilities who have been affected by sterilisation and reproductive health issues attended the Special Interest Group Forum (the proceedings from the Special Interest Group Forum are provided later in this Report).

Sixteen women with disabilities attended the National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities in Sydney. Women with intellectual, cognitive, physical, and sensory disabilities were represented at the Forum. The Forum also included representation of women with disabilities from Non-English speaking background; indigenous background, and rural/remote locations. Most States and Territories were represented at the Forum, including a representative from New Zealand. The women with disabilities attending the Forum ranged from 18 years of age onwards.

An enormous amount of planning and organising went into the National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities. The Project Officer and the Forum facilitator worked with each woman on a one to one basis prior to the Forum. A number of support structures were put in place prior, during and after the Forum. On site counselling services were made available, as was attendant care and other support workers. All access requirements of each woman were addressed on an individual basis.

More detail about the planning and organising of the Forum is provided in Appendix 3.

A Guide to Planning and Organising an Accessible Workshop for Women with Disabilities is also provided in Appendix 4.

6.1.2. Purposes of the Forum

The purposes of the National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities were:

- to provide a safe, supportive and inclusive environment for women with disabilities to speak out about their experiences of sterilisation and reproductive health issues;
- to name the impacts of sterilisation on women with disabilities;
- to identify specific issues in reproductive health for women with disabilities;
- to identify future actions and outcomes and supports for women with disabilities in relation to sterilisation and reproductive health;
- to further support forum participants as delegates to the Disability with Attitude Conference, as representatives of WWDA and particularly in relation to conference content around sterilisation and reproductive issues (ie Prof Adrienne Asch's keynote address, related paper presentations and Special Interest Group Meeting.)

6.1.3. The Forum Program

The Program for the National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities was determined by the Forum facilitator, the Project Steering Committee, and women with disabilities participating in the Forum.

The Program included:

- welcome by WWDA President;
- establishment of a Group Agreement;
- identification of the expectations of participants;
- identification of issues in groups;
- actions for the future;
- questions and comments from participants;
- closing comments – by Professor Adrienne Asch;
- review.

The Program for the Forum was structured to ensure that participants had sufficient breaks and opportunities to debrief where necessary.

6.2. The National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities Forum Proceedings

Welcome by WWDA President – Keran Howe

"I'd like to warmly welcome everyone who has come to the National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities today. This forum is a first for WWDA and a first for all women with disabilities in Australia – an opportunity for women with disabilities who have experienced or are concerned with sterilisation and reproductive health issues to come together. It's an important occasion during which we can start to talk about the issues that need to be addressed for women with disabilities. We need to acknowledge those who have been sterilised and talk about what we want to do to make sure it doesn't happen to others. WWDA is committed to the process we are beginning today. We will ensure that we report and represent what comes out of today and work hard to make sure that changes are made."

6.2.1. Group Agreement

Those present at the Forum agreed to the following:

"We will observe confidentiality – no one will be identified beyond the forum."

"We will not tell others what we say and what we hear others say in a way that they can be identified."

"We will respect individual zones – each person can say as little or as much as they feel they can."

"One person will talk at a time and the others will listen to them."

"We make a commitment to the outcomes of the Forum – we will each do as much as we can to make sure that what comes out of the forum."

"No one will use jargon or big words when they are talking so that everyone can understand what is being said."

"Everyone will speak up when they are talking so that all participants can hear what is being said."

"We will take care of ourselves and support each other to say the things we feel able to say."

"We will give all participants the time they need to express the things they want to say."

6.2.2. Participant Expectations

Participants spent some time sharing with others their expectations for the Forum by responding to the following question:

The main thing I want to get out of today is…

"That the experiences of women with disabilities who have been sterilised or who have their reproductive rights infringed be acknowledged and recognised."

"That we talk about women's stories and not just about what Doctors, Lawyers, Governments, carers and others think about what should happen."

"That everyone at the forum have the chance to have their voices heard."

"That we all have the chance to learn about people's experiences of sterilisation."

"That we are able to talk to other women with disabilities about their experiences and we can each talk about our own experiences."

"That we can come up with some ideas about how to stop sterilisation of all people."

"That we can get used to talking about these difficult things with other people being around."

"That we can share our stories and help each other to tell them."

"That by telling about the things that have happened to us we can begin a process that will give us our freedom."

In the review session at the end of the Forum participants identified that all these expectations had been met.

6.2.3. Small Group Discussion: Session One

The participants broke into small groups of four, each group with its own facilitator/scribe to discuss their responses to the following statement:

What impact can sterilisation have on women with disabilities.....

Loss of Identity

"For me it has meant a denial of my womanhood."

"It has resulted in loss of my identity as a woman, as a sexual being."

"I have been denied the same joys and aspirations as other women."

"The psychological effects are huge – it takes away your feelings of womanhood."

Experience of Powerlessness

"Women with intellectual disability don't always understand what sterilisation means until later after it has happened to them and later will be too late."

"I have always had a fear of speaking out about it – it's been very isolating."

"I want to help others who don't have a voice, to stop it happening to them – I feel powerless to do that."

"I have been raped."

Cultural Impacts

"Because I will not go through obvious menopause, in my culture that means I have no marker for becoming an 'elder'."

"It is a basic disrespect of our beliefs in how we should live our lives."

Health Effects

“Because I have had important parts of my body taken away it is hard to find out what is really going on in my body.”

“I worry about the future health effects like osteoporosis and other problems.”

“I will have no way of knowing about the onset of my menopause.”

“I know it has resulted in hormone changes in my body that wouldn’t have happened otherwise.”

Effects on Relationships

“It can lead to the break up of relationships.”

“Women who have been sterilised may fear rejection by their partner.”

“Other people don’t understand what it means in your life and it’s very hard to explain that to people.”

“It stops women from having children if they want to.”

“Other women don’t understand what its like for us – it sets us apart from them.”

Lack of choice

“For many women it’s about other people making your choices for you.”

“It is taking away a woman’s right to choose how she wants her life to be.”

“It means you are locked into one form of contraception – you can’t make a choice.”

Loss

“It can bring on early menopause, a loss of the normal things that happen in life.”

“For me it is about living with loss.”

“It really affects my self esteem.”

“It has stopped me having a normal life.”

“Its about loss of control.”

“For me it has meant a loss of trust – especially of doctors – those who women with disabilities often have to place their trust.”

“You miss having periods.”

Feelings

“I feel anger.”

“I have a blockage of emotions.”

“It’s a great emotional upheaval.”

“I feel alone and isolated.”

“The pain is hard to bear.”

“I have a fear of not being seen as a sexual identity – of sexual rejection.”

“I have feelings of rejection.”

Lack of services

“There is no information available for us.”

“The fact that services are not there is no reason for sterilisation.”

“There are not enough services or people to listen.”

6.2.4. Small Group Discussion: Session Two

The participants broke into small groups of four, each group with its own facilitator/scribe to discuss their responses to the following statement:

What changes need to happen for women with disabilities to have a better experience ...

Information

“There needs to be better explanations for women.”

“We need to be given more information about our body.”

“We need to have information about the whole process and what it means so that we can make an informed choice.”

“We need to build a data base on health issues specifically for women who have been sterilised.”

Self Determination

“It time people started to listen! And do what we want.”

“It’s absolutely necessary to empower women with disabilities to make decisions.”

“Let us be in charge of our own bodies.”

“Women with disabilities need to have more involvement in the investigation stage so we can say what we want.”

Support

“We need to start support groups for women who this has happened to.”

“We have to encourage self-advocacy – help women with intellectual disability to say what they want in their lives.”

“We have to provide individuals with proper support to make the right decision for them.”

Education

“Educate professionals especially doctors and support workers so that they understand how it can affect our lives.”

“We must change doctors’ attitudes.”

“It is important that we educate the appropriate people to listen to women with disabilities in the investigation process.”

“We need to see a change in attitude.”

“We have to publicise the issue through public seminars and debates.”

“We must help services listen better to the issues for women with disabilities.”

“We need to educate all the services that have a role to play in making this happen.”

“We need to educate the community, to get them to see it is about the lives of women with disabilities.”

“We need to be changing education at all levels.”

Give us a Voice

“We have to break the silence about what has happened.”

“We must make sure the voices of women with disabilities are heard at international and UN conventions.”

Lobby Governments

“We have to change the law so that it stops happening.”

“We need to send a message to politicians that sterilisation is about women with disabilities and how they live their lives.”

6.2.5. Small Group Discussion: Session Three

The participants broke into small groups of four, each group with its own facilitator/scribe to discuss their responses to the following statement:

What needs to stop happening …

"Don't ignore what we have been going through."

"Don't think you know what a woman who is sterilised is thinking."

"Stop dictating to us about our lives."

"No forced sterilisation."

"Don't treat us like children."

"Don't push parents into sterilisation."

"Stop it happening."

"Stop other people making our choices."

"Stop doing sterilisations without people's permission."

"Don't assume health professionals know what is best for women."

6.2.6. Forum Evaluation

The participants responded to the following statement:

One thing about today for me...

“It’s been a great start to even better things to come – change can happen.”

“Great!”

“It’s been the start of real friendship for me.”

“Excellent.”

“Its made me realise I would like to help other women in this situation too.”

“Meeting other people who have had similar experiences was good.”

“It’s been very fulfilling.”

“I learnt a lot.”

“I would like to help promote the issue further.”

“Meeting new people was great.”

“It hasn’t been long enough.”

“It has been very empowering and I now have feelings of hope for the future.”

“It’s really helped my understanding of the issues.”

“It has been very good: I learnt a lot and met new people.”

“I feel I got out what I wanted to say.”

“In terms of the process – the facilitators have been really wonderful.”

“I learned a lot, I would like to help other women too.”

“I want to see some follow up.”

“Mixed feelings – I feel stuck. I don’t know how this is going to help other people.”

I feel moved.

“It was fantastic having our opinion heard.”

“It’s been very valuable.”

“I learned a lot and would like to learn more.”

“I felt happy about what was being said.”

“It’s the beginning of peace for me.”

“We should set up a buddy system so that we can continue to help and support each other.”

6.2.6. A Final Word from the Women

“We need to understand that there are two issues:

- **women who have already been sterilised; and**
- **how to stop it happening to others.**

We need to remember that there are many women in institutions with high support needs that don’t have a voice and can’t speak out like the women here at the Forum. Often these women don’t know they have been sterilised. How are we going to support these women?”

6.3. Women's Personal Stories

Several women with disabilities attending the Forum offered to tell their personal stories. These stories are reproduced here, with the women's consent. Names have been changed.

"A Journey to Hell and Back" – Mary's Story

1973 1st Hell

"In 1973 my parents checked into things, regarding periods and child birth. I was 12 at the time and had never had a period. Some months leading up to the operation in 1973, there were few talks about the fears of me dying if I became pregnant. As I was 12, and many of my friends were dying from other conditions, this scared the hell out of me.

I wasn't aware of the full implications of what was to follow – the first hysterectomy. I knew I was going into hospital, but had no idea why. I have no memory of the operation or the days in hospital – other than being on edge. When I came home from hospital I still had little idea what had happened, only that I was no longer able to have kids. Other than a sore stomach I just didn't understand the implications of things. I had no counselling.

1975 – "Fred"

In the middle of 1975 during a stay on the school hospital ward I overheard girls in the ward speak of Fred. I figured Fred was a new boy. I asked of him, saying I hadn't seen a new boy at school. The girls laughed at me, and poked fun. He wasn't a boy; they were talking of their periods. Without knowing it, I went into deep depression. I became very silent. From then on I stuck to myself, and haven't since felt comfortable with girls or women of any ages, for fear of being laughed at.

1977 2nd Hell

March 1977, I went to the toilet. I wiped myself as normal and saw thick dark blood. I didn't feel sick at all, no pain or anything that could have shown what was to happen. Since then I look at the toilet paper each time I wipe for fear of blood.

I was admitted to hospital again. I was more terrified this time. I knew more (to a point) of what was happening. Something had gone wrong in 1973 and my hell was to start over again. After my parents left the hospital a nurse came to me and asked me to sign a form. She said my parents had forgotten one and I had to do so otherwise the operation wouldn't take place. I recall asking her if it was OK, knowing I had just turned 16, that it wasn't legal for a person my age to sign papers. She stated it was OK and I had to. With nerves shot and in pain emotionally, I signed. For years I thought if I hadn't signed the papers the operation wouldn't have happened. I now realise there was no other option to have an internal examination, but I still blame myself for signing the papers.

After this operation I was an emotional wreck. I felt ashamed of what happened and had no idea who to turn to or what to do. I hid all that had happened to me. When I was about 25 it dawned on me that I had run away from anything to do with girls and did all I could to skirt around the subject they would bring up regarding periods. In truth I am amazed looking back that it wasn't picked up and that I wasn't spoken to about keeping to myself. But no one came up to me, nor was I given any sort of emotional help in any way.

1984 – Work

I started working in September 1984. I realised a few months after working I hated being with women, and my self-respect on realising this, went down badly. I realised then that due to the hell I had gone through myself esteem was bad all those years. I went through stages of reflection of my past at school with the other girls,"Fred," and many other things. From then to this day I don't mix with women unless men are there. From the time I started working until now it's a daily struggle coping with just women. My social life is restricted, as I also realised that if I"hang" around just men my name would not be good, thus I started keeping to myself.

1986 – Wig

In 1979 when 18 my hair, which had in the past been very thick, started thinning just as a man's does. By 1986 when 25 it was receding. My mum suggested getting a wig – I jumped at it. The man fitting me for the wig said that it looked like I had problems with my hormones. I went into shock. No other women in my family have hair loss, men lost some in their 50s but not like this, women and men with my disability are not more prone to hair loss than others. The only thing that makes me different is having my womb and cervix taken from me at 12 and 16.

1989-90 – An Understanding Doctor

By 1989 I knew that my womb and cervix had been taken from me, and somehow the womb grew back. At this time I met a doctor who really listened to me. From the first time I met this doctor he's been giving me more and more confidence and assistance in understanding what happened. Since then until now I have spent time carefully getting information.

1999 – Menopause scare and rebirth

I have regular bone scan and blood tests to determine whether I am in menopause. Waiting for the test results is always traumatic but in 1999 the results suggested I may have been in menopause. I have no other way of knowing – I've never had a period, the idea of being unable to even feel menopause start was driving me crazy. The results eventually showed I was not in menopause but it was a terrible time.

At this time I was also diagnosed with PTSD (Post Traumatic Stress Disorder), and referred to a psychologist. I recall looking at the GP in disbelief. After years of thinking I was nuts, and begging for help, years of hell, at last I was being believed in. The psychologist helped to answer why I felt I was living in three time zones, 12, 16, and what ever age I'm at the time, why information doesn't sink in, fear of being around women. All I had been feeling wasn't in my mind, but normal given the hell I've gone through.

2001 – Women With Disabilities Australia (WWDA) Forum

I heard about a forum that Women With Disabilities Australia (WWDA) were running about Sterilisation and Reproductive Rights of Women With Disabilities. I was accepted to attend but as the time got closer, it dawned on me that for 36 hours straight I would be with women and women only, discussing something that I had wanted to talk about for years but also to run away from. I was excited and terrified.

The Forum was more than I thought it would be. I wasn't alone. I had people looking after me, just for the hell I went through and for no other reason. I did a lot of reflection on how I had coped since 1973 and am amazed that I am still alive. The effect of going to the Forum was beyond words. I'm just over the moon. I feel stronger than I've ever felt.

Conclusion

From my own reflection of life, hearing other women speak up, and from my research I've learnt many things. All women I've met and have read of, or seen on TV, have not come out of this without either physical health problems or emotional health problems. We are all in truth gravely ill, and I use those words on purpose. Yet we have no medical assistance of any kind, the people who did the crime are not paying the time, and they have co-offenders – people who won't help us. We who have gone through this hell, have had no choice. It's a form of rape in the worst way.

The issues it raises are almost beyond words. The medical world use the excuse in many cases of coping with periods. In truth it's the case that they fear us passing on a condition and this is a quick, cheap and easy way out. We are not wanted in society, and this is a way to ensure we don't bring forth others. Preventing us from being born, and causing our death before we are given life. It's society's way of saying we aren't wanted."

"Realisation" – Jackie's Story

"I was fortunate to be accepted as part of a group of women to attend a forum on the sterilisation of disabled women in Australia in February 2001. Being the only non-Australian I did wonder what experiences I had that would be of benefit to this discussion, however I had my own reasons for attending and I didn't realise how relevant these experiences were until I began to hear and feel the experiences of others.

In 1993 I had a hysterectomy after an exploratory operation to try and explain some pain I was having. The surgery showed the womb to be normal, yet they removed it. I had little self-esteem at that point. I was facing a progressive disability and I had also to deal with being in a violent relationship at that time. I pushed this experience to the back of my mind until the afternoon when I sat in this Sydney hotel and began to hear the stories of other women and began to realise, I had also been sterilised. I began to realise I had also not been given the information I should have, or the chance to grieve the loss of a part of me that should have been mine to choose whether I keep or not.

In New Zealand, little is said or discussed on this issue, in fact, I do not recall any discussion of this in the disabled women's networks I know exist here. I know it exists, I know children are sterilised to prevent them facing menstruation as young women and to reduce the workload for their carers and parents. I know women have been lied to and told they were having other surgery when in fact they are being sterilised.

I was impressed at the advocacy support for the women with intellectual disabilities at the Forum and have never seen such wonderful support of women by women at such an intense level. I came to meet some intellectually disabled women who impressed me with their determination and strength as they also had to come to terms with the things that had been done to them. What distressed me was how much control doctors and carers have had in these women's histories and how little is done today to remove these controls and to encourage disabled women to live independent and empowered as they choose to live and not as others choose for them.

I have been left to wonder where to from here, and coming back to New Zealand I have a sense of isolation and a removal from the support I felt with such intensity at this Sterilisation Forum in that one afternoon. Women there who had assumed names, who were afraid to be too open in case it impacts on their lives they have made for themselves now speaking out of the pain and loss they have felt. There were women there who have seen the impact on their whole family, facing their pain not just at this Forum but also at the conference that followed.

I left realising I am in a position many women in our communities with disabilities are not in. I have educated myself, despite the discrimination doing so. I have a voice many do not have and I am independent and empowered. I can speak out on this issue and raise their voices in the community. I am however, left to ask myself how."

"Being the Woman I Am" – Helen's Story

"It has been 4 years and 4 months – I was 23 years of age. I learned I was pregnant to my husband of just over a year.

I sat in the doctor's office in disbelief and total dread. This was something we had been trying to prevent. Despite 'expert' doctors telling me I would never get pregnant, I somehow knew that they were wrong. They were wrong that I would never get a cycle, so how could they definitely say I wouldn't get pregnant?

For the past 2 years, we had been trying to find a suitable contraception. This wasn't easy – my disability meant that I was of an extremely low body weight for my age – contraceptive pills weren't designed for women my size. We had experimented with some pills that just gave horrific side-effects. We used condoms – but this was definitely unsatisfactory on a long term basis, and had side-effects of their own. Eventually, in frustration, we resorted to using "safe" methods – but it went wrong.

Now I was pregnant

As I sat in the doctor's office, trying to understand, I didn't blame her – but I wanted to tell all those other (male) 'experts' that had been consulted 'I told you so!' Our doctor had done her best to find what she could for us, but they kept telling her it was an unnecessary concern. But they were wrong.

Now what?

As we sat in the doctor's office, we knew it wouldn't be kept. It would be impossible. All my life, I was told my disability meant it would be life-threatening to try and carry a baby to term – I was too small, and I wouldn't have the physical strength to cope with the stress on my body. I would have to abort it.

But how?

As we sat in the doctor's office, we were told what arrangements would be made if my body didn't self-abort. There wasn't much time – decisions had to be made now.

My body didn't self-abort, so I went to hospital for a 'procedure.' I was told everything would be OK after that. They were wrong.

Suddenly things were different. How could I kill that baby? I want to be a mother – a mother to our baby. Why doesn't anyone understand? Why am I jealous of pregnant friends? I never wanted kids; I chose to terminate; why hasn't my life moved on? I'm drowning; I need help; I feel better today – I don't need help; I'm drowning again. Maybe they were wrong about my chances of surviving pregnancy – they were wrong about everything else. Maybe my body didn't self-terminate because it didn't need to?

We continued the search for effective contraception. My biggest fear was having to go through all that again – am I safe? Will this pill work? I was told 'There's only one way to find out' – I guess I can't expect anything more from a male 'expert.'

Two years of excruciating pain. The only release was through finding Jesus.

Now I am 27 – still married; still childless – but safe, and at peace with the past. Someday I want to be a mother to our child – when we are both ready. Our doctor will support us when the time comes. Having that choice is part of being the woman I am."

"The Birthday Present" – Louise's Story

"I had the operation so that I won't have children. It was Mum's idea because at that time she reckons I couldn't handle the children that probably would have turned out like I am. Because I am backward, they think they'll turn out like I am and they didn't want me to have children. It was on my 18th birthday that I had the operation. We went to the specialist, it was his idea to get it done. He was talking to Mum, I had to go in and do some therapy with Mum to see how my reflexes were. That's when they knew I couldn't handle children. They tried me on the pill, it didn't work because I was sick all the time with it.

All I know is that I was doing work experience at that time and I was at school. I was on my way back down to school. I saw my father out the front, thought something was strange. It was about 12.30 and he didn't usually come at that time. I didn't know anything about it until then. I went home and I had to pack my bag and they told me I was going to have an operation. I was a bit frightened. I saw the doctor just before I went into the theatre that afternoon. I didn't know the doctor. I went in on my birthday.

I didn't really understand what was going on at that stage. It was after I had it done, when I came out of hospital, that they told me that I couldn't have children. I had my tubes tied and burnt. I felt upset that I couldn't have children. It was a big shock. I've told my boyfriends about it. They get a bit upset because I can't have them but they have been pretty good. I don't really have anyone else to talk to about it. I have talked with a couple of other people about it. They have kept it to themselves.

I keep on asking Mum about it. She talked to me about it a couple of times but lately she hasn't. She wants to let it drop. At the time I wanted to talk about it more but I am getting used to it being like I am now. I sometimes get upset about it when I talk to her about it. I get upset mainly because Mum made the decision for me. At the time I feel I would have been able to make a decision. If they came and asked me I would have told them. I would have said yes. I think they should have asked me. They should ask other people too. I think other people with learning difficulties would be able to understand what it means. They should have a talk with the person first before they talk with the parents. If they did it by pictures it would be good. I think it should be up to the person to make their own mind up."

"A Mother's Tale" – Georgina's Story

"I've lived through some terrible times in my life. When I married my first husband I couldn't go to work and be married and disabled – it was physically too much for me. By the time I had my first baby my husband and I were back living with my mother. We employed a maid to look after the baby. I was 21 and I was really sick and my husband didn't know what to do.

I had two caesareans. Two babies four years apart. My first husband took us to New Guinea and when we got there he took up with another woman. He left us alone and didn't look after us. The children had second class food. The baby used to cry all the time; it used to keep the neighbours awake. It cried because he wouldn't buy it a cot to sleep in and it was tired all the time. After my second baby my marriage broke up. I think my husband couldn't cope with my disability and the babies. He couldn't cope with a modern woman.

I got sick and I thought I was going to die and so I brought the children back to live with my mother because I thought they would be well cared for when I died. My mother could never cope with my disability and wanted me out of her life. She always told me what a terrible person I was – all my life.

She was threatening the kids horribly and she was employing live-in maids who were too old to look after the kids. They used to treat the poor little kids terrible. There weren't any services or social workers around in those days. I tried to take the children away from home. I needed to get them away. I didn't care about me, I needed to get them away. One night I took them away – I only stayed away for about an hour. I didn't know where we were going to go, I just know I had to get them away. But I had to come back because they were so scared. It was a very bad experience and they'd had so many bad experiences.

After this my mother took out a court order for interim custody – on the grounds that I was an unfit mother because of my disability. I couldn't go to court because there was no one to take me. It made me feel very angry. We had the welfare involved and they knew what was happening but their hands were tied. What could they have done? She was a powerful business woman. The welfare department was dying to take the kids away because they knew the kids were being psychologically damaged but they didn't have a mark on them so there was nothing they could do. No one asked me anything about what I wanted or thought should happen.

After my mother got custody of the children, she decided to put me in a nursing home. I was very lucky because no beds became available for two years. Then a temporary bed became available. I was also lucky after I got in there because the management changed and they decided to change the nursing home from one for elderly people to one for people with disabilities. I met my second husband in there and we moved out several years later in to a group home and then into our own house.

My mother didn't bring the children to see me there. My son came on his own on his bicycle and by that stage he was a big strong boy and she was 75 and couldn't stop him. But she didn't let my daughter come to see me. I have tried to explain it to them but they don't want to accept it. They don't want to talk about it. I try but they don't want to and they are adults and they can make their own decisions. I think they are still suffering."

6.4. Report on Sterilisation and Reproductive Health for Women and Girls with Disabilities – Special Interest Group Forum

The WWDA National Forum on Sterilisation and Reproductive Health was held as an adjunct to the Disability with Attitude Conference. At the conference a Special Interest Group Meeting was convened for interested delegates to come together to discuss future directions and strategies for action on the issue. Sixty academics, government policy advisers, service providers, disability advocates and people with disabilities who have an interest in the area, together with women with disabilities who have been affected by sterilisation and reproductive health issues attended. The Special Interest Group was facilitated by Susan Halliday, Federal Sex Discrimination Commissioner, (and previous Acting Disability Discrimination Commissioner), Human Rights and Equal Opportunity Commission.

Helen Meekosha, WWDA Vice President welcomed participants, saying that in view of the level of interest the WWDA National Forum on Sterilisation and Reproductive Health of Women and Girls with Disabilities had generated within the academic, professional and disability communities, the meeting was an opportunity to begin a process of collaboration between WWDA and other stakeholders to set an agenda for change in the issues of sterilisation, reproductive rights and parenting for women with disabilities. She said that the WWDA project was most importantly providing an opportunity for women to speak out, but would also examine the research literature and establish what is happening in other countries. She reaffirmed WWDA's commitment to speak out and lobby government, the medical profession and the legal profession and those working in human rights on behalf of women with disabilities.

> *One of the main thrusts at WWDA for a long time has been violence against women and this is another form of violence. As long as we continue to be funded we will be working on this issue.*

Susan Halliday (HREOC) addressed the meeting, acknowledging the work already started by the late Commissioner Elizabeth Hastings and stating HREOC's intention to re-ignite the debate by commissioning a further report as a follow up to the 1997 *"The Sterilisation of Young Women and Girls in Australia"* (This follow up report *"The Sterilisation of Girls and Young Women in Australia – Issues & Progress"* was released in April 2001). The Commission felt there had been an insufficient response to the original report, in particular in relation to the figures of official and unofficial sterilisations and from the government in respect of what action was taken after the report.

Commissioner Halliday commended WWDA on its staging of the National Forum in providing an opportunity for women to tell their stories while being protected and feeling safe. She pointed out that although there may be an expectation that WWDA should continue to fund activity in this area this would not be possible as WWDA is a small organisation and does not have the resources to do this.

> *This meeting is an opportunity to open the door to the other people – the medical practitioners, the academics, carers, advocates, supporters and governments who can help better educate the community, who can lobby the politicians, who can work with HREOC and with WWDA to see what they can do to progress the issue and ensure there are no further victims.*

Commissioner Halliday acknowledged that funding is a key issue but pointed out that the purpose of the meeting was to discuss the specific issues that needed to be addressed including:

- where do those women go now they have told their stories and what sort of support do they need?
- recognising there are stories told on behalf of others that were not represented at the Forum, some because they don't know they've been sterilised, others who don't understand the concept of sterilisation, others who are not in a position to attend and potential victims;
- understanding the personal impact for those women and the impact for the community if we don't start to manage the issues that came to the fore in the Forum;
- addressing the need to have better management strategies for when people breach the legislation;
- developing strategies to deal with the fact that people feel that the official processes are too hard or inappropriate and bring those people on board to understand why they are there and start respecting them.

6.4.1. Comments from the Audience

> "A way disabled people could understand is if we draw pictures and gave them books and information. I think that would help a great deal."

> "I am one of the people who is being talked about and I am taking a big risk on behalf of myself and my family in speaking up. I would like to know what is being done for us who have had this done twenty or thirty years ago? I don't have an intellectual disability and it was done before I started having a period. What research is being done to help us who were young children that went through this, and when we go through menopause? It can affect our health in the future. I think of this as my real disability – the physical one that you see isn't real – the one I had happen to me when I was 12 is the main one and I don't have anyone to turn to."

Commissioner Halliday responded to this comment by emphasising the need to understand the serious issues of risk and confidentiality:

> *We need spokespeople in positions such as mine or the head of WWDA who can speak out publicly and who bear no personal risk.*

"I think there are several different elements here that might need to be looked at in a process – on a personal level, yes I have been sterilised. On a level as an academic and as someone who is looking for a solution – setting up something like rape crisis centres of support network centres for women who have been sterilised to address the past issues and the issues of grief and healing. We need to look at taking on a process of where to from here. The report is one. One of the recommendations I would make is possibly setting up a board with disabled skilled people on that board, not professionals and medical people but skilled people, especially women, who will address the issues of sterilisation as requests for approval for sterilisation or other issues come in – so that it is not run by outsiders, but it is run by us, for us and about us. My next recommendation is that we take it internationally, UN Convention on disability rights. We currently have women's rights at that international level. These reports need to go internationally. At the national level I believe that proper legislation, hard law not soft law, needs to be made enforceable and accessible. Legal Aid needs to be available. From the outset there needs to be an accessible and affordable process. The ordinary person that is dealing with the personal level should be able to access help without getting frustrated at the legal world."

Commissioner Halliday responded by commenting that this gives us another argument as to why we should have signed the optional protocol as Australia, it would have been advantageous specifically in this area where there is no domestic legislation or means by which you can follow up injustice in this country in certain areas that we are dealing with now.

"Having worked with a lot of women with intellectual disabilities who have been sterilised I think it is vitally important that their parents and guardians are being educated about their child's sexuality as well. A lot of the people that I have worked with have very influential parents who are very good at telling their children that that is what they need and that there is no point going down the track of having relationships with other people. So I think the education of the parents of people with disabilities is incredibly important as well. I think that needs to be a government initiative but I also think you can have laws that cover issues but on the everyday level there still are people out there who find it incredibly difficult to understand that their sons or daughters who have disabilities are sexual beings. It needs to happen all the way down from government to parents being given the opportunity to attend seminars, forums to be able to ask questions."

“I think it is really important to acknowledge that we have heard about how complex disability is and how complex motherhood is and of any area of concern this is an area that transcends the medical, legal and intensely private. I think there is a real need for very strong alliances between research and activism and for support for people. If we do go for a legal response it is going to require incredibly courageous women and it is going to require an incredible amount of support for those women. What we need around this are some very strong alliances and some real clarity about what can we do and what are the kinds of responses do we need to do to get as far as we can with it. I think that in other countries there have been legal cases, there are class actions, women in Alberta who were wrongfully sterilised against their will – these are women who could give informed consent are now being compensated by the Province of Alberta to the tune of $80 million plus. We can’t lose sight of the fact that for every one of those women to go to court and tell their story, to stand up and be public about it cost them dearly and no amount of money can compensate for that cost. We have to take a public stand, we do need strong alliances, we need research, we need the data, we need to go to politicians and say “this is a reality, this is how many women we know about who have been lawfully sterilised, this is how many women who have been unlawfully sterilised.” It is an incredibly entrenched problem and it does go to deep attitudes in our society that women with disabilities don’t deserve to be mothers, they don’t even deserve to menstruate. It does go to the heart of those values. I am all for some very powerful alliances here – this is not something that any one of us can do on our own.”

Susan Halliday responded to this by stressing the importance of women’s groups, conservative, left, right, and religious, coming together. Women make up 55% of Australia’s population and are capable of enormous political impact.

Helen Meekosha took up this point by adding that women with disabilities are very poor and very isolated.

> *There is a limit to what the women who have spoken out and WWDA can do. We need women working in the health sector to speak out, women working as academics who can write and women professionals who can raise this as a human rights issue.*

Professor Adrienne Asch commented:

> *There are so many fronts on which we all have to work – I think the Forum on Thursday and this conversation today are incredibly important. Any way that the stories can get out, of what it has meant to women with the whole range of disabilities – physical, sensory, cognitive, emotional – who have been sterilised against their will. The world does need to know those stories to understand and women’s groups need to know those stories to understand why women with disabilities like other women need the choice*

to decide whether to become mothers. It is going to take courage and research and publicity, not necessarily of people's names but of people's stories to get people to understand. I think the problem is that the alliances with the mainstream women's movement have been very hard to make, especially around reproductive issues because there is so much stuff and sacredness about what it means and what an appropriate parent is. In America, and I suspect it is a little bit true here, a lot of the society that we live in has notions that children are possessions and that adults have rights to children. Children are possessions and they should be high quality and adults have rights to high quality possessions. I don't know that children are possessions and I don't know that parenthood is necessarily a right – we don't own children, we should be thinking about sterilisation and its aftermath in the context of what is good for children and what is an effective parent. I think we need to say as much about the capacities of women with disabilities to be good parents as we do to talk about how terrible it is that women have been deprived of their opportunities to be parents. I don't think we can just talk about the cruelty of that deprivation without communicating the capacity of women to make contributions to children in that way. There is too much hostility to disability. If we just talk deprivation people won't believe that we can be good parents – we have to get that word out. We shouldn't have to bear that burden of proof – but we do. It is not a happy comment but I think it is true.

"I have been to many conferences where we talk too much and nothing happens. I would like to see centres or somewhere that has information and support that women can go and get the information they need to make up their minds about whether they want to have children, if they don't want to have children. It is not up to doctors or professionals. We should set up support groups for parents with a disability, because when we are parents and have a disability then we are not fit for anything. I think if there were more services and more support, there would be less women having abortions. I want to see something happening in the Australian disability movement."

"I don't know what it is like to be sterilised and not be able to have a period and not be able to have children. I don't know what that's like but I do know what it is like for people who haven't got a voice and need so much a voice. What happens for people who don't have a voice – I am mainly talking about people who are in institutions. Is there any way for people who are in institutions to have someone to help them not be sterilised or people who live at home with their parents? They are the people I find where I work haven't got a voice. I find the suggestion to do a picture booklet a good one."

"We've obviously got a very big problem which requires a very big solution and we've got all sorts of institutional and structural issues that need to be identified and dealt with. I don't know that as a rights movement we have identified the platform on which we want to disaggregate and deal with each part of this issue. I think we need to get together and think through how we are going to address these."

"I was also sterilised and I wasn't ever told when I was getting it done. The specialist told mum about it but I didn't know I'd had it done until I was 18."

"I see a need to convene some kind of interagency of people who are working around this issue. Clearly WWDA doesn't have the resources to continue to drive it – also WWDA shouldn't. Organisations like mine – FPA Health – have a strong commitment to the sexual and reproductive rights of all women and we need to take some responsibility. I am volunteering us to at least take some responsibility for bringing together an interagency forum where we can work together."

Closing Comment From Susan Halliday

The last couple of days have put some incredible issues on the table and also bought to the fore some very brave people. I think we should be very grateful to you for taking the risk and we will adhere to the confidential nature of the discussion today.

I think what we do now have is a series of ideas, suggestions and some commitments to groups meeting across the different disciplines to move these issues forward. Mindful of the fact that WWDA is not in a position to fund it or to lead it necessarily but to be an expert group in consultation with. The research and work being done needs to be compiled and it needs be made public and we need a louder voice. We need to put a lot more work into encouraging other women to join with women with disabilities on this set of issues. I am sure WWDA will carry on its work. I think it is time to be lobbying long and hard and that is not just politicians, but also the Office of the Status of Women both Federally and in the States and your State Equal Opportunity Commissions. Never deny yourself access to any area where you might be able to have a say. Thank you for your input and I hope this is the beginning of a very successful endeavour.

6.5. National Reproductive Rights for Women With Disabilities Network

A major initiative of the sterilisation and reproductive health for women and girls with disabilities special interest group meeting at the Disability with Attitude Conference was the resolution that FPA Health NSW will convene an interagency group. Following is an outline of the network's membership and operating brief.

6.5.1. A Network Supporting Reproductive Rights for Women with Disabilities

> *It is about opening the door to other people who can help better educate the community, who can lobby the politicians, who can work with HREOC and WWDA to get it up and going.*
>
> (Susan Halliday, Sterilisation Special Interest Group)

It is proposed to establish a national Network consisting of service providers, women with disabilities and other interested individuals to progress reproductive rights issues for women with disabilities. This would include but not be limited to addressing the issue of forced sterilisation of women with disabilities.

This Network would be auspiced by FPA Health (formerly Family Planning NSW), which has a long history of advocating on sexual and reproductive rights for women with disabilities.

6.5.2. Network Membership

Membership will be open to individuals and organisations committed to the reproductive rights of women with disabilities. In the initial phase, priority will be given to ensuring that the following organisations/statutory bodies are represented:

- Human Rights and Equal Opportunity Commission;
- Office for the Status of Women;
- Women With Disabilities Australia;
- Guardianship Boards/Offices of the Public Advocate;
- Commonwealth Department of Health and Aged Care;
- The Royal College of Obstetricians and Gynaecologists;
- Family and Community Services;
- Law Reform Commission;
- Academics;

- Attorney-General's Department;
- FPA Health;
- National Council for Intellectual Disability.

In the long term it is hoped that the Network would also include members who are:

- academics/researchers;
- disability service providers;
- advocates;
- medical practitioners;
- community members;
- other individuals who support the reproductive rights of women with disabilities.

6.5.3. Network Objectives

The Network will meet regularly in order to:

- *maintain a database* of action being undertaken;
- *co-ordinate action* being taken on reproductive rights for women with disabilities, in order to minimise duplication and increase opportunities for partnerships;
- *identify gaps* in action being taken in this area.

The role of the Network will be primarily a co-ordination and linkages role.

6.5.4. Network Structure

The Network will meet quarterly, with the first meeting being convened within one month of the release of this Report. Options for effective national participation will be explored, and may include teleconferencing and video conferencing. FPA Health will seek funding for a Project Officer in the initial set-up phase of this Network.

The Network has the potential to establish sub-committees on particular topics of interest or relevance (eg developing a service model to provide information and support to women with disabilities to identify alternatives to sterilisation), and to advocate and/or progress these issues.

For further information on the Network please contact:

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6.6. The Elizabeth Hastings Memorial Address – *Sterilisation, Reproduction and Parenthood for Women and Girls with Disabilities*, by Professor Adrienne Asch

This Keynote Address was presented by Professor Adrienne Asch (Henry R. Luce Professor in Biology, Ethics and the Politics of Human Reproduction, Wellesley College, Massachusetts, USA.) and sponsored by Women With Disabilities Australia (WWDA) with support from the Pamela Denoon Trust. The Address was delivered to the International Conference – Disability with Attitude: Critical Issues 20 Years After International Year of Disabled People. (IYDP). Sydney, February 2001.

The world of family is very much influenced by public policy. It's also highly charged emotional terrain – disability in family, the situation of people with disabilities as parents or prospective parents, the situation with people with disabilities as potential children. Disability and family creates a situation somewhat different from other non-dominant groups. When we think of racial characteristics, or ethnicity or religion, we tend to think of those as parents pass them on to children. Children may reject their religion later, but parents provide that shaping influence. If you come from a Greek speaking home, you may chose to learn English and never speak Greek, but you are Greek in some sense. Those kinds of ethnicity or religious phenomena are passed down and we might reject them or decide how much of them to incorporate, but people with those characteristics usually share them with their families.

For people with disabilities, our situation is much more like those situations of Gays and Lesbians who don't necessarily grow up in families who share the characteristic of a non-dominant sexual orientation. It's not something people are born with, maybe they are predisposed by some genetic characteristic. It can emerge for people at different times in life, just as impairment can. It can change just as impairment can and just as impairment can, it can alienate us and our so called family of origin from us. We can be made to feel very different and estranged from those that we take or that we are told by society to take and expect as the sources of our deepest intimacy and understanding and empathy and refuge from the outside world.
The family as home.

For people with disabilities, family may not be home. Trying to get a grip on what disability really means, might turn the world upside down. I want to propose that if we are going to really figure out what it means for people with disabilities to be acceptable parents or to be acceptable children, we as society will have to get a grip on what it means to be a parent and what it means to be a child – what we expect out of those social roles. We know what a parent is – someone who produces or helps to produce, either by providing sperm or providing eggs or providing a uterus – a child. A child is a creature born of a parent. We know what a biological parent and a biological child are, but what we expect of biologic children and biologic parents is a social phenomenon and how disability fits into that is a social phenomenon.

Sterilisation tends to affect more women than it does men, but what I have to say does affect men. There are boys and men who are sterilised against their will, even if it isn't as frequent as there are girls and women sterilised against their will, but if I use female pronouns, men please forgive me, you've had it your way for many years.

If a woman with disability is tragic and helpless, how can we imagine that she can care for anyone else? If someone with a disability is tragic, why would anyone else with a disability want to be brought into the world? Let's start with the woman with a disability as a parent and the matter of sterilisation. There was a workshop two days ago, I attended part of it and I've talked with other people who attended all of it, about the power of that experience of women talking about sterilisation, much of it involuntary, much of it against their will, sometimes not even with their knowledge and absolutely not with their consent. Sterilisation imposed by institutions and institutional policies, sterilisation imposed by doctors, sterilisation insisted upon by parents for various reasons.

The woman with the disability would not be able to care for a child; the woman with a disability might have transmitted that disability to that child and that would be a terrible thing. The woman with a disability would not be able to continue to care for herself and would have a less good life than she was having if she became pregnant and had a child. The society was already spending so much on the woman with disability that how could it spend more on the woman with the disability and pick up the job that the woman with the disability wouldn't be able to do with raising the child.

When we talk about why women with disabilities and men are sterilised, usually the reasons are someone believes it's going to be bad for them to have children, it's going to be bad for their children to have people with disabilities as parents and it's going to be bad for society to deal not only with the disabled person, but with a disabled person and that person's children, either because those children will acquire disability or because the environment in the home will not be a suitable environment for a non-disabled child to grow up in.

Those are the reasons that are given. Sometimes they sound benign, but when sterilisation happens against the will of the person who is sterilised, it is an unequivocal moral wrong. It cannot be justified. When we heard the voices of women in the workshop the other day, they talked about the losses; the loss of choice, the loss of self determination, the loss of control over their lives, the loss of their sense of freedom, the loss of their sense of personal identity as sexual beings, fear of changes in their relationships. They were now different from other women. Other women were not sterilised, they were. Would their partners reject them? Would they find partners at all if they didn't have them and they had to tell their partners that they were sterile, infertile, wouldn't be able to have children? Loss of relationships with possible children, a sense of powerless. Betrayal by people they had wanted to trust.

There is no question that there is nothing good, nothing to be tolerated, about involuntary sterilisation. It is something that we all over the world must continue to fight. This workshop in Australia, the first time for many women to talk about this experience with one another, to be validated, to be heard, to be assured that their sense of betrayal and hurt and anger was an understandable, realistic response to a cruel thing that had been done. But as important as that is, that is the easy part of what we can say. No one, no right thinking person is going to object when we say it is unfair to sterilise people against their will, but then we have to go from there and ask two bigger questions.

- what is an appropriate process to help people to make a good decision about whether they want to be parents?
- what do we want, what do we expect, what does a society, and what does a culture in the 21st century want to expect parents to do for children?

Parents were expected to do one thing 500 years ago or a thousand years ago and some other things now. Many of us, many people all over the world, no matter who brought us up, can say that our parents at one or another time failed us. They didn't pay attention, they paid too much attention, they gave us another sibling or they didn't give us another sibling, they spent too much money on us or too little, they worked and they were never here to talk to us, they were home and they never left us alone – take your pick.

Any person over the age of ten I'm sure has a complaint about his or her parents. It does not matter who they were. It keeps the therapeutic business happy. Some people have real complaints, there is abuse, there is neglect, there is a failure of empathy that is not just temporary, but sometimes is very deep. What do we want of parents? Is there any reason to think that impairment is in the mix of what we want? How do we think about impairment in that mix of what we want? Are there ever situations where a particular set of physical conditions, biologic conditions interacting with a set of circumstances should or could make someone decide not to be a parent? We don't have good answers to that because all the legal protections we have to try to prevent involuntary sterilisation go to the question of the process of making the decision.

Let me give you an example of a difficult case, not one that I don't have an answer to or that we might not jointly get an answer to, but one that's important nonetheless to show just how complicated this is. A case that occurred in the State of Pennsylvania in the United States in the last 10 years. A woman of twenty-four, with what people considered significant cognitive and physical disabilities – epilepsy and developmental disability. Her epilepsy was controlled by medication, but this woman had seizures, roughly 50 seizures a year, even after medication. Some of the seizures lasted an hour or more, even with medication. She needed to be monitored, well at least according to the Court, many many times a day, hundreds of times a day, to make sure that she wasn't having a seizure. She had no expressive language, so she could not communicate that she was having a seizure. She had receptive language – she could understand a lot that was said to her, was an affectionate and mobile person, had relationships with warmth in them, but very little ability – that was ascertained by the court – to express her own wishes. Her mother petitioned the court so that she could live in a community residence, not in an institution, so that she could get a job, so that she could have friendships and live in a group home. She also petitioned the court for this woman to be sterilised.

The court made no attempt, as far as we can tell, to determine what this young woman's wishes were, what she understood about such concepts as sex, sexual intercourse, pregnancy, reproduction, parents, children. It also made no attempt to figure out what other kinds of contraception she might have been able to use. There were several medical reasons to believe that some kinds of contraception would be medically dangerous and might have hurt her. There was considerable fear that a pregnancy would have killed her, that her epilepsy and other physical disabilities were significantly of the sort that could have been compromised by pregnancy. No one believed that she could be a mother to a child if she became pregnant and then delivered a child. She required constant supervision herself. That is what was believed. Could she care for a child? It was believed that she could not. I don't know. We don't have the data to know whether that particular opinion was wrong. We do know that no attempt was made to get her wishes, her experience, her understanding.

The court did order the sterilisation and viewed it not as involuntary because it was ordered at the wishes of a parent and a guardian. Was it an involuntary sterilisation? Yes, I think it was. What would a process have been that would have been a fair process to make sure that her self-determination was taken into account. I think we know that people with very limited expressive ability, verbally, do express their wishes and their preferences. They run, they smile, people show delight in all kinds of things and aversion. We can break things down into plain English. With time, many complicated concepts can be expressed in ways that people of all sorts of ages and abilities can understand them and we know that in this situation, that wasn't done. What would it have taken to do that. I think we don't know. I think that is very hard work and most people and most institutions and most parents and most doctors are not taking the time, and I think we as women with disabilities and we as people with disabilities are going to have to define the process of what it would mean to break down those questions so that people with whatever limited or whatever difference in level of ability could be asked for their wishes. That's hard enough. Then we have to think about what it means to be a parent.

Suppose this young woman had been able to say after she understood what sterilisation meant, "no, I don't want to be sterilised." Maybe she wouldn't have used words, but she would have shaken her fist or she would have vigorously shaken her head or she would have run the other way. I don't know how she would have expressed herself, but she could have expressed herself. Suppose she said I want to be a mother, would she understand what it is to be a mother? Let's assume that it takes a village to raise a child and that any mother, no matter what the level of impairment or non-impairment needs or benefits from the support of a father, an aunt, of a grandmother, or an neighbour of an older sibling or of an older child who is a sibling to the new child, of a day care centre.

People don't raise children alone. If they do, they have a horrible time and so do their children. What services would be required for any of us with impairments to provide our child a safe, stimulating, nurturing environment. What is safe, what is stimulating, what is nurturing? How nurturing, how safe, how stimulating? Those are all things we must figure out, along with society and the culture in which we live. We don't have a consensus on that. We know that the sterilisations of women with disabilities occur in a context of women who are not sterilised having their children often taken away from them in custody disputes. In social welfare departments coming into peoples homes and saying "You use a wheelchair, how can you change a baby's diaper, how can you run after that toddler?" "You are deaf. How can you provide your child with ordinary language." "You are blind. How can you see that medication that your child is going to open, because only children can open child proof bottles of medication?"

Now, lots of those intrusive, noisy, rude, unfair questions are just that. They don't ask parents without so-called impairments if they can do those things. The burden of proof on women with disabilities to be mothers is often very high. It is the burden of proof on potential partners that we bear; it's the burden of proof with our families, it's a burden of proof with the State and it's unfair. It is a denial of equal protection. It is denial of reproductive liberty, and a denial of our family liberty, our liberty to be intimate, our liberty to have a full and deep and important, enriched relationships. We bear a horrible burden of proof to get people to understand that with persistence, with services, with support, we are most of us, many of us, quite capable if we wish, to be parents, to raise children. If we can't physically touch a child because of a mobility impairment, we have other ways of communicating with a child and showing love and showing interest. If we can't meet a child's smile by smiling exactly when the child smiles, we can cue or we can sing, or we can tickle or we can laugh or we can do some other thing to communicate love, to communicate interest.

If we can't physically run after a child, people who use motorised wheelchairs can go a lot faster than a lot of people who can walk. Some of the things that the so-called mother must do are things that have to be done but does a mother have to do them, or a father? If we use personal assistance services or readers or interpreters or job coaches to help us with certain activities because of our impairments, it may be that some of the activities involved in child raising can also be transferred at least in part to the assistance of others. The personal attendant who helps someone get up in the morning can also help a child get off to school or a little one get dressed, but at what point – and this is where I think we don't have answers because we have not really asked the questions in a concentrated way – at what point, what are the things that we really think are essential to being a parent, to being a mother or a father, to being the person of first resort and last resort for a child. Are there impairments that interact with their environment in such a way that parenthood will be difficult, might not be something that we want to propose or encourage. We can, I'm sure, think of plenty of unimpaired people who should not have been parents, but we also have to face as a movement, that that is a question we need to ask for ourselves.

I don't know that we have consensus in the society of what makes a good parent. I don't think we have consensus within our own community of women with disabilities or people with disabilities about how disability interacts with parenthood. I think we know what the horrible evils are, but there are lots of grey area cases where I think we don't know and I think that's what we have to do. There is research that is being done about how children adapt to the capacities of their parents. We all have to adapt to the capacities and failings of our parents and low and behold, the ten month old who is going to be picked up by a parent who uses a wheelchair has figured out how to help the mother or father who uses a wheelchair pick them up.

We do as a movement need to debate what are the things that we think that really count in being a parent and how does impairment affect those. It is a role reversal. Nobody expects people with disabilities to be parents because we can't take care of ourselves, that we can change. We can show that we are the ones in charge, not our two year olds.

If we are going to prevent involuntary sterilisation, we are going to have to make sure that we find processes and methods of communicating with people, so that people get to express their wishes and that they are asked questions in whatever way and however much time it takes so that peoples wishes get known. Then we have to think about what is the essence of parenthood that we want to stand up for all parents, for all children in society.

Now, let me say just a bit about the matter of disability and family and being disabled children. On the topic of prenatal testing and selective abortion – what does it mean now that we can test for various characteristics, spina bifida, Down syndrome, muscular dystrophy, haemophilia, sickle cell anaemia, cystic fibrosis and other things? Should prospective parents do those tests, should they prevent disability in their child if they can by aborting a foetus shown to have those traits? When it's justified, it's justified for the same reasons that sterilisation is justified. It's going to harm the child to be disabled, it's going to harm their family because it's going to be a burden to have a disabled child and it's going to cost the society money.

Now, whatever we think about the merits of abortion, whatever we think about the merits or the problems of impairment, I think we probably as a movement would agree that nobody should be telling the world it is immoral to bring children who will have disabilities into the world. It may be a choice that we want prospective parents to be able to make. They may want to take into account the costs, the financial costs, the burdens, whatever those emotional burdens are, the disappointments, the pain that children will go through, the physical pain, the psychic pain, the social isolation. But it is not something, anymore than sterilisation, that should be forced on women and men as grown ups or as disabled people in the world. Forced abortion, coerced abortion, pressured abortion by professionals should not be forced on prospective parents who might be happy to raise a child who will have a disability. It ís the same issue flipped around.

Is it OK for disabled people to be in the world and function in as many roles as they want, as we want? Yes, it's all right to be children, it's all right for us to be parents, it's all right for us to be partners. It's all right for us, not just to have those public things of jobs and homes and education, those are hard enough. But jobs and houses and education, no matter how wonderful they are, are limited in their depth of significance if they don't come with community and intimacy and love and acceptance and belonging. We may choose our families and they don't have to be from our blood; we may adopt or we may have friends as family, but we as people with disabilities need to feel that we belong in the world; that it is respectable and legitimate to be in the world, impairment or not, and that is something that the fight to get people to think prenatal testing and to forbid involuntary sterilisation is about.

It is a fight to say it is legitimate. It may not be spectacular to have our impairments. We don't have to celebrate them, we don't have to hate them. They are there, we may celebrate them if we wish. We don't have to celebrate them, but they are legitimate ways to live in the world. It is respectable to be a person with a disability and it is respectable to be a person with a disability and raise a child. It is respectable to be a person with a disability and to be the child of a parent who said yes I know there was prenatal testing, I didn't want it, I didn't care, I knew that I could raise and love and enjoy a child regardless of that impairment and yes I knew that impairment might cause a lot of physical pain, but it would be possible for my child to endure physical pain and get things out of life just as I get things out of life when I endure other kinds of pain. That's not a choice that anybody should be forced to make, but it is not a choice that people should be forced not to make and that is part of our movement as well.

I want to end this by saying, we need to assert our rights and needs for support and solidarity to be family members because without intimacy, I'm not sure it's worth living in this world.

Section Seven: WWDA National Forum on Sterilisation and Reproductive Health for Women and Girls with Disabilities – Project Recommendations

The right to bodily integrity and the right of a woman to make choices about her reproduction are enshrined in the United Nations Declaration on Human Rights. In Australia in the 21st century there are numbers of women and girls with disabilities who have been and are currently being denied their human rights to make informed choices about their bodies and their reproductive lives (Brady, Briton & Grover 2001).

Women with disabilities have spoken out at the first National Forum on Sterilisation and Reproductive Health about the impact of all these issues on their lives. They have spoken about sterilisation as a life sentence, the loss and betrayal and the health effects they can anticipate. Their message is to listen to women and learn from them so that healing can take place for those already affected and safeguards can be put in place to prevent others being denied their human rights.

There are a number of recommendations stemming from WWDA's National Project on Sterilisation and Reproductive Health for Women and Girls with Disabilities. The recommendations have been grouped under the following headings:

1. **Reconciliation**
2. **Co-ordinated Approach to Legislative and Policy Development**
3. **Information, Support and Service Models**
4. **Consent**
5. **Reproductive Health Care**
6. **Data Collection**
7. **Education.**

Project Recommendations

1. Reconciliation

1.1. The Federal Government act immediately to redress the human rights violations against women and girls with disabilities who have been sterilised without their consent. In the process of reconciliation, financial compensation and an official apology for discrimination should be provided.

1.2. The Commonwealth Department of Health & Aged Care, through the National Women's Health Program, act immediately to establish support and counselling for survivors of forced sterilisation. The establishment of any support and counselling services must be done in consultation with women with disabilities.

2. Co-ordinated Approach to Legislative and Policy Development

2.1. The Federal Attorney General's Department co-ordinate the establishment of a National Working Party to develop and implement a five year Action Plan based on the recommendations of this report, and the recommendations of the report by Brady, Briton & Grover (2001) *The Sterilisation of Girls and Young Women in Australia – Issues & Progress.* The National Working Party should encompass membership which demonstrates a whole-of-government approach. Membership should include representatives from:

- Women With Disabilities Australia (WWDA);
- National Women's Justice Coalition (NWJC);
- Commonwealth Office of the Status of Women (OSW);
- FPA Health NSW;
- Aboriginal & Torres Strait Islander Commission (ATSIC);
- National Ethnic Disability Alliance (NEDA);
- Federal Attorney General's Department;
- Human Rights and Equal Opportunity Commission (HREOC);
- Commonwealth Department of Health & Aged Care;
- Commonwealth Department of Family & Community Services (FACS);
- Commonwealth Department of Education, Training & Youth Affairs (DETYA);
- Australian Medical Association (AMA);
- Royal College of Obstetricians and Gynaecologists;
- Royal Australian College of General Practice (RACGP);
- Law Society of Australia (or a nominated legal representative);
- National Reproductive Rights for Women with Disabilities Network (as described in this report).

2.2. This National Working party should be funded and appropriately resourced.

2.3. The National Working Party review all current protocols and legal avenues dealing with the issue of sterilisation and recommend uniform measures which can be enacted by all States and Territories. Those recommendations can then be enacted through Commonwealth/State funding agreements such as: the Commonwealth/State Medicare Agreement and/or the Commonwealth/State Disability Agreement.

2.4. Any reforms must be based on the premise that the forced sterilisation of girls and women with disabilities is a human rights issue. Reforms must reflect that any sterilisation carried out without the informed consent of a person is a forced sterilisation and that applications to sterilise must be seen as procedures *done to* women with disabilities not procedures *done for* them.

2.5. Any reforms must address the issue of forced sterilisation for all women and girls with disabilities, including those with psychiatric, physical, cognitive, and sensory disabilities.

2.6. The Federal Government establish mechanisms to ensure that any action or progress on the issue of sterilisation of girls and women with disabilities undertaken by Government is reported back to Women With Disabilities Australia (WWDA).

3. Information, Support and Service Models

3.1. The Commonwealth Department of Health & Aged Care fund a fulltime Project Officer position for Women With Disabilities Australia (WWDA) for a period of three years to:

- research and develop accessible information resources for girls and women with disabilities regarding sterilisation and the implications of such procedures;
- research and develop best practice service models to support women and girls with disabilities who have undergone forced sterilisation, as well as those seeking information and support regarding the decision to undergo sterilisation and broader reproductive health issues.

3.2. The Commonwealth Department of Health & Aged Care fund FPA Health (NSW) to establish and operate the National Reproductive Rights for Women With Disabilities Network (as described in this report). The Network would consist of women with disabilities, service providers, policy makers and other interested individuals to progress reproductive rights issues for women with disabilities. This would include but not be limited to addressing the issue of forced sterilisation of women with disabilities.

4. Consent

4.1. The Federal Government act immediately to ban all sterilisations of girls under the age of 18 years, unless the sterilisation is being performed as a life saving measure or medical emergency. Implicit in this should be the recognition that girls under the age of 18 years cannot be expected to provide informed consent to sterilisation. Sterilisations should never occur until an age where the ability to give informed consent can be determined.

4.2. The Federal Attorney General's Department undertake an investigation into the issue of 'consent' as it applies to sterilisation and other reproductive health issues for women and girls with disabilities of all ages.

4.3. The Federal Attorney General's Department undertake an immediate review of procedures and processes currently in place for sterilisations occurring to girls and women with disabilities who are deemed 'incapable of giving informed consent.' Any review must address the following issues:

- who should determine that a person is incapable of giving informed consent; and,
- what processes and mechanisms should be used to determine that a person is incapable of giving informed consent.

4.4. The Federal Attorney General's Department develop and establish an independent mechanism to establish whether informed consent can or cannot be given.

5. Reproductive Health Care

5.1. The Commonwealth Department of Health & Aged Care fund a national project on reproductive health care for girls and women with disabilities which:

- addresses the process, concerns, and issues identified in this report, along with the incidence of forced sterilisation for ALL women with disabilities, including those with psychiatric, cognitive, sensory and physical disabilities;
- researches the long-term physical and mental health and social effects of sterilisation;
- researches the practice of menstrual suppression of girls and women with disabilities, including those in group homes and other forms of institutional care. Research into menstrual suppression practices must include:
  - an investigation into the use of Depo-Provera and other injectable contraceptives; the contraceptive pill; and other forms of contraception;
  - an investigation into the use of contraception as a form of social control of girls and women with disabilities;
  - an investigation into the process of Substitute Decision Making;
  - an investigation into the long-term physical and mental health and social effects of menstrual suppression practices.

5.2. The Australian Division of General Practice fund a national project to educate and inform general practitioners on:

- their obligations under the *Disability Discrimination Act (DDA) 1992;*
- sexual health issues (contraception, sexual health, fertility management, pregnancy, menopause, breast and cervical cancer screening) for women with disabilities;
- sterilisation as a human rights issue;
- options for menstrual management;
- services that are available for general practitioners to refer women and girls with disabilities to.

5.3. The Australian Medical Association (AMA) in conjunction with the Royal College of Obstetricians and Gynaecologists undertake responsibility for the development of an Information Package on the legal, medical, and social implications of forced sterilisation and menstrual suppression practices.

5.4. The Commonwealth Department of Health & Aged Care fund the development of national sexual health protocols for women with disabilities which incorporate options for menstrual management and contraception.

6. Data Collection

6.1. The Australian Institute of Health & Welfare (AIHW) be responsible for the co-ordination, collation and analysis of reliable statistics on forced sterilisation, including those currently being performed and those that have been performed in the past. Any data collection system developed must incorporate provision for an independent means of checking the database for accuracy and comprehensiveness of records.

6.2. The Commonwealth Department for Health & Aged Care examine how data on sterilisation of women with disabilities is currently collected, and investigate the possibility of developing coding information which provides more accurate and reliable statistics on sterilisations of women and girls with disabilities, including those with psychiatric, cognitive, sensory and physical disabilities.

7. Education

7.1. The Federal Government, through the Department of Education, Training and Youth Affairs (DETYA) develop national protocols for health education curriculum (beginning at primary school level) which incorporate models of diversity that portray positive images of people with disabilities as parents and as sexual beings.

7.2. The Commonwealth Department of Education, Training and Youth Affairs (DETYA) fund a fulltime Project Officer position for Women With Disabilities Australia (WWDA) for a period of two years to:

- conduct a national project which educates and informs women with disabilities of their reproductive health rights, including their right to sexuality and their right to parent.

Appendix One: About Women with Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is the national peak organisation for women with all types of disabilities in Australia. It is a federating body of individuals and networks in each State and Territory of Australia and is made up of women with disabilities and associated organisations. The national secretariat is located in Canberra. WWDA is run *by* women with disabilities, *for* women with disabilities. It is the only organisation of its kind in Australia and one of only a very small number internationally. WWDA is inclusive and does not discriminate against any disability. WWDA seeks to ensure opportunities in all walks of life for all women with disabilities. In this it aims to increase awareness of, and address issues faced by, women with disabilities in the community. It links women with disabilities from around Australia, providing opportunities for them to identify and discuss issues of common concern. WWDA works in partnership with other disability organisations and women's organisations and generates and disseminates information to women with disabilities, their families, carers, service providers, government and the media.

WWDA has national and international membership, from both individuals and organisations. Women With Disabilities Australia (WWDA) is a proactive organisation that works hard to effect systemic change for women with disabilities at all levels of society. Development of WWDA policies and programs is based on the identified needs and concerns of women with disabilities in Australia. WWDA is a non-party political organisation that cuts across political, economic, social and ethnic barriers. WWDA seeks to ensure the advancement of education of society to the status and needs of women with disabilities in order to promote equity, reduce suffering, poverty, discrimination and exploitation of women with disabilities. WWDA is unique, in that it operates as a national disability organisation; a national women's organisation; and a national human rights organisation.

WWDA is managed by a National Executive Committee, which is made up of women with disabilities and which is elected each year at the Annual General Meeting. Each State and Territory of Australia is represented on the National Executive Committee. The members of WWDA are actively involved in the decision-making processes of the organisation. WWDA is a registered charitable organisation with Public Benevolent Institution status which means that donations made to the organisation over $2 are tax deductible.

Major Functions of Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is at the forefront of support and advocacy, with, and on behalf of, women with disabilities in Australia, both individually and collectively. WWDA's major roles, functions, and activities include (but are not restricted to):

1. **Provision of direct practical assistance to individual women with disabilities** – which can include crisis intervention; transport; emotional support; counselling; information provision; referral; organising accommodation, respite etc; provision of attendant care support; arranging appointments; assisting with communication needs; processing information in accessible formats; organising provision of services from other organisations; accompanying women with disabilities to meetings and other functions; assisting women with disabilities to understand and fill out forms; assisting women with disabilities to access bureaucracies; provision of advocacy on their

behalf as required; provision of training; rehabilitation; employment, volunteering opportunities, and so on.

2. **Provision of systemic advocacy for women with disabilities collectively** – which can include: community education; awareness raising; consultation; representation on advisory bodies, Committees, Working Parties, Steering Groups; submission writing; lobbying; ministerial delegations; appearances at parliamentary or other types of inquiries; development of public campaigns; use of the media; training and education of service providers; development of models of best practice in accessible website design and content; production of accessible journals and Newsletters; conducting of national, State/Territory, regional and local Conferences, seminars and forums; and so on.

3. **Research and policy development** – which can include qualitative and quantitative research methodologies; provision of the structures, mechanisms and expertise for research into issues of concern to women with disabilities such as: violence; the interaction between gender and disability; sexuality and reproductive health; telecommunications; ageing; health; employment; stereotyping in the media; citizenship; leadership and mentoring; unlawful sterilisation; disability service provision; and much more; development and publishing of Resource Kits, Training Manuals, research reports, Conference papers; journal articles; etc.

4. **Project development and implementation** – which can include needs based planning; issue based project development and implementation at national, State/territory, regional, and local levels; development of models of best practice in project development for people with disabilities (including models of inclusive training and education packages etc); publishing of Project Reports; advocacy stemming from Project recommendations and outcomes; production of Disability Project Management Guidelines; etc.

5. **Addressing the issue of empowerment and women with disabilities, both individually and collectively** – which can include provision of opportunities for women with disabilities to come together in groups; share experiences; share information; develop relationships; organise around issues or problems that are unique to them; provide support to one another; and develop social networks and alliances (such processes assist women with disabilities to improve their self-esteem, increase self-confidence, and develop new knowledge and skills); creating opportunities for, and supporting women with disabilities in leadership and mentoring roles; creating and facilitating opportunities for women with disabilities to develop the confidence and skills to take up representation activities and positions within their local communities and at State, National and international levels; provision of information, knowledge, resources and analytical skills on how bureaucratic and political structures function, as well as provide an entry point into the political decision-making processes.

6. **Quality improvement** – this includes self-assessment of performance utilising the Community Health and Primary Health Care Accreditation Standards Program (as there are no specific Practice Standards in Australia for national charitable organisations; national advocacy organisations; national disability organisations; or national women's organisations). Other quality improvement processes include: strategic planning; program and project evaluation; development

of, and reporting against performance measurers and indicators; random surveys of member satisfaction; development and implementation of mechanisms to enable feedback from members and other stakeholders, such as electronic based discussion group; website feedback form; Newsletter Evaluation form; and so on.

Women With Disabilities Australia (WWDA) is an organisation which is multi-functional; has an extensive reach across all sectors and the community in general; and is extremely diverse in the range of activities it undertakes, and roles it performs. WWDA works closely with member organisations, other peak bodies, other disability organisations, women's organisations, and organisations across a range of sectors, including health, aged care, community welfare, transport, arts and communication, employment, education and training, environment and more. WWDA has extensive links and networks with government departments and agencies at all levels, as well as links with industry, the private sector, and a large number of international organisations and institutions.

Membership of Women With Disabilities Australia (WWDA)

WWDA has 3 classes of membership:

- **Full Membership** is open to all women with a disability who live in Australia. Fee for full membership is: $5 for unwaged/pension, or free if unable to pay; and $10 for waged individuals;
- **Associate Membership** is open to individuals and/or organisations supportive of the aims and objectives of WWDA. The fee for associate membership is $10 for unwaged individuals and $25 for waged individuals. The fee for organisations wishing to become associate members is: $30 for organisations with an income of less than $100,000 per annum; $45 for organisations with an income between $100,000 – $200,000 per annum; and $65 for organisations with an income of more than $200,000 per annum;
- **Organisation Membership** is open to organisations which are supportive of the aims and objectives of WWDA but must have a majority of women with disabilities as members. The fee for organisation membership is $20.

People can become members of WWDA by completing a membership form (available from the WWDA website or from the National WWDA Office). Membership requests can also be forwarded to WWDA via email to: wwda@ozemail.com.au or by contacting the National WWDA Office.

Appendix Two: Sterilisation of Women and Young Girls with an Intellectual Disability: Report to the Senate tabled by the Minister for Family & Community Services and the Minister Assisting the Prime Minister for the Status of Women

6 December 2000

This report covers the background to the issue of sterilisation of women with disabilities, provides recent statistics on sterilisation procedures, and details a cross-departmental response to the Senate's calls for a review of relevant legal, ethical and human rights mechanisms and the commissioning of research. It has been compiled as a result of a collaboration between staff of the Departments of Family and Community Services and Health and Aged Care, the Attorney-General's Department and the Office of the Status of Women in the Department of the Prime Minister and Cabinet.

Background

On 15 March 2000, the Senate agreed to the following resolution:

> That the Senate –
>
> (a) notes:
>
> (i) that in 1992 the High Court, in what has come to be known as Marion's case, decided that the non-therapeutic sterilisation of an intellectually-disabled minor could not be authorised without a court order,
>
> (ii) the findings of Cathy Spicer, who reports that recent statistics show an increase in the rate of sterilisation procedures performed on women and young girls with an intellectual disability, and
>
> (iii) that there is no comprehensive research regarding the sterilisation of women with an intellectual disability; and
>
> (b) calls on the Government to:
>
> (i) conduct a review of the legal, ethical and human rights mechanisms in place, or needed, to protect the rights and interests of the reproductive health of women with intellectual and other disabilities, and;
>
> (ii) commission research on the practice, effects and implications of the sterilisation of women with intellectual and other disabilities.

On 26 April 2000, the Minister for Family & Community Services provided an interim response to the Senate, saying that the Department of Family & Community Services would take the lead in co-ordinating a cross-departmental response, and that she would report back to the Senate by the end of November 2000.

Statistics on Sterilisations of Young Women with an Intellectual Disability

A comprehensive review of available national data was undertaken in an attempt to ascertain the incidence of sterilisation of women and young girls with intellectual disabilities. The following data sources were examined; however, each has some limitations as detailed below.

1. The most relevant source is the National Hospital Morbidity Database, collated by the Australian Institute of Health and Welfare (AIHW). This covers sterilisation procedures undertaken on admitted patients in both private and public hospitals, and has the advantage of allowing for extraction of specific data relating to young women with a recorded diagnosis of intellectual disability. Essentially all public hospital admissions are included, as are almost all private hospital admissions.

   According to this database, between 1993-94 and 1998-99, there was a total of 22 admissions for females under 18 years with a diagnosis of intellectual disability, during which a procedure that can be used for sterilisation was performed, in Australian public and private hospitals combined. (Because the numbers reported by each State/Territory in each year are so small, analysis at that level is not useful. Release at the jurisdictional level could also potentially infringe privacy.) There does not seem to be a pattern of an increase in sterilisations on women and young girls with an intellectual disability, since the numbers have declined from a high of 7 in 1994-95 to 2 in 1998-99.

   The disadvantages of these data are that:

   - they have been collated only since 1993-94, so national data relating to the period prior to the establishment of the law following Marion's case, mentioned in the Senate resolution under (a) (i), are not available;
   - from 1993-94 to 1995-96, age group and not age was reported in Queensland and South Australia. Data reported for these years in these States is for females aged under 15 years;
   - there is no routinely available independent means of checking the database for accuracy and comprehensiveness of records. The data in the records are derived from the information in the hospital's medical records for the patient and is extracted by coders located in individual hospitals; and – whether an additional diagnosis of intellectual disability is recorded is dependent on whether it was considered by the clinician and coder to have affected the admission for the purpose of the principal diagnosis.

2. The second relevant source is the statistics provided by the Family Court of Australia on the numbers of sterilisations that had been authorised by the Family Court for the calendar years 1994-1999. The Court has acknowledged the help of Susan Brady of the University of Queensland in compiling these statistics. These statistics showed that there had been a total of 14 applications to the Family Court for sterilisations during that 6 year period, with 1 application withdrawn at directions hearing, and one appeal on a first instance judgment which overturned the decision not to sterilise. There were thus 13 applications for sterilisation approved. These data also show a decline in the number of applications for sterilisations, from a high of 5 in 1994 to 0 in 1999.

3. The third source of data investigated for this review was the Health Insurance Commission's Medicare claims data. These data have two major limitations for this purpose: there is no way of knowing how many of the young females undergoing sterilisation procedures may have an intellectual disability, and the data do not include public patients undergoing procedures in public hospitals. However, a detailed review of these data was undertaken by the Department of Health and Aged Care and the Department's comments are provided in Attachment 1.

Conclusions

It is not possible to ascertain the precise number of unauthorised sterilisation procedures that may be being performed on women with intellectual disabilities. The data presented above are indicative only.

There are four possible explanations for the discrepancy between the totals produced by the first two data sources:

a) The difference in reporting periods (financial years and calendar years) may account for some of the mismatch;

b) At least 2 sterilisations performed on young women with intellectual disability between 1993-94 and 1998-99 were undertaken for clearly therapeutic reasons, for which court authorisation was not necessary;

c) up to 7 sterilisations performed on young women with intellectual disability between 1993-94 and 1998-99 may have been authorised by tribunals other than the Family Court of Australia; and

d) up to 7 sterilisations performed on young women with intellectual disability between 1993-94 and 1998-99 may have been unauthorised.

These figures are only from official sources. It is possible that there are unrecorded and unauthorised non-therapeutic sterilisations of young women with intellectual disability being undertaken in Australia.

Review of Legal, Ethical and Human Rights Mechanisms

This section of the report outlines the efforts that have been made in Australia to prevent unauthorised sterilisations of young women with intellectual disability since the 1997 publication by the *Human Rights and Equal Opportunity Commission of Sterilisation of Girls and Young Women, A Legal, Medical and Social Context*, by Susan Brady and Dr Sonia Grover.

The following actions have been taken to date:

The Attorney General is working to ensure that medical practitioners understand their legal obligations in relation to non-therapeutic sterilisation procedures carried out on minors with an intellectual disability.

Letter from Attorney-General to Colleges of Medicine

The possible incidents of unauthorised sterilisations indicate that some doctors may not be aware of their legal obligations in this area. The Attorney-General has written to Australian medical colleges and associations to inform them of the law and procedure surrounding the non-therapeutic sterilisation of minors with an intellectual disability. An open version of this letter will be provided to selected Australian medical journals for publication.

Amendment to Legal Aid guidelines

The Commonwealth Attorney-General has also approved revised Commonwealth Priorities and Guidelines for Legal Assistance in Respect of Matters Arising Under Commonwealth Law, with these coming into effect on 1 July 2000. The Guidelines reflect the Government's policy of encouraging parents to act lawfully by seeking a court order for special medical procedures such as sterilisation, by making legal aid more accessible and clarifying who is eligible. The Guidelines also provide that legal assistance should be granted for the separate representation of a child in any Family Court case relating to special medical procedures such as sterilisation. The means test is not applied in such cases, and a Legal Aid Commission must not try to recover any of the costs of the child's representative from the child's parents, whether they are legally assisted or not. In addition, legal aid must be provided to the parents of a child in any Family Court case relating to special medical procedures (including sterilisation), where the parents meet the means test. These guidelines apply to Family Law Act matters heard in any court, including the Federal Magistrates Service.

Changes to the Medicare Benefits Schedule

On 1 November 1998 an amendment was made to the Notes for Guidance in the Medicare Benefits Schedule to include guidelines provided by the Human Rights and Equal Opportunity Commission on this matter. The Medicare Benefits Schedule Book now includes the following:

> "(1) It is unlawful throughout Australia to conduct a sterilisation procedure on a minor (under 18 years of age) which is not a by-product of surgery appropriately carried out to treat malfunction or disease (eg malignancies of the reproductive tract). Parents and guardians have no legal authority to consent on behalf of minors to such sterilisation procedures.
>
> (2) Practitioners may be subject to criminal and civil liability action if the sterilisation procedure is not authorised by the Family Court of Australia or a Court or Tribunal with jurisdiction to give such authorisation."

Safeguarding the integrity of the Medicare claims data

The Health Insurance Commission has introduced a number of safeguards for ensuring the integrity of the Medicare data associated with such claims. The Medicare payments system now precludes the payment of claims for these services where the patient is 17 years and under, until the claim is verified with the practitioner. This restriction cannot be by-passed by Medicare claims assessors. Once verification is obtained, the facility to process such claims is only provided by a senior Health Insurance Commission officer. This should prevent processing errors in such data in the future. Verification does not extend to whether the service was authorised by the relevant court or tribunal. Unless a medical board or court decision deems otherwise, the payment of Medicare benefits assumes that a medical service was clinically relevant and performed in accordance with professional standards and relevant Commonwealth and State law.

Information to and from Family Planning Organisations

Details of the Senate's resolution were provided by the Department of Health and Aged Care to all Australian Family Planning Organisations. The opportunity was taken to seek information on the type of resources and opportunities currently provided for professionals and parents or guardians in connection with the sexuality of young people with disabilities. Family Planning Organisations in most States and Territories offer sex education tailored for the special needs of this group. For example, one-on-one consultations; workshops for people with an intellectual disability, their parents or guardians, doctors, nurses, other health professionals, teachers, disability workers; and Information/Fact Sheets. The issues covered are menstrual management advice; alternative contraception options; the necessity for safe sex practices (regardless of sterilisation); legal process, for example, in regard to obtaining consent to and seeking authorisation for sterilisation; and referrals. Health professionals, parents and guardians contemplating sterilisation of young people with disabilities are welcome to use the services provided by the Family Planning Organisations.

College of Obstetricians and Gynaecologists' Statements and Resources

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists published a statement (3.9) in June 1998, which directs its members to note that the performance of sterilisation of intellectually disabled females must be in accord with the current law of the relevant jurisdiction. This statement was re-endorsed in October 2000. Several Resource Units have been published by the College for continuing medical education of their members. (These Resource Units include the disclaimer: "The content of the Resource Unit indicates the author's opinion, and not necessarily that of the RANZCOG.") These have included one on "Menstrual and contraceptive management for women with intellectual disabilities" by Dr Sonia Grover, first released on 30 April 1997, and another titled "Consent for Operation on Mentally Retarded Minors which may interfere with their future fertility" by Professor Alex Crandon, first released on 31 August 1998. It is the responsibility of State and Territory governments to ensure that members of the medical profession comply with current laws of the relevant jurisdiction.

Research on the Practice, Effects and Implications of the Sterilisation of Women with Intellectual and Other Disabilities

The Senate's resolution noted that very little research on the non-therapeutic sterilisation of women and girls with an intellectual disability has been done. A first step in redressing this has been the grant of $25,000 to Women with Disabilities Australia by the Commonwealth Office of the Status of Women to undertake a National Project on Sterilisation and Health of Women and Girls with Disabilities. The Project has two main components:

- background research which will examine international and national developments in the area; and
- a National Forum which will draw together women with disabilities, academics and researchers, and policy makers to critically analyse the issue and develop strategies to advance debate and action.

The National Forum will be conducted as an adjunct to the International Conference "Disability with Attitude: Critical Issues 20 Years after International Year of Disabled Persons" which is being held in Sydney in February 2001. The National Forum will also draw on the expertise of two world renowned International experts on Reproductive Health and Disability (Drs Adrienne Asch and Tom Shakespeare) who are attending the International Disability conference, and who have agreed to participate in the National Forum.

Attachment 1

Comments on Medicare data

The Senate's resolution noted a report that recent statistics showed an increase in the rate of sterilisation procedures performed on women and young girls with an intellectual disability. The Senate reference is to a literature review produced by Cathy Spicer while on a placement from the University of Canberra with Women with Disabilities Australia. The most recent reference that her review quotes in relation to these statistics was to the report prepared by Susan Brady & Dr Sonia Grover and published in 1997 by the Human Rights and Equal Opportunity Commission. Brady & Grover's *Sterilisation of Girls and Young Women, A Legal, Medical and Social Context* suggested, based on Medicare data, that significant numbers of minors were undergoing sterilisation procedures.

Medicare benefits are only payable for clinically relevant services, that is, services generally accepted by the medical profession as being necessary for the appropriate treatment of the patient concerned. The Department of Health & Aged Care has reviewed the data, and the Spicer & Brady and Grover assessments do not accord with the Department's findings. These show the following Medicare claims for sterilisations of all females aged under18 that were performed in Australian private hospitals and on private patients in public hospitals:

1996-97: 7

1997-98: 0

1998-99: 4.

The number and proportion of these claims that may relate to females with intellectual or other disabilities is unknown, and claims for periods prior to 1996-97 could not be verified because Medicare claims histories are culled after 2 years. There appear to be several reasons for the differences in these assessments. The first is that care needs to be exercised in the selection of the associated Medicare item numbers. The second is that care should also be taken when looking at Medicare data in very small numbers as issues such as data entry errors can significantly distort reports.

Selection of Medicare data

The Department's analysis was based on services included in the Medicare Benefits Schedule (MBS) that would result in sterilisation, with the exception of those services that are specified as being for the treatment of particular medical conditions. Also excluded were those services that constitute "global" items which incorporate a number of different procedures, some of which would not result in sterilisation.

Excluded services

The following services were not included in the Department's review:

- certain hysterectomy services: The Department did not include hysterectomy services that specify the procedure in the context of treatment of disease, such as endometriosis, pelvic inflammatory disease, tumours and carcinoma, on the basis that such services would have been provided for therapeutic reasons;
- endometrial ablation: Endometrial ablation services were excluded because they are listed in the Medicare Benefits Schedule specifically for the treatment of certain pathological conditions, ie Item 35622 covers endometrial ablation for the treatment of chronic refractorymenorrhagia;

Item 35638 also covers endometrial ablation but specifically for the treatment of moderate to severe endometriosis; Item 35638 is also a "global" item which provides for a range of services some of which, such as division of adhesions, would not result in sterilisation. Information is not available from the Medicare database as to which of the multiple services covered under a "global" item was provided to the patient;

- ovarian procedures: A number of ovarian procedures were excluded also. These are "global" items which include services, such as removal of ovarian cyst, which would not result in sterilisation. Again, Medicare data does not provide information about which procedure, under a "global" item, has been provided to the patient. The 1995-1997 data in Brady & Grover appear to have been derived from Medicare statistics. Brady & Grover do not seem to have made the same distinctions as the Department when selecting Medicare items and some of the above services appear to have been included in the data used in their report. It is not clear how the data they reported for the period 1987-1994 were derived.

Distortions in the Medicare data

The second reason that would explain the discrepancy between this Department's findings and those published in Brady & Grover is that, when looking at MBS data in very small numbers, issues such as processing errors can significantly distort reports. The Health Insurance Commission has checked actual claims records for the data listed above and has verified that these figures are correct. These data exclude those records that the Health Insurance Commission found were the subject of processing errors such as the incorrect recording of the service against the child rather than the mother, errors in itemisation by the doctor's rooms or date of birth errors on the Medicare enrolment file. The Health Insurance Commission has now corrected the patients' Medicare records in these cases.

Data periods

The Health Insurance Commission was only able to verify the data against actual claims records for the period 1997-2000, as Medicare claims' histories are culled after 2 years. The Health Insurance Commission has no means of verifying the remaining data. It was considered inappropriate for the Commission to seek that doctors verify their records because firstly, these claims were up to 13 years old and secondly, this would raise privacy issues about obtaining the patient's consent. Further, the Health Insurance Commission felt that it would not be appropriate for HIC staff to question patients about their medical history (particularly medical history of this nature).

Appendix Three: Planning and Organising the National Forum on Sterilisation and Reproductive Health for Women and Girls with Disabilities

The National Forum on Sterilisation and Reproductive Health for Women and Girls with Disabilities aimed to provide a safe and secure space for women who have been affected by Sterilisation and other reproductive health issues to come together and share their experiences. It also aimed to provide a structure in which those women could acknowledge the effects on their lives and identify ways forward to prevent the same things occurring for women in the future.

Finding women who were willing to speak out and building a trusting and supportive relationship with those women was a critical process in the planning of the forum. Working through organisations which deal with disability issues in sexuality, support for parenting, self advocacy and other specific support groups was important to establish connections with women who may be interested in attending. Preparation of information about the Forum in a variety of formats (including Plain English) was also critical so that women could make informed decisions about whether they would benefit from attending. Time and effort to meet with or talk on the phone with potential participants to answer any concerns or questions was a major requirement in helping women make the decision to participate.

Women with disabilities may be very isolated and in this case they were being asked to come and speak out about something that they may not have spoken about at any other time in their lives. Providing adequate support and counselling during the process was a primary concern. Several decisions were made in an effort to ensure this including:

- women with disabilities only, with a minimum number of trained facilitators, to attend the Forum;
- availability of support and counselling both during and after the Forum;
- setting up a buddy system within the group of women so that each person had someone they could turn to for support who would know what they were likely to be going through.

To ensure effective outcomes for both the women attending the Forum and for WWDA was also an important concern. While the Forum was an opportunity to speak out about experiences, it was considered critical that concrete outcomes and directions for the future were also arrived at. The skill of well-briefed and sensitive facilitators was critical here. A concerted effort pre-forum to allow the participants talk about their own experiences enabled them to air many painful issues and served to focus their thoughts on what they wanted to say and hear at the Forum itself.

Logistics and venues are important aspects in planning any event of this kind, particularly in relation to issues of physical and information accessibility. In some senses, although complex, this is the easy part. The commitment to recognising women's individual support needs in attending and creating a safe and secure environment which supported them to have their say was a much more critical part of the process. By creating this kind of a space, the women who attended were able to come together as a group and offer each other, many for the first time, a realisation that they were not alone, recognition and acknowledgement of their experiences of loss and alienation and support and strength to move on and change the conditions that allowed these things to happen to them. This remains for the women who attended, the most commented and commended outcome.

Appendix Four: Consulting with Women With Disabilities – Planning and Organising and Accessible Workshop

Women with disabilities have a right to be consulted on matters relating to their own lives. Consultation is a key part of the policy development process and plays an important role in ensuring that programs, services and policies are as effective as possible in meeting the needs of the community. Given that women with disabilities make up over 19% of our population it is crucial that consultation processes are accessible for them.

Many women with disabilities have specific needs that are not always obvious to those in the position of making policy, developing programs and undertaking planning. Ensuring that women with disabilities are included in consultation processes will enable the development of services, programs and facilities that are inclusive of the whole community. Good consultation will also ensure that:

- better services are developed for all members of the community;
- better meeting the needs of women with disabilities will often benefit others also; and
- there is greater likelihood that the expectations and needs of women with disabilities will be met by Government, non-government, and other sectors.

Consultation with women with disabilities should focus on the woman with disability and where appropriate, include family members, carers and advocates.

If you are planning a face-to-face consultation process with women with disabilities through mechanisms such as Workshops, Focus Groups, and so on, here are some issues you should consider. This is by no means an exhaustive list – it is a good idea to contact Women With Disabilities Australia (WWDA) to obtain advice and expertise in relation to consulting with women with disabilities.

1. Publicising Your Consultation Workshop

- utilise existing networks to disseminate information about the consultation (eg email lists; national peak disability organisations; national and state/territory women's organisations; inserts to newsletters; text only emails to each State & Territory Blind Society);
- plan the consultation well in advance, ensuring that women with disabilities have plenty of lead-time to prepare their responses and consult amongst their own networks. Ideally, women with disabilities should be given 3 months to consult within their own networks, and prepare responses to consultations;

2. Identifying the Particular Needs of Workshop Participants

- information should be collected on each participant prior to conducting the Consultation Workshop;
- information should be as detailed as possible and should include specific needs, for example:
  - does the individual have any allergies and/or particular medical conditions that consultation organisers should be made aware of?
  - does the individual require attendant care?
  - do they need a commode chair?
  - what type of seating do they require? (ie wheelchair; high back chair with arm rests etc);
- speak directly with each participant prior to the consultation workshop to double check that all needs will be met;
- ask each participant to provide details of an emergency contact.

3. Communication and Information Preparation

- provide a noticeboard at the workshop (and accommodation venue if the Workshop involves participants being accommodated), which includes: general housekeeping issues and messages (ie taxi arrival times, checkout times; facilitator and/or organiser contact details);
- hire hearing loops and Auslan Interpreters if necessary. Also investigate real time captioning if deaf and/or hearing-impaired individuals are participating in the Consultation Workshop;
- secure volunteers for note taking if required;
- provide accessible information formats as required for each participant. Communication and information needs of each individual should be determined prior to the Workshop. Accessible information includes: large print; braille, ASCII, electronic format; Plain English; languages other than English, Compic, and audiotape.

4. Workshop Venue

- ask people with disabilities themselves for advice on accessible venues;
- choose a venue close to accessible public transport;
- ensure that accessible toilets and telephones are available to participants;
- contract a person with a disability to assess accessibility of the venue;
- check that childcare and nappy change facilities are available if necessary;
- organise for high straight back chairs with armrests, wheelchairs, walking sticks, and crutches to use if required;
- ensure that a room is booked for use as a rest room and/or time out room. The room should have a bed and should be well ventilated;

- provide access to grass and water for guide dogs if necessary;
- ensure that Emergency Exit information is provided in alternative formats as required;
- ensure that venue policies and procedures are provided in alternative formats as required.

5. Accommodation

- find out what methods of payment are acceptable and notify participants;
- physically check that accessible rooms are accessible for each participant. Contract a person with a disability to check accessibility of rooms;
- ensure that accommodation meets the individual needs of each participant. Things to consider include:
    - telephones in each room;
    - lift buttons within reach from sitting position;
    - bathrooms with shower chairs, foot stools, shower hoses, accessible mirrors;
    - recharge facilities in rooms for electric wheel chair batteries and mobile phones;
    - emergency exit information is provided in alternative formats as required.

6. Catering

- check dietary requirements of each participant (eg allergies; smaller, more frequent meals; special needs);
- provide substantial morning and afternoon tea;
- drinks (iced water, orange juice, tea and coffee need to be available at all times).

7. Attendant Care

- determine each participants attendant care requirements prior to the Workshop;
- employ attendant carers as required;
- ensure that support workers are available as required;
- assess the need to have experienced counsellors on hand (this is often vital for debriefing after intense workshops);
- ensure that volunteers are available as required (eg guides, note taking, facilitating communication between participants, assisting with food and drinks etc).

8. Travel and Transport

- do not rely on accessible taxis being available when you need them. Hire an accessible taxi shuttle for the duration of the event;
- send each participant multiple cab vouchers and instructions on usage, prior to the Workshop;
- check accessible parking and toilet facilities at workshop and accommodation venue, train stations and airport.

Appendix Five: National Forum Expression of Interest Flier

Sterilisation and Reproductive Health of Women with Disabilities in Australia – *Moving Forward*

WWDA National Forum
Sydney
Thursday 15 February 2001

Sterilisation is one of the major issues confronting women with disabilities. There has been very little research conducted, by any sector, on the issue of unlawful sterilisation, and more broadly, on the issue of reproductive health of women with disabilities in Australia. The limited research that has occurred has generally not included or involved women with disabilities. Women with disabilities, particularly women with intellectual disabilities have had little opportunity to speak about their experiences, or participate in legislative, policy and/or program development.

Women With Disabilities Australia (WWDA) has secured funding from the Commonwealth Office of the Status of Women to conduct a National Forum on Sterilisation and Reproductive Health of Women with Disabilities in Australia. The National Forum will be conducted in conjunction with the International Conference "Disability with Attitude: Critical Issues 20 Years after International Year of The Disabled Person" being held in Sydney in February 2001.

WWDA is seeking women with disabilities interested in attending the Forum. The funding WWDA has received for the Forum will enable 4 women with disabilities from interstate (including rural and remote areas of NSW) to attend the Forum, and 16 women with disabilities from the Sydney metropolitan area.

The WWDA National Forum on Sterilisation and Reproductive Health of Women with Disabilities will aim to give women with disabilities an opportunity to speak about their experiences and issues in relation to reproductive health, including sterilisation.

The Forum will also aim to:

- identify key areas and issues requiring further research and action;
- develop practical strategies which participants and relevant organisations can implement;
- provide a supportive environment for sharing of information, networking, and learning from international experience.

An Application Form and process is currently being developed, and will be forwarded to those who have registered their interest in attending the Forum. To have your name included on the Register of Interest list, please contact WWDA by phone, fax or email. Please provide your contact details and your preferred method of receiving further information.

This information is also available in Plain English format.

Expressions of Interest should be lodged with WWDA no later than Thursday September 30 2000.

Women With Disabilities Australia (WWDA)
PO Box 229 Dickson 2602 ACT
Ph: 02 6242 1310 Fax: 02 6242 1314 Mobile: 0407 301 746
Email: wwda@ozemail.com.au
Website: http://www.wwda.org.au
Contact: Carolyn Frohmader, Executive Director

Disability Conference 16 – 17 February 2001

The forum is being run in association with the conference **Disability with Attitude: Critical Issues 20 years After IYDP.**

For information about the conference contact:

Social Relations of Disability Research Network,
School of Social Work, Level 15 Matthews Building,
University of New South Wales, Sydney NSW 2052
Ph: 02 9385 1870 Fax: 02 9662 8991
Email: dwaconf@unsw.edu.au
www.arts.unsw.edu.au/socialwork.disability.htm

Please pass this on to any women with disabilities you know of who may be interested.

Appendix Six: National Forum Expression of Interest Flier (Plain English Version)

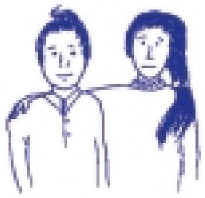
Sterilisation and Your Rights
Moving Forward

Women With Disabilities Australia
National Forum
Sydney
Thursday 15 February 2001

Women With Disabilities Australia (WWDA) is holding a Forum to talk about sterilisation of women with disabilities. This is the first time women with disabilities will get together to talk about their experiences and their rights.

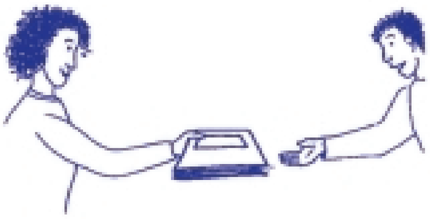
The Forum will:

- support women to talk about what has happened in the past;
- discuss what should happen in the future;



- plan how we can make changes happen.

After the Forum there will be a report to the government to let them know what changes should be made.



Funding to come to the Forum

WWDA has some money to support women with disabilities to come to the Forum.

What to do if you want to come

If you want to come to the forum and talk about this important issue contact WWDA before **September 30 2000.**

Women With Disabilities Australia (WWDA)
PO Box 229 Dickson 2602 ACT
Ph: 02 6242 1310 Fax: 02 6242 1314
Mobile: 0407 301 746
Email: wwda@ozemail.com.au
Website: http://www.wwda.org.au
Contact: Carolyn Frohmader, Executive Director

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Ph: 02 9385 1870 Fax: 02 9662 8991
Email: dwaconf@unsw.edu.au
www.arts.unsw.edu.au/socialwork.disability.htm

Please pass this on to any women with disabilities you know of who may be interested.

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Appendix Eight: Useful Organisations and Resources

Organisations

Women With Disabilities Australia (WWDA)

Post Office Box 605, Rosny Park 7018
Tasmania AUSTRALIA
Ph: +61 3 6244 8288 or +61 3 6253 5104
Fax: +61 3 62448255
Mobile: 0407 301 746
Email: wwda@ozemail.com.au
Website: http://www.wwda.org.au
Contact: Carolyn Frohmader, Executive Director

Human Rights and Equal Opportunity Commission (HREOC)

Level 8 Picadilly Towers
133 Castlereigh St
Sydney 2000 NSW
Ph: 02 9248 9600

National Council on Intellectual Disability (NCID)

PO Box 771, Mawson 2607 ACT
Ph: 02 6296 4400 Fax: 02 6294 4488
Mobile: 0407 406 647
Email: ncid@dice.org.au

Contact the National Council on Intellectual Disability for contact details of State/Territory branches.

Guardianship Boards

Contact Guardianship Boards in your State/Territory

FPA Health (NSW)

Sexuality and Human Rights Team
328-336 Liverpool Rd
Ashfield NSW 2131
Ph: 02 9716 6099
Fax: 02 9716 6164
Email: fpahealth@fpahealth.org.au
Email: carinah@fpahealth.fpahealth.org.au

STAR Victoria

2nd Floor Ross House
247-251 Flinders Lane
Melbourne VIC 3000
Ph: 03 9650 2730
Fax: 03 9650 6972
Email: starvic@infoxchange.net.au

Family Planning Organisations

Contact Family Planning Organisations in your State/Territory

Government Disability Departments

Contact Government Disability Departments in your State/Territory

Websites

Women With Disabilities Australia (WWDA)

http://www.wwda.org.au
This extensive site has been developed to meet the needs of a wide range of users, including women with disabilities, community care workers, policy makers, organisations in the disability and women's sectors, academics, researchers, and so on. The site has been developed in such a way that it can be regularly built upon and updated.

Disabled Women's Sexual and Reproductive Health Resource Packet

http://www.empowermentzone.com/repropak.txt
This Resource Package was developed by the *Americans with Disabilities Act* and Reproductive Health Project (California Family Health Council). The package contains resource information (booklets, videos, manuals), as well as a bibliography. Ordering and contact details are provided on the site.

The Sexual Health Network

http://sexualhealth.com/
The Sexual Health Network is dedicated to providing easy access to sexuality information, education, counselling, therapy, medical attention, and other sexuality resources for people with disability, illness, or other health related problems. The Sexual Health Network also provides continuing education and training for health professionals and facilitates educational groups for people with disability or illness.

Human Rights and Equal Opportunity Commission (HREOC) Disability Rights

http://www.hreoc.gov.au/disability_rights/index.html
This site provides information about: disability rights; the Disability Discrimination Commissioner's reports to the Commission; frequently asked questions and answers; disability standards and guidelines, Action Plans lodged under the Disability Discrimination Act; determinations and summaries of public inquiries into complaints; major reports examining the human rights of people with a disability; links and contact information for other relevant organisations.

Gimpgirl

http://www.gimpgirl.com
A website with information for young women with disabilities.

Global Reproductive Health Forum

http://www.hsph.harvard.edu/organisations/healthnet/
Website of the Global Reproductive Health Forum

National Women's Health Information Center (NWHIC) – Women with DisAbilities

http://www.4woman.gov/wwd/index.htm
This site has been developed by the National Women's Health Information Center, (a service of the United States Public Health Service's Office on Women's Health) to help women overcome social, financial, physical, or other kinds of barriers to health care services and information. This site addresses numerous issues of particular interest to women with disabilities, such as abuse; parenting; reproductive health; breast health; substance

abuse; and sexuality. It also offers general resources about critical health issues for a variety of disabilities, including physical, neurological, hearing, speech, and visual impairment. It provides information on psychiatric, learning, and developmental disabilities. You will also find information on US federal laws and regulations that protect disabled citizens, services and support resources, news about medical research, statistical information on disabled women, and information for healthcare professionals on improving healthcare access for women with physical limitations.

Websites for State and Territory Government Disability Agencies & Programs

ACT Government Disability Programs

http://www.act.gov.au/services/health/community/disability.html

NSW Ageing & Disability Department

http://www.add.nsw.gov.au/

Disability Services Queensland

http://www.disability.qld.gov.au/

Tasmanian Department of Health & Human Services – Disability Support

http://www.dchs.tas.gov.au/services/providing_support/index.html

Northern Territory Government Disability Services

http://www.nt.gov.au/nths/

Victorian Department of Human Services – Disability Services Division

http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/

Disability Services Commission of Western Australia

http://www.dsc.wa.gov.au/

South Australian Department of Human Services

http://www.health.sa.gov.au/

Electronic Mailing Lists

Electronic mailing lists provide forums for Internet users to participate in discussions or receive information on thousands of topics. When you subscribe to a list, your name and email address is automatically added to the list. You will receive a standard letter of welcome (via email) telling you about the list. From that time on, you will receive all mail (postings) sent to the list by its members. You may follow the discussions or join in on them. If you respond, you can send your response to the list (in which case, all members of the list will receive it), or to an individual on the list. You can signoff (unsubscribe) from a list at any time. You can also get a listing of all the members of a list and their e-mail addresses.

More information about electronic mailing lists can be found at:
http://www.ifla.org/I/training/listserv/lists.htm

You can also search CataList, the official catalog of LISTSERV lists at:
http://www.lsoft.com/lists/listref.html

The following lists are just some of the lists that may be of interest to women with disabilities.

WWDA-DISCUSS

List name: Women With Disabilities Australia (WWDA) Discussion List

Description: wwda-discuss is an email list to facilitate discussion between members of Women With Disabilities Australia (WWDA), and other women with disabilities. It has been established to share information, network, raise issues, participate in research and consultations, and much more. wwda-discuss is a private list, which means that subscribers to the list are approved by the list facilitator before joining.

List owner: Carolyn Frohmader, email: wwda@ozemail.com.au

Web page: http://www.wwda.org.au

To subscribe: go to: http://www.nwjc.org.au/avcwl/lists/info/wwda-discuss.html
and hit the button that says Subscribe to this list. You will then need to fill in your details. Once your subscription has been approved, you are then part of the wwda-discuss list.

D-W.I.L.D

List name: Women's International Linkage on Disability

Description: d-wild (Women's International Linkage on Disability) is a free international email list service for women with disabilities and women allies.

To subscribe: Send an email message to: d-wild-owner@yahoogroups.com

QUEERLADIES

List name: QueerLadies

Description: QueerLadies is a list for lesbian, bisexual and transgendered women with disabilities of all ages. QueerLadies is a monitored list.

List owner: Jen Panattoni

Web page: http://www.gimpgirl.com/lists/queerladies/qlsu.html

To subscribe: go to website: http://www.gimpgirl.com/lists/queerladies/qlsu.html

SEX AND DISABILITY RESEARCH

The purpose of this list is to discuss research on issues of sexuality and disability.

To subscribe: go to website: http://groups.yahoo.com/group/SexDisabilityResearch/

DISABILITY RESEARCH

List name: The Disability-Research Discussion List

Description: This list provides a forum for discussion on all aspects of disability research – both theoretical and practical. The list is intended for all those interested in research as it affects disabled people both in the UK and internationally. It provides a forum for the exchange of ideas, information and news, particularly among researchers working within a social model approach.

List owner: Mark Priestley

To subscribe: You can join the list by sending the following message to: mailbase@mailbase.ac.uk
Join disability-research <your firstname><your lastname>

ICAD-L

List name: ICAD-L

Description: ICAD-L is an electronic mail network on the topic of abuse and disability.

List owner: Dick Sobsey email: dick_sobsey@psych.educ.ualberta.ca

To subscribe: send an email message to: listserv@ualtavm.bitnet
that reads SUBscribe icad-l <your firstname><your lastname>

BIOETHICS

List name: International Network on Bioethics and Disability

Description: Open to everyone who is interested in how bioethics affect disabled people, other marginalised groups and the public at large and how bioethical theories affect human/equality rights. Please note that although the term disability is used in societies for people labelled as having a medical condition or disease or genetic 'defect' we believe that disability is a consequence of the societal prejudice, exclusion and environmental societal structures people labelled as having a medical condition or disease or genetic 'defect' are experiencing.

List owner: Christopher Newell and Gregor Wolbring

Web page: http://www.onelist.com/community/Bioethics

To subscribe: Send email to: bioethics-subscribe@onelist.com
Once you send an email to bioethics-subscribe@onelist.com you will get a message back from onelist which you just send back to them with the reply button.

Films

***The Sterilisation of Leilani Muir* (1996). Directed by Glynis Whiting. Producers: Jerry Krepakevich, Graydon McCrea. Original Title Code : 119C 9196 019**

Twenty-five years ago Leilani Muir was informed she would never be able to conceive a child. Unbeknownst to her, at the age of fourteen, she had already been sexually sterilised, by an Act of the Alberta government. The film entwines her personal search for justice with the background story of eugenics, a respected 'science' during the early decades of the twentieth century. In 1928, the Alberta government, supported by some of society's most prominent members, passed the Sterilisation Act. By the time the Act was repealed in 1972, the lives of nearly 3,000 individuals were irreparably changed. Included in the wide net of people considered 'unfit' to bear children were new immigrants, alcoholics, epileptics, unwed mothers, the poor and native people. The film opens as Leilani concludes years of emotional and legal preparation and steps into court to sue the Alberta government.

For more information contact:

National Film Board of Canada
International program
3155 Cote de Liesse Road
Saint-Laurent, Québec
Canada H4N 2N4
Phone: (514) 283-9439
Fax: (514) 496-1895
Email: AsiaPacific@nfb.ca and LatinAmerica@nfb.ca
Website: http://www.nfb.ca/E/

***Wounded Wombs* (2001) Directed by Diane Maroger.**

A film on the coercive sterilisation of a disabled woman (not yet available in Australia).

Information about the film is available on the website: http://users.skynet.be/sky65730/edd-99-fr/P-R-final.htm However, the website information is currently only available in French.

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