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Chapter 2

International Perspectives on the Sterilization of Women with Intellectual Disabilities

Liz Tilley, Jan Walmsley and Sarah Earle

The literature on human reproduction has, with some notable exceptions, ostensibly ignored the experiences of people with intellectual disabilities. Reproductive rights have been central to much feminist social sciences literature in this field and the right of women to 'control their own bodies' remains the cornerstone of this debate (see Petchesky 1986). Whilst some commentators have extended this to include the experiences of disabled women (see Morris 1996) disability is most often featured in the context of new reproductive technologies (see Shaw 2004) and so the experiences of disabled women have remained outside of mainstream debate.

In this chapter we focus on the sterilization of women with intellectual disabilities. We offer an international perspective, although one which draws predominantly on evidence from modern western societies, with a special focus on the UK context. In part it is a historical review, since the practice of involuntary sterilization is now subject to strict legal regulation. However, despite developments in Human Rights and Mental Capacity legislation, lack of control over contraceptive and reproductive choices continues to feature in the lives of women with intellectual disabilities. While the mass involuntary sterilization of women with intellectual disabilities is no longer a feature of current policy and practice in western societies, other forms of reproductive control – notably the use of long-term

contraception such as Depo Provera¹ - appear to be commonly used. In this chapter we draw upon the authors' interests in oral history, life story approaches, social policy and health sociology to explore this hidden area of reproductive loss.

A Short History of Sterilization

There is a long and dishonourable history of sterilizing women with intellectual disabilities in western societies. In the early twentieth century, the practice of sterilizing women without their consent was legalized by statute in the majority of US states, in two Canadian provinces, in Sweden, Iceland, Switzerland, Austria, Denmark and Norway. It was mooted seriously in the UK in the 1930s; in 1934 the recommendation of the departmental Committee on Sterilisation (most commonly referred to as the Brock Committee) was *not* to legalize sterilization without consent (see Thomson 1998 for a detailed discussion). Legislation permitting sterilization remained on the statute books of many countries until the 1970s but it now has been largely abandoned.

The literature suggests that the sterilization of women with intellectual disabilities stemmed from the belief that 'mental defect' was inherited (Jones 1986, Laughlin 1926, reprinted 2004, Reilly 1977). It is thus explicitly associated with the era of eugenics. For example, Park and Radford cite a post-World War 2 Canadian paper entitled 'Sterilise the Unfit' in which they argued that:

The free propagation of mental subnormals is carrying us far in the direction of race deterioration. (Hincks 1946 quoted in Park and Radford 1998:319)

¹ Depo-Provera (medroxyprogesterone acetate) is an injectable medicine that prevents conception for up to 3 months with each injection. It works by preventing the ovarian egg cells from maturing and releasing from the ovary.

Sterilization was only one weapon in the armoury of eugenicists in the UK (and elsewhere). The fear that people with intellectual disabilities would reproduce was also the driving force behind the segregated institutionalization of people with intellectual disabilities (Jackson 2000). The 1913 Mental Deficiency Act in England and Wales required Local Authorities to place people in institutions if they were deemed 'feeble minded', 'morally defective', 'imbeciles' or 'idiots'. Eventually, this resulted in the creation of large institutions, in which people were housed, with strict segregation of the sexes designed to prevent men and women having sexual intercourse. Those people who avoided institutionalization were supervised in the community and many lived with their family. Minute and detailed scrutiny of homes was part of the role of Mental Deficiency Visitors in the inter-war period; Visitors (mostly women) usually worked in a voluntary capacity and their role included the provision of family support, as well as surveillance (Walmsley and Rolph 2001). Visitors were required to complete documentation which included the question: '(f) Is it considered that the control available would prevent the defective from procreating children?' (Board of Control Model Form 1929) For authorities mindful of expense, it was tempting to regard sterilization as a relatively inexpensive way of discharging their obligation to prevent people with intellectual disabilities from conceiving, and there is clear evidence of English Local Authorities campaigning for such legislation at the end of the 1920s (Fennell 1996).

The English Board of Control archives show that child-rearing was of greater concern when people with intellectual disabilities were married, as being married allowed couples to keep their children (Board of Control Annual Report 1926). These sentiments were echoed at a local level, as shown by research in the English county of Somerset. The

local Mental Deficiency Committee argued that if a known defective young woman was married then the Committee could not exercise its powers under the Mental Deficiency Act. This afforded the possibility that she could go on to have a large family, which would be prevented if controlled in an institutional setting. As such, the Committee pressed for changes in the law through the introduction of certificates of fitness before marriage that could prevent mentally defective people from marrying in the first place (Fennell 1996).

However, as we argue in this chapter and elsewhere (Tilley et al. 2012), it is a mistake to regard sterilization as a mere historical aberration. Arguably, the credibility of scientific eugenicism waned following the Holocaust, but sterilization continued to be practised extensively in many countries after the discrediting of Nazi ideals, well into the 1970s. Instead, sterilization became reframed as being of social and therapeutic benefit (Dyer 1987, Thomson 1998), ideas which still persist today and carry unfortunate consequences for women's rights and reproductive choice.

Sterilization and Institutions

Much of the evidence concerning historical sterilization practices in the international context relates to institutions. In a number of those jurisdictions where it was legal to impose involuntary sterilization it appears to have become routine to sterilize inmates, mostly women, though in both California (Edgerton 1967) and Alberta (Park and Radford 1998) men were also sterilized. Indeed, in both California and Alberta it appears that sterilization was practiced on most if not all (female and male) residents (Edgerton 1967, Park and Radford 1998). In an interview recorded in 2010, Leilani Muir, who had been an inmate of the Provincial Training School in Red Deer, Alberta, recalled that she was subjected to a routinized practice:

I was taken to the clinic. I was told when I got there that I was going to have my appendix out. I wasn't in any pain, but I was just doing what I was told. There was four of us who had the surgery the same day. I did not know that my life would be ruined for the rest of my life that day.
(Open University on i-Tunes U, 2010)

In Sweden and Iceland, sterilization appears to have been a prerequisite for discharge from institutions and also fairly routinized (Stefansdóttir and Hreinsdóttir 2011). Kristina Engwall's (2004) research into Vastra Mark in Sweden indicates that undergoing voluntary sterilization was a condition of women being released, and notes that out of 481 medical case files '15... explicitly reported that the patient objected to sterilization. However, if not consenting meant remaining in the institution, it can hardly be termed "voluntary"' (2004: 89). Ragnheiður, an Icelandic woman who had been institutionalised in the late twentieth century recalled:

It is so strange. When I moved to the group home I had to undergo sterilization. I didn't agree but I had to agree because otherwise I would not be allowed to move from the institution.
(Stefansdóttir and Hreinsdóttir 2011)

Ladd Taylor (2004), writing about Minnesota, also indicates that agreement to being sterilized enabled women to stay out of institutions, and that this was fiscally driven, to save the cost of an institutional place.

Most of the historical evidence relating to the sterilization of women with intellectual disabilities is from institutions, and countries and states where involuntary sterilization was legally sanctioned.. Formally, mass sterilizations of people with intellectual disabilities practised legally ended in the 1970s when the legislation was repealed. Next we explore the much less well-documented evidence of sterilization practice in the community.

Sterilization Outside Institutions

In the UK, legislation sanctioning the involuntary sterilization of women with intellectual disabilities was never passed². However, this does not mean that sterilization was not practised before 1988, only that it was not routinely documented and emergent oral history evidence indicates that sterilization was not uncommon. People were frequently deceived about what was going to happen, for example, Ebba Hreinsdóttir, whose mother agreed to have her sterilized at the age of 14, was told she was to have her appendix removed, just like Leilani Muir in Canada.

Although evidence is extremely limited, some individuals in the UK were apparently encouraged to undergo sterilization following institutional discharge.. Irene, interviewed by Walmsley in 1991, recalled this series of events following discharge from a long stay hospital. We estimate the date of the operation to be mid 1970s:

Then I went in Luton and Dunstable Hospital, operation, sterilized.

.....

²Prior to 1988 it was unclear whether it was lawful or unlawful to sterilize a woman over the age of 18 who was deemed 'non compos mentos' and could not give her consent to the procedure. Whilst the courts did have some powers regarding sterilization decisions relating to minors, there was no power, in statute or common law, for the courts to sanction the procedure when the person reached the age of 18 if that person could not give consent (TheMentalWeb.com 2011). Professionals undertaking the procedure ran the risk of being accused of medical battery. Following the case of Re F, it was set down in common law that court approval would be required before any such procedure for contraceptive reasons took place; and that approval would only be granted as a last resort and in the best interests of the patient, to guard against sterilization being performed for the sake of convenience. See <http://www.thementalweb.com/index.php/caselaw/cases-pre-2009/93-re-f-mental-patient-sterilisation-1990-2-ac-1-hl.html> for a detailed account of this case.

Long while ago Mr. Brennan down the Centre, he says 'Irene, you don't want a baby'. Mr. Brennan went up there; he said 'I don't want Irene to have that baby'. Took me in the clinic, test me. Yeh, I'm all right, I'm on pills. Oh God, God, tempers, throwing things. I can't remember him, I can't remember anybody, it's those tablets. When I went in the clinic me blood pressure went up high. You know what it was, it's them pills. I'm not taking them no more. Then they took me in the hospital, then I'm all right. Yeah, Doctor Hamilton operated, 10 hours I was underneath. (Walmsley 1991 unpublished interview transcript)

One could not say that Irene was deceived, indeed she appeared to welcome the opportunity to be sterilized, and to come off the contraceptive pill. When she was interviewed she was in a long-term relationship with a man, and apparently enjoying her sex life. The apparent informality of the process Irene described is striking. Its very normality is indicated by this chance comment by a member of a UK women's group: 'People like us don't have babies. No one in the centre does apart from staff. Some people have their stomachs taken out' (Atkinson and Williams 1990: 175).

Evidence suggests that sterilization may have been quite common in England until relatively recently. A survey undertaken in England c.1990 found that over half of 274 responding family members would have or had considered sterilization for their child (Bambrick and Roberts 1991, quoted in Stansfield, Holland Clare 2007: 35). Roy et al.'s study (1993) found that alternative contraception had not been explored by family members considering sterilization (quoted in Stansfield 2007: 36). The most recent research study on the subject in England and Wales was a detailed review of 73 applications for sterilization which went before the Official Solicitor between 1988 and 1999 (Stansfield, Holland Clare 2007). Under mental capacity legislation in England and Wales (Mental Capacity Act 2005), sterilization is only lawful if an individual has the mental capacity to consent. If he or she

lacks capacity there has to be a formal application to the court for contraceptive purposes. If sterilization is considered to be for 'therapeutic' purposes however, and in the best interests of the person, an application may not be needed (Stansfield 2007). The Court must be satisfied that the individual is unable to consent, and that the sterilization is in their best interests because of likelihood of pregnancy, the probable risks of pregnancy and parenthood (psychological damage) and the efficacy of alternative contraception.

Seventy of the cases examined by Stansfield, Holland Clare (2007). were women, three were men, and 37 per cent were minors. The average age of the women in question was 21.4 years. Of these:

- 75 per cent were not in established relationships
- 21 (29 per cent) were known to be sexually active
- 86 per cent had never been pregnant
- 25 per cent were probably the victims of sexual abuse – in nine cases sexual abuse was documented, in a further nine non-consensual sexual activity was suspected
- More than a third were using recognised chemical or mechanical contraception
- A third of women were subjected to supervision as a method contraception.

Thirty-one sterilizations were approved, 28 of these were tubal ligation, and three were hysterectomies. Six procedures went ahead without the need for court approval because the procedure was deemed 'therapeutic', the procedure purporting significant physical, psychological and/or social benefits. Thus, roughly half the cases that were considered were deemed suitable for sterilization.

Stansfield, Holland Clare (2007) explored UK case records from 1988 until 1999; but there is very little evidence on practices after this period, despite the implementation of the Mental Capacity Act 2005 in England and Wales which in principle provides a new framework for decision-making in relation to reproductive rights. However, there is some recent evidence about practice in the past ten years from other western countries. For example, a Belgian study of 397 women aged 18-46 found that 22 per cent had been sterilized (Servais et al. 2004, and a Dutch study involving 397 women aged 15-59 of whom 112 were using contraception, found that 25 had been sterilized, 20 of these prior to 2000 (van Schroyen Lantman-de Valk, Rooks and Maaskant 2011). Under New Zealand law people with intellectual disabilities may be sterilized, without their consent, and court authorisation is not always necessary (Hamilton 2011).

Reproductive Rights, Motives and Decision-making

We have noted the historical justifications for sterilization, in particular the eugenic belief that mental defect was inherited, and the belief that sterilization can have social and therapeutic benefits. More recent research into why women are sterilized, or given long-acting contraception, share common features, and indicate why control of reproduction for women with intellectual disabilities remains a contentious area.

Roets et al. (2006) report their experiences in Belgium in which a young woman with intellectual disabilities and her mother were actively canvassed by professionals to consent to sterilization in ways that appeared disturbingly misleading. While the procedure was first mooted as a means of reducing the discomfort of menstruation, it became apparent that the real concern was the possibility of an unplanned pregnancy (although the woman involved was not in a relationship, nor sexually active at the time). There is also evidence that women

in the UK are placed on contraception without making an informed choice when they are neither sexually active nor experience menstrual difficulties that might be resolved by taking the contraceptive pill (McCarthy 2009a). In this study McCarthy found that only five of these women had made a choice to take the contraceptive, the other 18 reported it had been the decision of a parent, carer or GP. Four of the women had started contraception prior to the age of consent (16) and six women were continuing either on the contraceptive pill or on Depo Provera into their mid to late 40s, although not in heterosexual relationships. McCarthy also described the caution inherent in administering contraception to women who were unlikely to become pregnant as the 'just in case approach', a belief that had been internalised by some of the women themselves. The attitude of the majority of her respondents was characterised as 'passive', accepting that others made the decision for them, and that they would be resisted if they sought to make a different choice: 'my dad would have something to say about it' said one (McCarthy 2009a: 367).

So, if women themselves are not making the decision, the question remains: who is? Mothers frequently appeared to instigate sterilization procedures. This was true for Ebba, the self advocate cited above, also for the majority of cases studied by Stansfield, Holland Clare (2007), and evidence from an earlier research study by Patterson–Keels et al. (1994, quoted in Stansfield 2007). In a case cited by Hollomotz (2011), a mother in law worked with the social worker to persuade a young woman with intellectual disabilities to have the operation. Interestingly, this was also true in a qualitative Taiwanese study by Chou and Lu (2011), who highlighted potential similarities in western and non-western approaches. In their small sample of 11 primary carers and four women with mild intellectual disabilities, Chou and Lu reported that mothers in law were significant decision makers, as were husbands. This is

explained that because the majority of the women were married and it was customary for their husband's family to take responsibility for decision making.

It is also possible that paid carers are influential, though this is an area that is under-researched. McCarthy (2009a) describes a complex set of relationships between carers, family members and family doctors which influenced the decision to place women on contraceptives. One of the authors (Walmsley), in discussion with a GP, was told that she had resisted expectations from staff at a local residential home to give Depo Provera injections to all the female residents to manage their menstruation. The previous GP who attended the home had performed this routinely.

The reasons given for sterilization in the various studies cited so far have common features. The first is the desire for a permanent solution to potential pregnancy, and concern about who may care for any grandchild. This was cited by Pauline, a woman from the UK who decided to have her daughter sterilized in 1970, at the age of 20. She stated in an interview:

I mean if she hadn't been sterilized think how many babies she would have had. (Open University on i-Tunes U 2010)

Pauline believed that she was giving her daughter freedom to have sexual relationships without fear of pregnancy – she also assumed that if children were born, then she would have to take care of them. In the study by Chou and Lu (2011) similar considerations applied. The sample included married women with children; it was assumed they were unable to care for them unaided and that to have more would be both onerous to other family members – husbands and mothers in law – and expensive.

However, fear of pregnancy cannot explain the need to sterilize women who are under 24-hour supervision and who have little opportunity to develop relationships with the opposite sex – this was true of the majority of women in the Stansfield, Holland Clare (2007) study. Van Schrojenstein Lantman-de Valk, Rooks and Maaskant (2011) noted that of the 112 women taking contraception in their study, only ten had possible sexual relationships. Like McCarthy (2009a), they also noted the practice of contraception continuing after the menopause or when the likelihood of sexual relationships was limited.

A second significant reason given for sterilizing women is the danger of sexual abuse. In the Taiwanese study one respondent commented:

My mother was scared that she might be 'chi-fu' (taken advantage of); so she made this decision (tubal ligation)...doing a tubal ligation would make her safe from pregnancy. (Chou and Lu 2011: 67-68)

In her interview, Pauline made reference to the occasion when her daughter had been abducted by a man and expressed relief that this had not led to a pregnancy. Sexual abuse, or its consequences, was a feature of the motives for sterilization applications in 25 per cent of the cases considered by Stansfield et al. Sterilization as a response to the possibility of abuse appears to be the result of faulty reasoning. Sterilization, or injected contraception, does not protect against abuse, merely the pregnancy that may result. The consequences can be chilling. For example, John Pring, the journalist who investigated long standing abuse, including rape, at the homes in the Longcare group in Buckinghamshire, England, in the 1990s noted:

Staff told me disturbing stories including how the GP had given contraceptive injections to at least five of Rowe's female 'favourites' one after the other in a toilet that led off the main

reception area, while he continued sitting with Rowe who was sitting at reception. (Pring 2005: 4)

The way the General Practitioner (GP) operated, in public, meant that the women had no opportunity to raise with him any objections to the practice, or to tell him of the abuse. This casual practice had enabled the home owner, Gordon Rowe, to continue to rape the women without fear of any consequences. We would suggest that giving contraception to women because they are at risk of sexual abuse is in itself abusive, and points to a lack of regard for their well being.

The final major reason cited for sterilizing women was the management of menstruation, something not mentioned in historical studies. In the Dutch study by van Schronstein de Valk et al. (2011) 'problems with menstruation' were cited in 35 cases (57 per cent). These problems included heavy flow, premenstrual syndrome and irregular periods. In a further 24 cases (39 per cent) problems with behaviour related to menstruation were cited, including: mood changes before or during menstruation, crying, self-injurious behavior, obsessive masturbation and problems with maintaining hygiene. Two women in the Chou and Lu (2011) study had hysterectomies to manage menstruation, both at the instigation of their mothers. Another mother in this study mentioned her daughter throwing sanitary towels away. This combined with fear that she would be abused by male students at her day care centre had led them to choose hysterectomy.

Management of menstruation is a task that will not necessarily be welcomed by family members or staff. However, convenience for the carer is a dubious argument for indefinitely placing women on long-acting contraception with possible adverse health consequences. It may explain, however, the practice of administering contraception to

women who are – in reality – at very low risk of pregnancy due to age or living circumstances (also noted by McCarthy 2009b, 2010b).

Parenting and Women with Intellectual Disabilities

At several points in this chapter we have suggested that control of women's reproductive capacity is partly to prevent conception, but also to preclude them from rearing children – the historical debates quoted from Somerset in the 1920s make this point very clearly. Of course, struggles for the right to reproduce are experienced by other groups of women who – for moral, political, social and religious reasons – are seen as unfit to mother:

There is a hierarchy of motherhood with the heterosexual, white, middle-class married woman being the most highly valued. 'Other' mothers, such as the lesbian mother, the mother on welfare, the teen mother and so on, are often stereotyped as inappropriate (Earle and Letherby 2003: 4).

The literature on contemporary parenting by women with intellectual disabilities is far more extensive than that on sterilization, contraception or reproductive rights (see Llewellyn et al. 2010 for a comprehensive international overview). Across the developed world (including Western Europe, Australia and North America), if women with intellectual disabilities get so far as to have children, they are very likely to have them removed. Figures are difficult to come by – partly because the label of intellectual disability is very broad and partly because the label is sometimes applied to people who appear to be 'unfit' parents. However, Llewellyn et al. (2010) quote figures of up to 48 per cent of women having their children removed in Western Europe and Australasia.

Parenting presents one of the most potent challenges to the upholding of women's rights. The literature points to the removal of children based on faulty premises, documented

in Australia, Iceland, UK and USA (McConnell et al. 2010). The first assumption is that parental intellectual disability is mistakenly taken for evidence of parental incapacity, and even in some US states is spelt out as a legitimate ground for terminating parental rights. The second is the belief that such people can never become good parents – and that they are subjected to tests and surveillance which other parents might also struggle to surmount, if they had similar treatment (Sigurjonsdóttir and Traustadóttir 2010).

Final Thoughts on Intellectual Disability and Reproductive Futures

It is possible that the sterilization of women with intellectual disabilities is falling into disuse in Western Europe and elsewhere. However, the existing research is limited in its scope, despite the fact that these issues continue to be brought to the public's attention (see McVeigh 2011 for information about a recent Court of Protection case in England). With the advent of Human Rights legislation, the UN Convention on the Rights of Persons with Disabilities to which many western countries are signatories, and in England and Wales, the Mental Capacity Act 2005, things may be changing. It is also possible that the availability of long-acting injectable contraception has made sterilization less attractive, given the legal safeguards surrounding its application. However, as McCarthy points out, ethical, moral and human rights issues have not disappeared just because the technology changes; she argues: 'when a woman ... is put on contraception for most or all of her reproductive life this is arguably a chemical sterilization, yet it has no legal scrutiny'. (2010b: 264)

In this chapter, we have laid out the evidence in the published literature on sterilization of women with intellectual disabilities. We have suggested that surgical sterilization is less prevalent than it was in the mid-twentieth century when thousands of women and some men also, were routinely sterilized. In some cases this was technically

voluntary, though if the consequences for women were that they remained in institutions if they chose not to accept sterilization, it cannot be seen as a free choice. However, administering contraception to women who are at low risk of pregnancy without their fully-informed consent appears to have continued.

This chapter shows how the reproductive lives of women with intellectual disabilities have been, and continue to be, controlled; and this control has been exercised through a variety of means, both legal and otherwise. We argue that it is imperative that women's agency is recognized, and acknowledge that for some women with intellectual disabilities such practices may create freedom, and may be a positive choice. Indeed, some of the conversations we have had with women indicate that sterilization was an option that they pursued, as it enabled them to participate in sexual relationships free from the worry of getting pregnant (Walmsley 1995).

However, the limited evidence on this subject suggests the wider picture is one of the systematic control of women's lives, creating a series of reproductive losses which have been endorsed and perpetuated by families, carers and practitioners. The practice of 'supervision', for example, means that many people with intellectual disabilities are prevented from expressing themselves sexually. As argued elsewhere,

Social groups that lack power, also lack the ability to define and regulate their own sexuality. In modern Western societies, sexuality is not seen as an integral part of the lives of disabled people.

Disabled people are expected neither to reproduce nor be reproduced. (Earle 2001: 435)

Just as supervision controls sexual expression, sterilization – including long-term contraceptive use – prevents a reproductive future.

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