

‘The Silence is roaring’: Sterilization, reproductive rights and women with intellectual disabilities

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Introduction

This paper reviews the history of sterilization of women labelled as having an intellectual disability, and considers its relevance to their reproductive choices and futures. Although involuntary sterilization is probably no longer a widespread practice in most Western countries, its history sheds light on contemporary practices which can be regarded as constituting a continuation of eugenic practices by other means.

The paper is written in the context of a lack of gender awareness in the literature on intellectual disability (Traustadottir and Johnson 2000; Mayes and Sigurjonsdottir 2010). Gender is central to understanding experiences and representations of human reproduction (Earle and Letherby 2003), and indeed it could be argued that individual experience can only be fully understood once the person becomes gendered. However, after a brief flowering in the 1990s (Atkinson and Walmsley 1995), women’s issues remain underrepresented in research and policy. Neither of the recent significant policy initiatives in England -Valuing People (DH 2001) or Valuing People Now (DH 2009) - make reference to gender issues, in contrast to challenges raised by ethnicity or people labelled with high support needs. Yet the limited research undertaken from a gender perspective indicates that women with intellectual disabilities do face particular issues including the high incidence of sexual abuse (Turk and Brown 1992; Walmsley 1993; McCarthy and

Thompson 1997 quoted in Fyson and Cromby 2010), low access to cancer screening (Nightingale 2003; Willis et al 2008), lack of agency over contraception (McCarthy 2009) and information about the menopause (McCarthy and Millard 2003). Parenting research is an exception, though, even here, as Mayes and Sigurjonsdottir (2010) argue, a lack of gender awareness prevails as fathers are usually ignored.

Likewise, the broader literature on human reproduction has, with some exceptions, largely ignored the needs and experiences of people with intellectual disabilities. The concept of reproductive rights has been central to feminist campaigns which have demanded the right of women to 'control their own bodies' (Petchesky 1986; Himmelweit 1988; Kitzinger 1992; Kallianes and Rubinfeld 1997; Rembis 2010). Whilst some writers have extended these debates to the experiences of disabled women (Finger, 1991; Morris, 1996), disability is most often discussed in the context of new technologies such as genetic diagnosis and diagnostic screening (Kerr and Shakespeare 2002; Sharp and Earle 2002; Shaw 2004; Shakespeare 2008; Rembis 2010). There is some recognition of difference and diversity, in that motherhood is only positively sanctioned within conducive economic, social and sexual circumstances whereby the rights of heterosexual, white, middle-class non-disabled women are privileged over those of 'others' (Letherby 1999; Ragone and Twine 2000; Earle and Letherby 2003). Otherwise the needs and experiences of women with intellectual disabilities are generally ignored.

This paper reviews the significance of sterilization in the light of historical and international perspectives before exploring accounts from both family members and survivors of involuntary sterilization, and ends by indicating connections between past and current practice relating to reproductive choice.

Methodological and ethical considerations

The data collected for this paper have come from a range of sources. A literature review was conducted using the search terms ‘sterilization’ and ‘learning / intellectual disabilities’, augmented by references from Stansfield’s doctorate (Stansfield 2007), and intellectual disabilities literature published since the 1960s (for example Edgerton 1967; Craft 1979). The majority of published literature on this topic emerges from the UK, the US, Canada, and the Nordic countries. Unpublished data from life stories collected for Walmsley’s (1995) PhD were also included.

Given the sensitivity of the topic, individual stories were collected through personal networks. The authors already knew Ebba Hreinsdottir (whose story is outlined below) and had heard her speak of being sterilized at a conference. She was approached for an interview for an Open University podcast on the topic (Open University on i-Tunes U 2010) through her friend, Gudrun Stefansdottir from the University of Iceland, who had accompanied her to the international conferences where we had met. As Leilani Muir’s story (see below) was already in the public domain, she was also contacted for the podcast via an academic contact, Claudia Malacrida. Pauline had mentioned having her daughter sterilized in an earlier research interview (Rolph 2002) and subsequently agreed to an interview specifically about the sterilization. After lengthy discussion she specifically requested that her first name be used, but not her surname, in order to protect her daughter’s identity.

The ethics of investigating a personal and rarely discussed topic are fraught. There is potential for implicit blaming of parents and professionals, for stirring long buried pain amongst women who have been sterilized, even for raising topics which could be the subject of legal redress. The

authors are confident that, with one exception, individuals quoted in the paper had every opportunity to understand the implications of speaking out. The exception, 'Anita' (pseudonym), is now dead. However, because of her commitment to speaking out publicly for the rights of people with intellectual disabilities, the decision was made to include her story, but conceal her identity.

It is also important that we acknowledge the limitations of our sampling method. Clearly we cannot claim to have drawn upon a representative sample. The data presented has come from people who have been outspoken on the subject and for whom sterilization was a contentious issue. As we argue in the paper, there is now an urgent need to build on this anecdotal evidence through a more sustained empirical investigation of the topic.

The rationale for sterilization – an historical review

The sterilization of women with intellectual disabilities was legal practice and common in a number of European countries and states in Canada and the US in the early to mid twentieth century. The literature is dominated by the view that this was inspired by the belief that 'mental defect' was inherited (Jones 1986; Laughlin 1926, reprinted 2004; Reilly 1977). Park and Radford (1998) argue that people with intellectual disabilities were targets because of societal fears about 'mentally deficient' people outnumbering those of 'normal' intelligence. If this was the case, then, arguably, the practice would die out as scientific belief in inherited defect waned. However, sterilization continued to be practised extensively in many countries well into the 1970s after the so-called discrediting of eugenic views associated with Nazism and the holocaust, because it was reframed on social or therapeutic grounds (Dyer 1987; Thomson 1998). An

argument used in the US and the Nordic countries was that some women were unfit for parenthood, indeed incapable of parenting adequately; sterilization would liberate such women, enabling them to live outside of institutions without the danger of pregnancy (Engwall 2004; Ladd-Taylor 2004). This would, in addition, save the cost of institutionalizing more women. As Ladd-Taylor contends in relation to Minnesota in the interwar period ‘sterilization policy was as much about preventing child rearing by the so-called feeble-minded as it was about preventing child bearing’ (Ladd-Taylor 2004: 289). It is this motivation that, we argue, remains prevalent in twenty-first century thinking and practice, given that currently between 40-60% of children born to parents with intellectual disabilities are removed from their care (Sigurjonsdottir and Traustadottir 2010: 50).

Kallianes and Rubenfield (1997) argue that disabled women’s reproductive rights are constrained by three factors: the assumption of asexuality, a lack of health care services and information, and social resistance to reproduction and mothering. They acknowledge that ‘disabled women’ are not an homogenous group but do not specifically consider the experiences of women with intellectual disabilities. The management and constraint of their reproduction and sexuality would suggest that women with intellectual disabilities have been and are regarded as sexually wayward and unruly, rather than straightforwardly asexual (Atkinson and Walmsley 1995; Parmenter 2001; Rafter 2004).

As for all women, bodily fluids such as menstrual blood, vaginal discharge and breast milk mark the female body as ‘messy’ (Martin 1989: 93). Sterilization may have been used to stop menstruation, as well as to manage sexuality and reproductive capacity. Ten of 73 referrals for sterilization made to the Official Solicitors in England and Wales between 1988 and 1999 were on the basis of ‘menstruation difficulties’ (Stansfield et al, 2007). Menstruation was also at the

centre of Alison Thorpe's case (Bowcott 2008). Her mother argued that a hysterectomy was necessary to prevent her then teenage daughter experiencing the 'pain, discomfort and indignity of menstruation' (Bowcott 2008). Although the hospital rejected the plea in 2008 on the grounds of insufficient clinical justification, the case raises important issues about parental perceptions of the impact of menstruation on disabled women's quality of life, and concerns about how this can be managed. The limited empirical evidence available for earlier historical periods has not revealed management of menstruation as a reason for sterilization, however, this remains a largely unspoken issue in intellectual disability and McCarthy (2009) surmises that management of menstrual bleeding continues to be a reason for using long-term contraceptive injections.

The international prevalence of involuntary sterilization

The sterilization of certain categories of individuals - 'criminals', 'rapists', 'epileptics', 'the insane and idiots' in state institutions (Kevles 1995) - was legal in some North American and European jurisdictions between the early twentieth century and the 1970s. Indiana was the first US state to legalize compulsory sterilization in 1907; by the end of the 1920s there were 24 US states where involuntary sterilization was legal; and 20,000 legal sterilizations had been performed by the mid-1930s (Kevles 1995: 112). The number of sterilizations continued to grow despite the scientific rationale of inherited defect being discredited. The Nazi excesses, often credited with undermining the eugenic case for sterilization, made little difference in practice. Between 1946 and 1956 13,000 US citizens were sterilized (Reilly 1977).

Two Canadian States, Alberta and British Columbia, passed laws permitting sterilization in the inter-war period; in 1926 and 1933 respectively. In 1937 and 1944 the Alberta legislation was strengthened to exonerate any practitioner from possible civil action (Park and Radford 1998)

and to permit castration. It remained in operation until 1972; between 1929 and 1969, 948 men and 1154 women are known to have been sterilized in Alberta (Park and Radford 1998).

Alberta, along with California (Edgerton 1967), appears to have been unusual in targeting almost as many men as women. Currently a major research programme is seeking to document personal stories of survivors of these sterilization programmes (Malacrida 2010).

In Europe, Sweden had the largest sterilization programme with 60,000 people, mostly women, sterilized between 1935 and 1976. In Denmark 6000 people were sterilized under a law passed in 1929. Similar legislation was passed in Austria, Norway, Iceland and Switzerland (Park and Radford 1998). Roets et al's paper (2006) indicates that in Belgium, sterilization continues to be strongly advocated, and Servais et al's research (2004), highlights that sterilization rates for women with intellectual disabilities continue to be high in that country (22.2% in a survey of 397 women in two provinces, three times the rate for the general population).

Most of what is known about sterilization is associated with institutional practices. Kristina Engwall, writing of the Swedish institution Vastra Mark, notes that some women were admitted in order to persuade them to accept sterilization, while others were discharged on condition that they accepted the procedure: 'The Swedish sterilization law was not compulsory but choices such as [remaining at the institution or being sterilized] do not correspond to what we today consider as a freely made decision' (Engwall 2004: 88).

Less is known about sterilization practices outside of institutions. From the 1970s, cases in the US increasingly had to undergo a process of judicial review (Reilly 1977). According to Reilly, writing at that time, this made physicians wary of responding to family requests for the sterilization of women. This hints at the roles played by families in instigating sterilization

referrals; and those of doctors who were approached in the decision-making process. It suggests a hidden history even in those places where sterilization is relatively well documented.

Sterilization in the UK

In contrast to those countries where compulsory sterilization was legal, we know relatively little about practice in the UK. Sterilization on any grounds for women with intellectual disabilities was assumed to be unlawful, because the Offences against the Person Act 1861 made it a crime to cause grievous bodily harm (Kevles 1995: 115). Compulsory sterilization of women with intellectual disabilities was advocated by campaigners in the early twentieth century, in the belief that it would reduce the frequency of 'feeble-mindedness' (Kevles 1995: 165) and some local groups campaigned for it to be legalized in the 1920s (Thomson 1998; Walmsley, Atkinson and Rolph 1999). The Brock Committee report (1934) argued that there was no case for compulsory sterilization, warning that it might encourage promiscuity; however, voluntary sterilization may be warranted where disorders had a genetic origin (Jones 1986). This gave rise to a fear that 'voluntary' sterilization might become a condition for release from institutions into the community (as highlighted by practices in Vastra Mark in Sweden), and that it would therefore be 'voluntary' only in name (Thomson, 1998). The Catholic Church and left wing intellectuals and politicians 'formed an increasingly potent anti sterilization coalition', according to Kevles, and 'the move to legalize voluntary sterilization failed utterly and was dead as a legislative issue by 1939' (Kevles 1995: 169).

Although Kevles argues - despite a lack of empirical evidence - that before the Second World War doctors in Britain were reluctant to perform sterilizations, his argument is implicitly challenged by reference to practices in Europe where sterilization of 'mentally defective' women was common. Kristina Engwall noted that laws permitting sterilization in the Nordic countries

were ‘regulating a previously unregulated area where personal and private initiatives had dominated’ (2004: 86). It seems unlikely that the situation in Britain was different, though we have as yet no evidence from the inter-war period.

By 1979 sterilization was being advocated as the most effective method of birth control for people with intellectual disabilities as an aspect of pre-marital counselling (Craft 1979; Hollomotz 2011), although the practice was contentious (Dyer 1987). Craft cited figures from his study of married couples that 13 of 34 couples had been sterilized. He acknowledged ‘it does raise the vexed issue of informed consent, as mentally handicapped people are often easily influenced by authority figures’ (Craft 1979: 358).

A survey undertaken in England c1990 found that over half of 274 responding family members would or had considered sterilization for their child (Bambrick and Roberts 1991, quoted in Stansfield 2007: 35). These considerations were prompted by their child moving away from home, displaying interest in the opposite sex, or becoming involved in a steady relationship (Bambrick and Roberts, 1991). Patterson–Keels et al’s research (1994, quoted in Stansfield 2007) found that most requests for sterilization were made by mothers, and that almost all mention coping with menstruation. 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 main source of knowledge about more recent UK cases has been legal records. Stansfield, Clare and Holland (2007) reviewed 73 referrals to the Official Solicitor’s Office (England and Wales) between 1988 and 1999 concerning people who were deemed to lack capacity. A Judge sitting in the Family Division of the High Court heard the evidence, and made a decision. Of the

73 cases reviewed, only three concerned men. The individuals were aged between 12 and 41 years. Most were young women described as having 'severe' intellectual disabilities living with their family. This research confirms the earlier findings that families prompted the request for sterilization. In roughly half of the 73 cases, sterilization went ahead. The authors note that the cases were referred at a much younger age than the norm; that in at least 9 and possibly 18 cases abuse was indicated; and that, given these women would be under 24 hour supervision on account of their high support needs, other contraceptive options could have been pursued.

The extent of referrals into the twenty-first century is unclear, particularly following the Mental Capacity Act (2005). Stansfield et al (2007) noted that only one referral had resulted in sterilization since 2002 (although this figure may now be out of date, given the date of the article). However, in the absence of subsequent empirical research it is impossible to assess the current extent of sterilization.

Oral history evidence

Although there has been little empirical research since the early 1990s with the exception of Stansfield et al (2007), there is some oral evidence relating to sterilization in the UK. It has emerged in the course of life history work (Atkinson and Williams 1990; Walmsley 1995), and in conversation with women, family members and practitioners. It confirms that sterilization took place outside institutions either at the instigation of families (usually without either the knowledge or consent of the woman), or as a result of negotiations between the woman and service providers.

In the mid-1990s, the second author spoke with 'Anita', a self-advocate who reported that while living with her family she had been sterilized without her knowledge at age 14 (in the early 1970s), and had been told it was to have her appendix out. She explained that she had not mentioned this when she had published her life story because she could not talk about it with a male interviewer, an indication of the methodological challenges of research on this topic (Walmsley 1995).

Following a passing reference to having her daughter sterilized made in a research interview (Rolph 2002), the second author contacted and interviewed Pauline, whose daughter was born in 1950. Pauline had her daughter sterilized aged 20. The decision was taken to prevent her daughter becoming pregnant:

For one reason, she would just go off with anyone. If someone made eyes at her in the street – she went missing didn't she?

She was near normal as far as looks were concerned, it was only when one got to know her that you realized she was handicapped – so she was fair game to anyone who came along.

Men or boys – it didn't matter if they were older or younger than her...then she went missing and this chap had her in a room, locked her up, we had to have the police and everything.

After that they put her in 'S' and she hated it – like a prison it was, a care unit for people with severe mental problems – she was locked up.

The police wanted us to take it to court but how can you have a handicap go to court and stand up – she wouldn't understand anything...he got away with what he'd done to her...I mean if she hadn't been sterilized think how many babies would she have had.

(Open University on i-Tunes U 2010)

Sterilization had not prevented her daughter being abducted and, presumably, sexually assaulted, however, Pauline was adamant that the operation had enabled her daughter to enjoy life, free of the fear of pregnancy. Pauline believed that she would have had to take responsibility for any offspring, because her daughter was incapable of looking after a child:

At least she could go out to places and I'd know she wouldn't get pregnant which would have been wrong. I'd have got sued for letting her go out, wouldn't I?...What would have happened if she'd had a young child – horrifying....

(ibid)

Persuading a doctor to undertake the procedure was not a major obstacle, once he was satisfied that Pauline's daughter had intellectual disabilities:

Well I went to my doctor and he sent me to a specialist – he thought she, looking normal, was ok, but then, when he interviewed her he said I'll do it, the operation.

I didn't have to go to court or anything...I made the decision as a mother and that was it...no legal things...no.

(ibid)

Just one person's story, but this is possibly the tip of an unexplored iceberg. The very simple procedure Pauline describes of visiting her doctor and informing him and the specialist that her daughter was 'handicapped' was enough to get the operation done. It is likely that other families had daughters sterilized on the grounds it would free them, and free themselves, as parents, of the possible consequences.

International comparisons

Accounts from other countries echo the experiences from the UK. Ebba Hreinsdottir was born in Iceland in 1950. Her experience resonates with Anita's. She recounted, through a translator, that her sterilization took place at age 14, at the instigation of her mother:

She was sterilized when she was 14 when she lived with her parents and siblings. But she didn't know about it until she was 27. She went to the sterilization as a child; she was told the appendix had to be removed and she was showing her grandmother the scar - she was sure it wasn't in the right place so she asked her grandmother, but her grandmother didn't want to talk about it and would talk about something else. She told her to play.

When she knew about it she was at the institution. Five women were going to be sterilized and they were having lessons about it and Ebba asked 'why am I not in this group?' And the woman told her she had been sterilized when she was 14.

(Open University on i-Tunes U 2010)

Ebba, via her translator, described the effect on her relationship with her mother: 'Ebba says, in the beginning she was angry but she's accepted it and she's not angry with her mum. She was

angry that she couldn't decide by herself. The decision was not hers' (Open University for iTunes U 2010). Through discussions with Gudrun, her supporter and translator, Ebba had come to realise that her mother had acted in good faith by the standards of the time: 'It's not their fault. It's the community that's decided to do this. It was her mother's decision as part of the society' (ibid). Ebba's account highlights the central role played by family members in decision-making, and suggests that obtaining a medical sterilization without consent or formal legal procedures was possible in Iceland as in England.

The experiences cited by Anita, Pauline and Ebba hint that sterilization as the outcome of private negotiations between medical practitioners and families may not have been uncommon.

Sterilization's 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).

The impact of sterilization on women's lives

Most research into sterilization has been by reference to legislation and eugenic debate. Its impact on women survivors has been little explored. The limited empirical evidence that exists suggests that women with intellectual disabilities express sadness, anger, regret and despair upon learning that they have been sterilized without consent. Engwall observes that 'it is difficult to find out what the feeble-minded women thought about sterilization from the written sources. Out of 481 medical case files, 15 ... explicitly reported that the patient objected to sterilization' (2004: 89). Park and Radford (1998) term their reading of the Alberta case files as 'history from

below'. The case files provide insight into what the authors call a 'new mode of surveillance' in the sense that the intended objective was anticipation and prevention of undesirable events.

The Alberta Living Archive Project aims to uncover and record the voices and experiences of survivors of involuntary sterilization. Leilani Muir, one of the Alberta survivors, said it had 'ruined' her life:

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)

She describes a cursory process:

We went before a board that day, but I only remember a couple of questions... Five minutes of time to wreck my life forever. It was like a conveyer belt of cattle. Stamped on all the files it had: clear, clear, clear. That was clear for the surgery. I didn't realize this 'til I got my files.

(ibid).

Other personal accounts have been published. Elaine Jessie, sterilized by the state of North Carolina in 1967, describes herself as being 'humiliated' and 'devastated' after discovering she had been sterilized while having an abortion for a child she conceived aged thirteen (Fields-Meyer and Helling 2003). Robert Edgerton, who researched the lives of former inmates of the California Pacific State Institution in the 1960s, reports that 44 of the 48 ex-patients he studied

had been sterilized. He wrote ‘unless there was a profoundly negative reaction on the part of a relative or guardian, surgical sterilization of both males and females was routinely performed’ (1967: 154). A minority, invariably single men, considered it a benefit, with one commenting ‘this way I can play around with the girls and I don’t have to worry about getting into no trouble’ (1967: 155). Most ex-patients, however, held strongly negative feelings:

They objected to it because it suggested to them their mortifying, degrading and punishing past ... As such it served as a permanent source of self doubt about their mental status. One woman ... ‘I still don’t know why they did that surgery to me. The sterilization wasn’t for punishment, was it? Was it because there was something wrong with my mind?’

(Ibid: 155)

Others described deep sadness at an inability to have children. Edgerton (1967) noted that sterilization impeded their ‘passing’ as normal, and that it inhibited marriage, because women were too ashamed to admit to their inability to have children due to their (concealed) institutional past. To explain the scar, women blamed it on appendectomy. Edgerton observes ‘this is a nice irony, since sterilization surgery was usually described to the patient as an appendectomy, rather than what it actually was’ (1967: 156). It seems that this particular deception travelled the world from Iceland to Britain to the USA to Canada.

Informed Consent?

Historically, whether a woman had the capacity to consent to sterilization procedures was routinely discarded. In the twenty-first century across most Western countries, greater emphasis is placed on enabling people with intellectual disabilities to be involved in decisions about their

lives (Johnson et al. 2010). The Mental Capacity Act 2005 (England & Wales) introduced a legal framework in which capacity is presumed, with assistance provided to ensure, as far as is reasonably possible, that people make decisions for themselves (Mandelstam 2009). If a person is deemed to lack such capacity, there follow procedures to guarantee that a decision is taken in that person's best interests. Decisions concerning sterilization, and the use of contraception, require careful consideration regarding how to involve women in the decision-making process. There is not yet sufficient data available to ascertain the impact of this legislation on practice. However, recent evidence from Belgium suggests that the boundary between what does and does not constitute 'informed consent' can be blurred. Despite the Medical Association declaring that sterilization could only be carried out where strictly necessary and with informed consent (Denekens 1992) there are reported examples of women in Belgium being pressurized by professionals, without clear explanation as to why such an intervention is needed, or what the impact will be (Roets et al, 2006).

In the broader context of choice and control over contraception, Michelle McCarthy's (2009) research indicates that contraception is prescribed at an earlier age and continues later than for non-disabled women, with an over reliance on carers to communicate with doctors. McCarthy (2009) observed a disregard for the health consequences of using Depo Provera for long periods and suggests that contraceptive devices are being used as a response to the danger of sexual abuse and rape; the 'just in case' approach, justifying contraceptive interventions even amongst women who are not sexually active, on the basis that something might happen to them at a future point. The rationale is not far removed from the case that was being made to sterilize institutionalized women in the so-called 'Eugenic era'. McCarthy (2009) also noted an unwarranted and exaggerated fear of the consequences of pregnancy; and that decisions

concerning contraception are informed by convenience for staff in managing women's periods. She concluded that her interviewees lacked autonomy or knowledge of alternatives, and played a largely passive role in determining whether to use contraception, and the range of choices available. She points out that whereas sterilization is subject to legal oversight no such safeguards exist for the use of long-term contraception such as Depo Provera: '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' (2010: 264).

Discussion: the case for further research

The evidence in this paper, albeit limited, suggests a strong rationale for further study of past practices regarding sterilization. The Ashley Case, in which parents of a severely disabled child sought growth attenuation, including sterilization, to keep her in a state of permanent childhood (BBC news online, 17th January 2007), and interest in *Project Prevention* which offers to pay drug users to undergo sterilization (BBC news online, 17th October 2010), indicate that the issues underlying policies of the past are not far from the surface (Lantos 2010). Research has rarely addressed the private use of sterilization, where families have apparently persuaded doctors to sterilize their daughters, often at an early age, and yet this is the picture emerging from the few personal accounts obtained to date.

Whilst medical technologies may have changed, essential questions about intellectually disabled women's rights to participate in decisions about their own reproductive futures remain. The literature surveyed in this paper, and the voices presented, suggest that the restrictions placed upon women with intellectual disabilities to participate in and manage their own reproductive

capacity have not gone away as institutions have closed. The dilemmas facing family members and professionals have not dissipated, merely because legislation and policy promote greater choice and control. Supporting people with learning disabilities to enjoy safe and responsible sexual lives is an aspect of practice that has lacked detailed exploration and reflection and the legal, political and social discourses surrounding intellectual disability and sex remain contentious and often hidden (Rogers 2009).

A strong rationale for further research is given by the Alberta Living Archive Research Project:

An understanding of the past here is of special relevance for ongoing discussions at the interface of reproductive choice, disability, human variation, and technology. Thus integral to the project is a communal space for the exploration of the relationships between the history documented and current policies and practices. Whether contemporary practices, such as recommended screening for Trisomy 21 (Down Syndrome) or selective abortion of “defective fetuses” constitute new forms of eugenics—*newgenics*, as it is sometimes put—remain topics of debate, which *Living Archives* will inform and advance.

(Wilson, 2010: 4)

The use of long term contraceptive injections, for ‘just in case’ reasons or to control menstruation, like parentally instigated sterilization in the past, sits in a shadowy space between legitimate and illegitimate medical practice. An important area for future investigation is how such practices are negotiated between individuals, their guardians, family members, advocates and professionals.

The last word is accorded to Ebba who has strong views about what should happen next. Her translator says: 'she thinks it's very important that women all over the world talk about it, as it's been such a secret all over the world' (Open University on i-Tunes U 2010). Ebba's anger abated as she was able to share the experience and understand the wider historical context in which it took place. In the history of sterilization, as in many other areas of intellectual disability history, the shadow of the institution and its now discredited practices has dominated, leaving a 'roaring silence' about the experiences of women, and men, outside its walls. The case for more research into this difficult area is strong. If the 'roaring silence' continues, very few survivors of the sterilization era will have the opportunity to share their experiences as Ebba did.

References

Atkinson D and Williams F (eds). 1990. *'Know Me As I Am': An anthology of prose, poetry and art by people with learning difficulties*. London: Hodder and Stoughton.

Atkinson D and Walmsley J 1995. 'A woman's place: issues of gender' in Ward L and Philpott T (eds) *Values and Visions: Changing ideas in services for people with learning difficulties* London: Butterworth Heinemann pp 218-231.

BBC news online, 2007. Campaign to prevent Ashley Case. 17th January 2007.

<http://news.bbc.co.uk/1/hi/health/6267929.stm> [last accessed 7th February 2011]

BBC news online, 2010. Charity offers UK drug addicts £200 to be sterilized. 17th October 2010.

<http://www.bbc.co.uk/news/uk-england-london-11545519> [last accessed: 7th February 2011].

Bowcott, O. 2008. Hospital refuses plea for hysterectomy on cerebral palsy girl. *Guardian online* <http://www.guardian.co.uk/society/2008/jan/19/nhs.healthandwellbeing> [last accessed 4th November 2010).

Craft, M. 1979. Personal Relationships and Partnerships for the Mentally Handicapped. In *Tredgold's Mental Retardation 12th Edition* 354-371. Ed. M. Craft. London: Bailliere Tindall.

Denekens, J. 1992. Sterilisatie en mentaal gehandicapten: wie beslist? (Antwerpen, Proefschrift ingediend tot het behalen van de grad can geaggregeerde voor hoger onderwijs ann de Universitaire Instelling Antwerpen, Departement Geneeskunde, Promotor Prof. Dr K. Van Camp).

Department of Health. 2001. *Valuing People: A new strategy for learning disability for the 21st century*. London: The Stationery Office

Department of Health. 2009. *Valuing People Now: A new three-year strategy for people with learning disabilities*. London: The Stationery Office

Dyer, C. 1987. 'Sterilisation of Mentally Handicapped Women' *British Medical Journal*, Vol. 294, pp.825.

Earle, S. and G. Letherby. 2003. *Gender, Identity and Reproduction: Social perspectives*. Houndsmills: Palgrave.

Edgerton, R. 1967. *The Cloak of Competence*. Berkeley: University of California Press.

Ehrenreich, C. and English D.. 1979. *For Her Own Good: 150 years of experts' advice to women*. London: Pluto.

Engwall, K. 2004. Implications of being diagnosed as a "feeble-minded woman". In *Gender and Disability Research in the Nordic Countries*, eds K. Kristiansen and R. Traustadottir. Sweden: Studentlitteratur.

Fields-Meyer, T. and Helling, S. 2003. Sterilized by the State: a woman fights back. *People* 60, no. 7.

Finger, A. 1991. *Past Due: a story of disability, pregnancy and birth* London: Women's Press.

Fyson, R. and Cromby, J. 2010. Memory, sexual abuse and the politics of learning disability. In Haaken, J. and Reavey, P. *Memory Matters: contexts for understanding sexual abuse recollections*. Hove: Routledge, p.157-174.

Himmelweit, S. 1988. More than "a woman's right to choose". *Feminist Review* 29: 38-53.

Hollomotz, A. 2011. *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

Johnson, K., Walmsley J. and Wolfe M. 2010. *People with intellectual disabilities: Towards a good life?* Bristol: The Policy Press.

Jones, G. 1986. *Social Hygiene in Twentieth Century Britain*. Worcester: Billing and Sons.

Kallianes, V. and Rubinfeld, P. 1997. Disabled women and reproductive rights. *Disability & Society* 12, no. 2: 203-222.

Kerr, A., and Shakespeare, T. 2002. *Genetic politics: From eugenics to genome*. Cheltenham: New Clarion Press.

Kevles, D. 1995. *In the Name of Eugenics*. Cambridge, Mass: Harvard University Press (2nd revised edition).

Kitzinger, S. 1992. Birth and violence against women: Generating hypotheses from women's accounts of unhappiness after childbirth. In *Women's Health Matters*. H. Roberts (ed.). London: Routledge.

Ladd Taylor, M. 2004. The “sociological advantages” of Sterilization Fiscal Policies and Feeble Minded Women in Interwar Minnesota. In *Mental Retardation in America* pp. 281-302 Eds. S. Noll and J. Trent J. New York: New York University Press.

Lantos, J. 2010. It's not the growth attenuation, it's sterilization. *The American Journal of Bioethics* 10, no. 1: 45-60.

Laughlin, H. 1926, reprinted 2004 The eugenical sterilization of the feeble- minded in Noll S and Trent JW (eds) *Mental Retardation in America* New York University Press. Pp. 225-231.

Lawson, W. 2005. *Sex, Sexuality and the Autistic Spectrum*. London: Jessica Kingsley Publishers.

Letherby, G. 1999. 'Other than mother and mothers as others: the experience of motherhood and non-motherhood in relation to 'infertility' and 'involuntary childlessness'', *Women's Studies International Forum*, 22:3 (1999) 359-372.

Llewellyn, G., R. Traustadottir, D. McConnell, H.B. Sigurjonsdottir (eds). 2010. *Parents with Intellectual Disabilities*. West Sussex: Wiley Blackwell.

Malacrida, C. 2010. 'Creating a Living Archive on Eugenics: Questions of Ethics, Scope and Access'. Presented October 23, 2010 at the Inaugural Public Conference of the Living Archives CURA. Edmonton, Alberta.

Mandelstam, M. 2009. *Safeguarding vulnerable adults and the law*. London: Jessica Kingsley Publishers.

Martin, E. 1989. *The Woman in the Body: a cultural analysis of reproduction*.
Buckingham: Open University Press.

Mayes, R. and Sigursjondottir H.B.. 2010. Becoming a Mother – Becoming a Father. In *Parents with Intellectual Disabilities* 17-32. Eds. G. Llewellyn, R. Traustadottir, D. McConnell and H.B. Sigurjonsdottir. West Sussex: Wiley Blackwell.

McCarthy, M., & Thompson, D. 1997. A Prevalence Study of Sexual Abuse of Adults with Intellectual Disabilities Referred for Sex Education. *Journal of Applied Research in Intellectual Disabilities*, 10, 2, 105-124.

McCarthy, M. and L. Millard. 2003. Discussing the menopause with women with learning disabilities. *British Journal of Learning Disabilities* 31, no. 1: 9-17.

McCarthy, M. 2009. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 32: 198-208.

McCarthy, M. 2010. The sexual lives of women with learning disabilities. In *Learning Disability: a Lifecycle Approach*. Eds G. Grant, P. Ramcharan, M. Flynn and M. Richardson 259-265. Maidenhead: Open University Press.

Morris, J. (ed) 1996. *Encounters with Strangers: feminism and disability* London: Women's Press.

Nightingale, C. 2003. Can women with learning disabilities access good health care? A case study of cervical screening. In *Women's Minds, Women's Bodies: An interdisciplinary approach to women's health*. Eds G. Boswell and F. Poland, 156-172. Houndsmills: Palgrave.

Open University on i-Tunes U. 2010.

<http://itunes.apple.com/WebObjects/MZStore.woa/wa/viewiTunesUCollection?id=393826122>

[last accessed 3rd February 2011]

Park, D.C. and J.P. Radford. 1998. From the Case Files: reconstructing a history of involuntary sterilization. *Disability and Society* 13, no. 3: 317-342.

Parmenter, T.R. 2001. Intellectual Disability – Quo Vadis? In *Handbook of Disability Studies* (eds) Albrecht, G.L., Seelman, K.D. and Bury, M. London: Sage Publications. Pp.267-296.

Petchesky, R.1986. Reproductive Freedom: Beyond a Woman's Right to Choose. *Signs* 5: 661-685.

Rafter, N. 2004. The criminalization of mental retardation In *Mental Retardation in America pp. 232-257* Eds. S. Noll and J. Trent J. New York: New York University Press.

Ragoné, H. and Twine, F. W., (eds) 2000. *Ideologies and Technologies of Motherhood: Race, Class, Sexuality, Nationalism* London: Routledge.

Reilly, P. 1977. *Genetics, Law and Social Policy*. Cambridge, Mass: Harvard University Press.

Rembis, M.A. 2010. (Re)Defining disability in the 'gene4tic age': behavioral genetics, 'new' eugenics and the future of impairment. *Disability & Society*, 24, no.5: 585-597.

- Roets, G., Adams M. and Van Hove G. 2006. Challenging the monologue about silent sterilization: implications for self-advocacy. *British Journal of Learning Disabilities* 34, no.3:167-174.
- Rogers, C. 2009. (S)excerpts from a Life Told: Sex, Gender and Learning Disability. *Sexualities* 12: 270-288.
- Rolph, S. 2002. *Reclaiming the Past: The Role of Local Mencap Societies in the Development of Community Care in East Anglia* Milton Keynes: Open University.
- Servais, L., Leach R., Jacques D. and Roussaux J.P. 2004. Sterilisation of intellectually disabled women. *European Psychiatry* 19 no. 7: 428 – 432.
- Shakespeare, T. 1998. Choices and rights: Eugenics, genetics and disability equality, *Disability & Society* 13 no. 5: 665-681.
- Sharp, K., and Earle S. 2002. Feminism, abortion and disability: Irreconcilable differences? *Disability & Society* 17, no. 2: 137–45.
- Shaw, A. 2004. Attitudes to genetic diagnosis and to the use of medical technologies in pregnancy: Some British Pakistani Perspectives. In *Reproductive agency, medicine and the state: Cultural transformations in childbearing* 1-24. Ed. M. Unnithan-Kumar. Oxford: Berghahn Books.
- Stansfield, A. 2007. ‘What factors influence decisions about the sterilization of women with learning disabilities, Unpublished MD, University of Leeds School of Medicine.

Stansfield, A., Clare, I. and Holland, A. 2007. The sterilization of people with intellectual disabilities in England and Wales in the period 1988-1999. *Journal of Intellectual Disability Research* 51, no. 8: 569-79.

Sigurjonsdottir HD and Traustadottir R (2010) Family within a Family in Llewellyn G, Traustadottir R, Mc Connell D and Sigurjonsdottir HB (eds) (2010) *Parents with Intellectual Disabilities* Wiley Blackwell pp. 49-62.

Thomson, M. 1998. *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain, c.1870-1959* Oxford: Clarendon Press.

Traustadottir R. and Johnson K. (eds) 2000: *Women with Intellectual Disabilities: Finding a Place in the World* London: Jessica Kingsley.

Turk V. and Brown H. 1992. The Sexual Abuse of Adults with Learning Disabilities: Results of a two year incidence survey, *Mental Handicap Research*.

Turner, B. S. 1995. [1987] *Medical Power and Social Knowledge* 2nd Edition. London: Sage.

Walmsley, J. (1993) 'Women First: Lessons in Participation' *Critical Social Policy* Issue 38 86-99.

Walmsley, J. 1995 'Gender, Caring and Learning Disability' Unpublished PhD thesis, the Open University, Milton Keynes.

Walmsley, J., Atkinson, D. and Rolph, S. 1999. Community Care and Mental Deficiency 1913-1945. In *Outside the Walls of the Asylum 181-203*. Eds. P. Bartlett and D. Wright. London: Athlone.

Willis, D.S., Kennedy, C.M. and Kilbride, L.. 2008. Breast cancer screening in women with learning disabilities: current knowledge and considerations. *British Journal of Learning Disabilities* 36, no.3: 171-184.