The human rights of women with intellectual disability

Ashwin Roy[1] • Ameeta Roy[2] • Meera Roy[3]

[1]Medical Student, Manchester Medical School, Manchester, UK
[2]D Phil Student, Public Health, Wolfson College, Oxford, UK
[3]Consultant Psychiatrist, Birmingham Community Healthcare Trust, Birmingham, UK
Correspondence to: Meera Roy. Email: meera.roy@gmail.com

DECLARATIONS

Competing interests
None declared

Funding
None

Ethical approval
Not sought as this was a literature review with no direct patient involvement

Guarantor
Meera Roy

Contributorship
AR and AR contributed equally

Acknowledgments
The authors would like to thank Ashok Roy, Consultant Psychiatrist, Coventry and Warwickshire Partnership Trust for his comments on the manuscript

Introduction

Sexual maturity and interest in sexual activity in women with intellectual disability may alarm their carers who are concerned about menstrual hygiene, sexual abuse, pregnancy and offspring who would have to be raised, and they may seek sterilization or hysterectomy as a solution. However, Article 5 of the United Nations Universal Declaration of Human Rights states that 'no one shall be subjected to torture or cruel or degrading treatment or punishment' and Article 16 confirms 'the right to marry and found a family.' These universal human rights articles are breached when people with intellectual disability lacking capacity to consent are sterilized.

Contraceptive sterilization for people with intellectual disability was an indirect consequence of the theory of evolution which Francis Galton interpreted in his book Hereditary Genius, published in 1869, to mean that humans may direct their own evolutionary future. He introduced the term 'eugenics' as the science of improving stock. In this paper, we review the practices in different countries by examining prominent cases and relevant articles.

Methods

We carried out a literature search on Medline and Google, using the terms learning disability, intellectual disability, mental retardation, mental handicap, mental subnormality, mental deficiency, sterilization, hysterectomy and contraception. Each English language paper and book was read by two of the authors and summarized.

Review

The practice of sterilizing women with intellectual disability should be examined in the context of its availability to non disabled women worldwide. In 2002, 74 countries had laws explicitly permitting contraceptive sterilization. It is implicit that these procedures are voluntary, and 24 countries had age and parity clauses which had to be met prior to surgery. In 25 countries it was also necessary to get the agreement of spouse, parent, guardian, physician or committee. In 55 countries the legal situation was unclear, but in 8 countries laws were explicitly only for therapeutic, medical or eugenic reasons compared to 28 countries in 1985.[1]

United Kingdom

The English eugenics society and the National Association for the Care of the Feeble-minded sought to legislate prevention of parenthood among those with an intellectual disability as eugenics suggested that 'mental deficiency' was hereditary, insusceptible to treatment and a danger to society. However, neither the 1907 Royal Commission nor the Mental Deficiency Act 1913 recommended this. The recommendation by the 1924 Joint committee of the Board of Education and the Board of Control, and the Department of Health in 1934, also did not lead to statute to sterilize people with an intellectual disability.[2]

In 1976, Mrs. Justice Heilbron ruled that sterilizing D, a 10-year-old-girl with Soto's syndrome, would deprive her of a fundamental right to reproduce. In 1987, the Law Lords

authorized sterilization of B, a 17-year-old-girl with severe intellectual disability and epilepsy, in her best interests. In the same year, they also ruled that it was not unlawful to terminate the pregnancy of a woman with severe intellectual disability in the absence of consent.[3] The House of Lords ruled that sterilization was in the best interests of F, a 36-year-old woman with severe intellectual disability, though it could not consent on her behalf and that the common law principle of necessity allowing doctors to treat unconscious patients extended to allow treatment if they were unable to consent when it was in their best interests. In a minor, surgery resulting in permanent infertility could only be carried out with the leave of the High Court Judge obtained in wardship proceedings. No Court had the jurisdiction to give or withhold consent in the matter of contraceptive sterilization of an adult unable to consent, nor did any relation or medical attendant. The individual could be represented by the official solicitor and the Court would assess whether the proposed treatment was in her best interests, making a declaration that the operation was lawful according to the facts of the case.[4]

The Mental Capacity Act (2005) provides independent mental capacity advisors to support those unable to consent to medical treatment if it is in their best interests. Deputies can be appointed for health and welfare issues by the new Court of Protection, but contraceptive sterilization still remains a special case.

Stansfield *et al.* (2007) found that 31 of the 73 referred to the official solicitor for sterilization between 1988 and 1999 had their applications approved. Following increased clarity provided by the Mental Capacity Act, the numbers declined further between 1999 and 2009 with 5 referrals and 1 authorisation. Roy[5] followed up 9 women referred for contraceptive sterilization in 1989 of whom one was recommended for sterilization. On 20 year follow-up, none of the 8 women in contact with services had sexual relationships or had become pregnant. Two had hysterectomies at 21 and 30 years on grounds of heavy painful periods. None of the remaining 6 women had been sterilized. Sterilization was considered at a much younger age in this cohort compared to 55 to 59 years for the surgery amongst women in England and Wales. This study demonstrated that with appropriate support, women with intellectual disability could avoid pregnancy without recourse to surgery.

United States of America

United States was the first country to undertake sterilization for eugenic purposes. In the early 1900s, American Eugenists argued that forced sterilization of people with intellectual disability was the best way to protect society. A Supreme Court judgement by Oliver Wendell Holmes in *Buck v Bell* in 1927 unleashed a wave of forced sterilization. By 1963, over 60,000 people were sterilized without consent.[6] Support from civil rights and feminist groups alongside negative association of eugenics with Nazi atrocities, led to this practice falling into disrepute. The sterilization of a girl with intellectual disability without consent in a publicly funded clinic led to the 1978 judgement forbidding the use of federal funds to sterilize anyone below the age of 21, incompetent (unable to consent) or institutionalized. But Reilly[7] showed that several state run eugenic sterilization programmes remained active long after scientists had refuted the eugenic thesis. The American College of Obstetrics and Gynaecologists recommended in 2007 that when a patient's mental capacity was limited and sterilization considered, the physician must consult with the patient's family, agents and other care givers to adopt a plan that protects what the group believed to be the patient's best interests while preserving autonomy. The focus has now moved to more appropriate gynaecological care for women with intellectual disability.[8]

Hysterectomy was seen as a reasonable means of fertility control because of the benefits in terms of personal hygiene, emotional outbursts, behaviour problems, and seizure activity in people with intellectual disability and epilepsy.[9] Passer *et al.*[10] interviewed parents of daughters with intellectual disability attending an adolescent clinic and found that interest in sterilization significantly correlated with increased severity of retardation and with difficulty teaching menstrual hygiene. Parents of girls with mild disability sought tubal ligation, and those whose daughters had severe disability chose hysterectomy, stressing their concern about menstrual management.

Parental concerns remain a live issue. Coombes[11] reported the case of Ashley, a 9-year-old girl with severe intellectual disability, whose parents obtained treatment for growth reduction followed by removal of breast buds and hysterectomy arguing that caring for children with profound intellectual disability could become more difficult with age and size. American College of Obstetrics and Gynaecology guidelines state that indications for hysterectomy and endometrial ablations in women with intellectual disability are the same as those of the general population, and physicians are urged to be aware of pressure from family members whose interests may not be the same as the patient's.

Canada

Sterilization was common;[12] Alberta and British Columbia enacted legislation for sterilization of the 'mentally defective' that remained in place till 1972. A landmark was reached in 1979 in the case of 'Eve', a 24 year old woman with intellectual disability, when an application made by her mother for the authorization of consent for tubal ligation was dismissed on grounds of deprivation of her right to reproduce, it was not required to preserve/protect her health and the Court had no jurisdiction to authorize sterilization for non-therapeutic reasons and neither could parents or guardians give third party consent.[13]

Australia

In the 1970s the standard management for all institutionalized women with intellectual disability was to induce amenorrhoea by the use of continuous progestagens or surgical approaches.

In 1988, the Family Court of Australia dismissed the application for an injunction sought by a 15-year-old girl with severe intellectual disability to prevent her parents from authorizing a doctor to perform a hysterectomy to prevent the onset of menstruation as it could affect her development and quality of life, and rejected the argument that alternatives should be tried before surgery. It held that parents had a right and duty to make decisions about treatment and major operations, whether their children had intellectual disability or not, and a Court should interfere only in exceptional circumstances; there was nothing warranting interference in this case, as the benefits of the operation outweighed the risks as well as the risks of alternative treatments.

In the same year, 1988, the Family Court authorized the hysterectomy on Jane, a 17-year-old girl with intellectual disability dismissing the injunction sought by the Public Advocate of Victoria, restraining her parents from having her sterilized without consent of the Court.

In 1989, the Family Court concluded that hysterectomy was justified on Elizabeth, a 15-year-old girl with epilepsy and intellectual disability, on account of increased risk of epileptic fits if the girl menstruated, dismissing the restraining order sought by The New South Wales Council for intellectual disability.

In the same year, the Family Court dismissed the injunction sought by the Attorney-General of Queensland to prevent the parents of S, a 12-year old girl with autism and intellectual disability from having a hysterectomy. The court held that the welfare of the daughter required the operation, basing its decision on the principle that the welfare of the child is paramount; rejecting arguments that it would interfere with a fundamental right and that a less drastic course of monitoring the child's future development should be followed.

However, since the 1992 ruling by the High Court of Australia on 'Marion', a 14-year-old girl with epilepy, deafness with intellectual disability, it has been unlawful to conduct a procedure that results in sterilization of a person unable to give informed consent without the legal authorization of the Family Court of Australia (under 18 years), or the Office of the Public Advocate and the Guardianship and Administration Board (18 years and over). However, Brady and Grover[14] presented evidence indicating that sterilization of girls since Marion's case far exceeded those authorized by courts and tribunals.

Grover[15] concluded that menstrual and contraceptive management for women with intellectual disability is similar to the general population. However, in 2010, the Family Court in Brisbane authorized the hysterectomy of an 11-year-old girl with Rett's syndrome. Her parents had requested the procedure on the advice of three Gynaecologists on the grounds that her epilepsy deteriorated during menstruation. Concerns

about such cases led to the United Nations Human Rights Council calling on Australia to prohibit sterilization of girls with disabilities.[16]

Germany

After the extensive sterilization programme in the United States, Nazis in Germany under Hitler, passed the 'Law for the Prevention of Progeny with Hereditary Diseases' or 'The Sterilization Law' in 1933 to weed out genetic defects from the German gene pool to create an 'Aryan master race' and provided for sterilization of both a eugenic and punitive nature. Those considered having 'poor genes' included paupers, epileptics, alcoholics, those with mental illness and intellectual disability. The group was later broadened to include others not considered socially desirable. An estimated 300,000 to 400,000 people were sterilized under the law, and a diagnosis of 'feeble mindedness' provided the grounds in the majority of the cases.[17] This was repealed in 1946 by the occupying powers.

Belgium

Servais *et al.*[18] found that prevalence of sterilization in women with intellectual disability was 3 times higher than that in the Belgian population and correlated with institutional factors. If they lived in institutions where sexual intercourse was allowed or contraception was required, they were more likely to be sterilized.

Scandinavia

Eugenics and the potential for social control and saving money on welfare spending were all drivers behind the Nordic sterilization laws. Under the 1934 law for the 'mentally handicapped' in Denmark, a person could be sterilized if judged to be unable to raise children or to facilitate release from confinement to more relaxed supervision. Until 1945, 78% of those sterilized had intellectual disability. The Sterilization Act of 1941 in Sweden was an important step in the direction of racial purity and allowed surgery without consent in those unable to do so. Thousands of Swedes were sterilized under compulsion under the Laws enacted in parliament in 1934 and the 1941 modification, repealed in 1975. In Norway, the Sterilization Act was passed in 1934 but only 2.5% of those sterilized had intellectual disability. The current law allows sterilization with the safeguard of a legal guardian.[19] In Finland, the 1935 and 1950 Sterilization laws had a eugenic spirit but the number of eugenic sterilizations remained low. The Castration Act was repealed in 2002.

Japan

A 'eugenic' law permitted involuntary sterilization of people with intellectual disability from 1948–1996. More than 16,500 women and men were sterilized against their will[20] during this period.

China

Kristof[21] reported that with the aim of improving 'population quality,' a number of Chinese provinces banned mentally retarded people from marrying unless they were sterilized first. If they evaded sterilization and became pregnant, abortion was obligatory. Gansu Province in north western China in 1988 became the first to adopt a law of eugenics which led to sterilization of more than 5,000 disabled people. Several other regions in China adopted similar eugenic policies. China's domestic policy towards women and children fell under international scrutiny following the promulgation of the country's Maternal and Child Health Law in 1995. It was seen in China as a means of prioritizing resources and improving quality of services, but in the West it was widely interpreted as a eugenic law.[22]

South Africa

Since 1975, 152 sterilizations were performed under the provisions of South Africa's Abortion and Sterilization Act No 2 (1975) at Pretoria's HF Verwoerd Hospital.[23] This Act authorized sterilization for women with severe intellectual disability, provided the procedure was performed in a state hospital, certified by 2 medical practitioners (1 psychiatrist), and the parent/guardian gave consent. Ninety-two percent of patients were under 20 years of age. Hysterectomy was the method of choice in women for whom menstrual hygiene was a problem; the remaining were sterilized by tubal ligation. Parents/guardians felt their daughters were calmer, cooperative,

productive, and less irritable once relieved of menstrual periods. The Sterilization Act 1998 is similar to the 1975 Act except the panel is multidisciplinary consisting of a doctor, psychologist/social worker and a nurse.

India

Sheth and Malpani[24] argued that specialist reproductive health services for women with disability were not economically viable, suggesting that hysterectomy was an effective means of managing menstrual hygiene and preventing unwanted pregnancies. The Indian Journal of Medical Ethics (1994) guidelines[25] address the issue of sterilization for this vulnerable group, emphasizing the need to adopt the least injurious option for the woman, regardless of interested parties. Where available support is poor, the shortcomings must be corrected before a decision is made that the woman is at risk of poor hygiene. Hysterectomy without help to maintain personal hygiene could not be justified. The guidelines followed the controversial hysterectomy of women with intellectual disability living in a state institution at a 'hysterectomy camp'.[26]

Taiwan

Chou and Lu[27] interviewed families of women with intellectual disability who underwent sterilization. Most of those who underwent tubal ligation were married and had mild intellectual disability; the decision was mostly post-partum and made by the husband or parents-in-law. The reasons for sterilization included: the woman's inability to care for the children, financial inability to raise children, the concern that disability may be hereditary and a perceived risk of pregnancy following rape. Almost none of the women were involved in decision-making, and some were not informed of the nature of the surgery.

Discussion

Although sterilization is no longer used for eugenic purposes, hysterectomies continue to be performed for menstrual management in several countries. This practice is not confined to developing countries but also in countries such as Australia and USA. The case of Ashley highlights that the rights of the person with intellectual disability can be superseded by interests of carers. McNeeley and Elkin[8] and Grover[15] provide examples of disabled women receiving age appropriate treatment similar to their peers. The use of vaginal route,[24] laparoscopic route,[28] for hysterectomy and endometrial ablation,[15] demonstrate the effort being made to reduce postoperative discomfort.

Women with intellectual disability can use the contraceptive pill, medroxyprogestrone injections, and progesterone only intra uterine devices for contraception and menstrual management. Together with behavioural management, these methods could help with menstrual hygiene. They should also have access to less invasive procedures, such as endometrial ablation, before hysterectomy is considered and be supported in decision making with information presented in the most accessible format. If they lack capacity then any treatment should be carried out only in their best interests after having consulted everyone who works with them. Several countries including the UK, regulate contraceptive practices for women with an intellectual disability by statute. This complies with the Universal Declaration of Human Rights by the United Nations General Assembly in 1948, moving away from the practices of the first half of the 20th century to 'improve the human race'.

It appears that worldwide, there is a slow but definite move to uphold the rights of people with intellectual disability in line with Universal Human Rights, with consideration of their capacity to consent and their best interest. It is important that gynaecologists and psychiatrists are aware of these issues and the practice of using the least restrictive option when dealing with women with intellectual disabilities.

References

1 Contraceptive sterilisation, Global issues and Trends Engender Health. 2002
2 Jones K. Mental Health and Social Policy 1945–1959. Routledge and Keegan Paul, 1960
3 Brahms D. Consent to abortion on behalf of a mentally handicapped woman. *Lancet* 1987;**1**:1386–7
4 Roy M, Corbett J, Newton J, Roy A. Assessment of fertility regulation in persons with a learning disability (mental handicap)-antecedents. *Journal of Obstetrics and Gynaecology* 1993;**13**:473–80
5 Roy M. A case note follow up of women with intellectual disability referred for sterilisation. *Journal of Intellectual Disabilities* 2010;**14**:1–10
6 Pham HH, Lerner BH. In the patient's best interest? Revisiting sexual autonomy and sterilization of

the developmentally disabled. *West J Med* 2001;**175**:280–3
7 Reilly PR. Involuntary sterilization in the United States: a surgical solution. *Q Rev Biol* 1987;**62**:153–70
8 McNeeley SG, Elkins TE. Gynaecologic surgery and surgical morbidity in mentally handicapped women. *Obstet Gynecol* 1989;**74**:155–8
9 Keith L. Abdominal hysterectomy for surgical sterilization in the mentally retarded: Letter. *Am J Obstet Gynecol* 1975;**123**:921
10 Passer A, Rauh J, Chamberlain A, McGrath M, Burket R. Issues in fertility control for mentally retarded female adolescents: II. Parental attitudes toward sterilization. *Pediatrics* 1984;**73**:451–4
11 Coombes R. Ashley X: A difficult moral choice. *BMJ* 2007;**334**:72–73
12 Evans KG. Sterilisation of the Mentally Retarded – a review. *Journal of Canadian Medical Association* 1980;**123**:1066–70
13 Sklar C. Consent, Sterilisation and mental incompetence; the case of 'Eve'. *The Canadian Nurse* 1980;**18**:14–16
14 Brady S, Grover S. The sterilisation of girls and young women in Australia: a legal, medical and social context. Canberra: Commonwealth Department of Health, Housing and Community Services, and Sydney: Human Rights and Equal Opportunity Commission, 1997
15 Grover SR. Menstrual and contraceptive management in women with an intellectual disability. *Medical Journal of Australia* 2002;**176**:108–110
16 WWDA (2011) United Nations calls on Australia to prohibit non-therapeutic sterilisation of girls with disabilities. WWDA-News (Issue One)
17 www.ushmm.org/handicapped (last accessed 23 December 2011)
18 Servais L, Leach R, Jacques D, Roussaux JP. Sterilisation of intellectually disabled women. *European Psychiatry* 2004;**19**:428–32
19 Gunnar Broberg, Roll-Hansen Nils. Eugenics and the welfare state: sterilization policy in Denmark, Sweden, Denmark and Finland. Michigan State University Press. East Lansing, Michigan. 2005
20 Tsuchiya T. Eugenic Sterilizations in Japan and Recent Demands for Apology: *A Report Newsletter of the Network on Ethics and Intellectual Disability* 1997:**3**:1–4
21 Kristof ND. Some Chinese Provinces Forcing Sterilization of Retarded Couples *New York Times*, August 15 1991
22 Hesketh T, Zhu WX. Maternal and child health in China. *BMJ* 1997;**314**:1898–900
23 Van der Merwe JV, Roux JP. Sterilization of mentally retarded persons. *Obstet Gynecol Surv* 1987;**42**:489–93
24 Sheth S, Malpani A. Vaginal hysterectomy for the management of menstruation in mentally retarded women. *Int J Gynaecol Obstet* 1991;**35**:319–21
25 Suggested guidelines for hysterectomy in mentally handicapped women. *Indian Journal of Medical Ethics* 1994:**2**(4)
26 Nandan G. Women in India forced to have hysterectomies. *BMJ* 1994;**308**:558
27 Chou YC, Lu ZY. Deciding about sterilisation: perspectives from women with an intellectual disability and their families in Taiwan. *J Intellect Disabil Res.* 2011;**55**:63–74
28 Agvateersiri G, Tingthanatikul Y, Srisombut C. Total Laparoscopic Hysterectomy in Mental Retardation Patients: A case report series. *Journal of the Medical association of Thailand* 2004;**87**