

Renu Barton-Hanson

Associate Professor of Law

Middlesex University

The Burroughs, Hendon, NW4 4UU

Sterilisation of men with intellectual disabilities: whose best interest is it anyway?

Abstract

This article examines the ethical and legal issues raised by the involuntary sterilisation of men with intellectual disability. It traces how, after the demise of eugenic reasoning, social policies of normalisation and care in the community provided new justifications for sterilisations. It examines how, ironically, modern arguments about promoting male sexual freedom have come to be used as a justification to sterilise. Through examination of recent cases on the sterilisation of men with intellectual disabilities, this article explores the legal framework of the 'best interests' test and 'least restrictive alternative' provisions in the Mental Capacity Act 2005 and argues that many sterilisations are unnecessary, disproportionate and not the least restrictive option. It also argues that the least restrictive alternative provisions contained in the 2005 Act need to be more rigorously applied.

Introduction

Involuntary sterilisation of people with intellectual disability raises a myriad of ethical and legal issues. This article assesses reported cases of sterilisation of men with intellectual disabilities heard in the English courts, namely the recent Court of Protection decision in *An NHS Trust v DE*¹ and the Court of Appeal decision in *Re A (Medical Treatment: Male Sterilisation)*.² It argues that many sterilisations are unnecessary,³ disproportionate and not

necessarily the least restrictive option available. It will argue that the individual must be protected by the Court of Protection and that the court in *DE*, in giving primacy to the views of his parents and medical professionals, may have diluted the application of the best interests test by emphasising the interests of others, particularly the family. Furthermore, the application of the least restrictive alternative provisions contained in the Mental Capacity Act 2005 were not rigorously applied and a preferable way forward is demonstrated by the recent case *Re Local Authority v K and others*⁴ where the least restrictive alternative provisions were more robustly implemented.

The paper begins with a brief review of the proportion of male: female intellectually disabled sterilisation cases, and then sets out an outline of the historical response of the state to the sexuality of the intellectually disabled in the form of eugenic policy at the turn of the 20th century. It then describes how the ‘medical model’ gave way to a ‘social model’ conception of disability, and a greater awareness of rights of people with intellectual disabilities to enjoy intimate relations. The paper examines how, simultaneously with these developments, social policy included the devolvement of responsibility to the family under the guise of care in the community programmes. It traces how contemporary discussion has engaged in a rights-based framework, described as a ‘paradigm shift’ heralded by the UN Convention on the Rights of Persons with Disabilities (CRPD). The paper then examines the legal framework of the best interests test and the least restrictive alternative provisions and argues, using these case studies, how social policy past and present has shaped and influenced judicial reasoning to justify sterilisation. It will also argue that there is a need for specialist services in sex education, counselling and support for parents and to assist people with intellectual disability to cultivate and develop their unique sexual identity and sexual space as a more humane and ethical way. This article focuses on issues raised by the applications for orders to sterilise men with intellectual disabilities.

Measuring the prevalence of male sterilisations

It is not possible to glean a comprehensive picture of numbers of sterilisations on men with intellectual disability from the literature, but the picture emerging from a combination of reported cases and research reveals that historically women have been disproportionately subjected to coerced and otherwise involuntary sterilisations.⁵ For example, research by Stansfield et al⁶ in the UK found that there were only three male sterilisation referrals out of a total of seventy three referrals to the Official Solicitor between 1988 and 1999. In a follow-up study by Roy there were five referrals with one authorisation, between 1999 and 2009, although it is not clear how many of these related to men.⁷ In the absence of empirical research it is not possible to estimate how many referrals are currently occurring in the UK.⁸

In the international context historically more than 70, 000 people with an intellectual disability were sterilised in the United States after *Buck v Bell* (explained below).⁹ In Canada between 1927 and 1972 the Eugenics Board of Alberta authorised 2500 sterilisations, of which 40.9% were on males and 59.1% were performed on females. Of those sterilisations that went ahead, 64.7% concerned females and 35.3% concerned males.¹⁰ Researchers in New Zealand and Australia comment on the lack of consistency in data and difficulties in obtaining the true extent of the number of applications. In the New Zealand context, Hamilton comments that the lack of numbers itself points to a troubling problem and the extent to which the issue is 'completely hidden'.¹¹ In the most recent examination in Australia 2013, the Senate Community Affairs References Committee ('Senate Committee') on Involuntary or Coerced Sterilisation of People with Disabilities in Australia, commented on the lack of uniform data and practice in relation to vasectomies in young men, although they noted that Medicare data on vasectomies in males aged 15 to 24 point to 430 vasectomies performed between 2003 and 2012 with an average of 44 a year.¹² Although it appears that there has been a decline in the use of sterilisation procedures both in the UK and

internationally, involuntary procedures on persons with intellectual disability continue to be used.¹³

History

Before turning to a more detailed account of the law it is worth exploring the contextual ethical and historical issues in which the issue of non-consensual sterilisation on people with intellectual disability is located. The question of basic and fundamental human rights was raised by Heilbron J in *Re D*,¹⁴ expressed as a right to procreate¹⁵ although contested by Lord Hailsham in *Re B*.¹⁶ These issues will not be explored in depth here.¹⁷

Lord Hailsham stated expressly that his judgment was not based on eugenic or other public policy arguments in *Re B*. This statement was repeated recently by Mr Justice Cobb in *Re DD*.¹⁸ Why did the judges feel it necessary to make such a proclamation? The answer lies in history. At the turn of the century stereotypical ideas included the notion that intellectually disabled people had excessive sexual urges which they were unable to control.¹⁹ The spectre of eugenics looms large over this topic and explains much of the anxiety and unease of commentators and judiciary alike.²⁰

Eugenics is essentially about the altering of genetics through engineering,²¹ the basic idea being to eliminate certain traits from the gene pool.²² The eugenics movement was launched by Sir Francis Galton in 1904 and the term 'survival of the fittest' was advanced by Herbert Spencer who argued that the so called 'unfit' were reproducing at a greater rate. People with intellectual disability were among these 'unfit',²³ and their continuing reproduction was thought to somehow undermine or dilute the intelligence of the population.²⁴ They were in essence not fit to produce children.

Supporters of eugenics based theories saw them translated into government policy and action in several American states where sterilisation was practised freely on people with intellectual disability²⁵ and was also adopted by some European countries.²⁶ By 1937 thirty one states as well as Canada had enacted eugenic sterilisation laws enabling forced sterilisations to be carried out with the aim of protecting the gene pool.²⁷ This policy was illustrated by the judiciary in a striking and often quoted passage by Justice Holmes in *Buck v Bell*²⁸ in 1927 where the United States Supreme Court upheld the Virginia sterilisation law thereby legitimising the sterilisation of thousands of people.

“We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for their lesser sacrifices, often not felt to be such by those concerned, in order to prevent our society being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind ... Three generations of imbeciles are enough.”²⁹

The history of sterilisation in England and Wales follows a different path with no compulsory sterilisation legislation enacted.³⁰ There was a growth in institutionalising people with intellectual disability where sterilisations, in the absence of compulsory legislation, may have been performed.³¹

The Ministry of Health set up the Brock Committee [1932-34] to consider the issue of sterilisation in England and Wales (in response to what King and Hansen assert was a belief about a growing populace of mentally disabled people) and attempted to bring the theoretical message into practice. They argue that while the Brock Committee realised the political difficulties in implementing these policies due to public hostility as well as opposition from

the Catholic Church, the Committee hoped that in time support may be raised. It was hoped this support would lead to a Royal Commission and eventually eugenics based legislation.³² Eugenics theories enjoyed much support among British leading intellectuals and thinkers and this context could not be divorced from the Committee deliberations and recommendations. Eugenists formed the Eugenics Society (established in 1907), an organisation that campaigned for sterilisation, successfully lobbied the Brock Committee and even had representation on it.³³ The backdrop of much of the discussion at this time was fear regarding degradation of the English race and the rising birth rate of the lower classes.³⁴ The Committee opined that there were a quarter of a million people who potentially could be sterilised and these people were treated with some distaste. King and Hansen sum up the Committee's beliefs about this section of people with intellectual disability: "*[the committee] believed this group both personally unhappy and a source of malaise for the rest of society.*"³⁵

By 1934 in the context of the political climate the Brock Committee opposed compulsory sterilisation but were in favour of voluntary sterilisation.³⁶ Strangely, the Committee argued that people with intellectual disability had the 'right' to sterilisation.³⁷ As to the question of how an incompetent patient may provide consent, Brock said:

*"the fact that many people are easily persuaded by those in whom they have confidence does not mean that they are really incapable of understanding the issues involved. I believe that high grade defectives are perfectly capable of understanding what sterilisation means, and I am confirmed in this view by letters I have seen from patients."*³⁸

In the event the conclusions did not lead to a Royal Commission or any further activity because of the horror stories emerging from Nazi Germany at that time where a large number of compulsory sterilisations were carried out. These events in effect torpedoed the support for any form of compulsory sterilisation and the report was forgotten about.³⁹ A growing

movement opposed eugenics in the 1920s and 1930s and the popularity of eugenic sterilisations waned considerably.

Social policy

More recently with eugenic considerations in retreat, sterilisation justifications have taken on more social and medical dimensions (such as menstrual management)⁴⁰ and with the advent of social policy of care in the community and deinstitutionalisation the nature of the justifications changed. The sexual needs and desires of people with intellectual disability were beginning to be recognised and a movement away from institutionalisation towards recognising their right to sexual expression began as trends towards normalisation which emerged in the last 30 or 40 years.⁴¹ Ladd-Taylor describes how normalization had a ‘contradictory impact,’ in that while leading to the closure of institutions, it led to parents wanting sterilisations to prevent their daughters falling pregnant.⁴²

Jones and Marks argued that, ironically, supporters of sterilisation gained ground by arguing that people with intellectual disability could enjoy greater freedoms and independence in the community if the risk of pregnancy was removed.⁴³ Certainly this argument was employed forcefully in *DE* as justification for his vasectomy (as shall be seen later).

In the UK, community care policies have since been replaced with ‘supported living’ policies, including individualised support packages and support to develop ‘person-centred’ plans.⁴⁴ The aim of this policy is to promote greater choice and control for people with intellectual disability.⁴⁵ Tobin and Luke document how the historical medical model of disability which viewed disability as an abnormality that needed to be fixed or controlled moved towards an understanding that it was society’s failure to accommodate an individual’s impairment. They summarise the policy as shifting from eugenics, welfarism and, more recently, towards a rights-based approach.⁴⁶ In respect of human rights, the entry into force of

the UN Convention on the Rights of Persons with Disabilities in May 2008 represents a paradigm shift in the concept of disability, embedding the principles of non-discrimination, autonomy and inclusion.⁴⁷ The rights-based model assures respect for the inherent dignity of persons with disabilities and the promotion of their human rights and freedoms.⁴⁸ More recently, and in line with this model, human rights groups describe forced sterilisation of persons with disabilities without consent as “a form of violence and torture, or other cruel, inhuman or degrading treatment”.⁴⁹

Parallel to this movement in social policy the financial costs of care programmes and the burden on the state came to be assessed. Lee and Morgan comment on the resource considerations and cost-cutting involved in the community care programme, and the consequent dangers of sterilisation for convenience.⁵⁰ In some cases with responsibility falling onto the family under the welfare approach, Tobin and Luke assert that:

*“The animating principle of this welfare approach was the concept of best interests. More specifically, parents, in collaboration with medical professionals, invariably determined that it would be in the best interests of a girl or woman with an intellectual disability to have the burdens caused by her reproductive system removed by way of sterilisation. In practice, this principle often operated as a ‘proxy’ for the interests of parents and other adults, and founded a vision of girls and women with intellectual disabilities as being necessarily incompetent and incapable of exercising any rights to reproductive autonomy.”*⁵¹

Ladd-Taylor describes the new social policy in the following way: *“In their [the critics’] view, substituted consent was simply another way by which coercive sterilization was made to look voluntary. Government control had become more sophisticated and appealing—and more subtle since the days when fear of ‘three generations of imbeciles’ justified compulsory sterilization”*.⁵² Goldhar argues that the hidden agenda of reducing the economic burden

should not be used as a smokescreen to sterilise people with intellectual disability so that they will be ‘easier to handle’ by parents who understandably may feel they are overwhelmed with the burden of care. Doctors, Goldhar notes, have assisted parents with this quick way out of the potential dilemmas faced, and therefore neither parents or doctors can be trusted to make sound sterilisation decisions.⁵³

In a recent survey to investigate the attitudes of Australian doctors to sterilisation of men and women with intellectual disability, Gilmore and Malcolm found 23% of the sample endorsed sterilisation as a desirable practice for men and 41% for women. The authors concluded “... *doctors see less sexual freedom as desirable for adults with ID [intellectual disability] compared with those without ID, and they are more cautious about parenting than other aspects of sexuality. The number of doctors agreeing with sterilisation is disturbing*”⁵⁴

Despite shifting social policy, it is interesting to observe how some vestiges of ‘medical model’ decision-making persist amongst the medical profession. Commenting on historical practices, Gilmore and Malcolm argue: “*The endorsement of sterilisation when there is a risk that the disability could be passed on to a child could in part reflect what the Australian Disability Discrimination Commissioner believes is a eugenic undercurrent to the practice of sterilisation for individuals with ID...influenced by their medical training, and the medical model of disability in which disability is viewed as an impairment to be cured or prevented.*”⁵⁵

These sentiments were also featured in submissions to the Australian Senate Committee:

“*Despite many submitters claiming that such thinking has 'moved on' significantly since the peak of the eugenic movement there was a pervading message from advocacy groups that some medical professionals and others in the community find it is very easy to have a kind of*

*either judicial or eugenic imperialism when it comes to making a decision about either the parents and carers or about the disabled young people or older people in question*⁵⁶

It is against this backdrop of evolving social policy that we now turn to consider the two reported cases on sterilisation on men with intellectual disabilities and assess whether the ‘undercurrents’ discussed above are still evident in the application of contemporary medical and legal decision making.

Background to *DE* and *Re A*

On the 16th August 2013 the Court of Protection made declarations sought by the NHS Foundation Trust that DE, a 37 year old man, be given a vasectomy. The unusual feature of this case was the gender of the patient. This is the first case in which the courts have authorised a non-therapeutic sterilisation on a man who is not able to consent to the surgery.⁵⁷ Fourteen years earlier in another male sterilisation case to reach the courts, *Re A (Medical Treatment: Male Sterilisation)*, the court of first instance and Court of Appeal had rejected the application for vasectomy of a man with Down’s Syndrome because, *inter alia*, the chances of A forming a sexual relationship were slim.

DE was reported as having intellectual disabilities constituting an ‘impairment or disturbance of the functioning of his brain or mind’, with an IQ of 40 which ranked him as having an adult mental age of between 6 and 9 years.⁵⁸ Living with and cared for by his parents, DE had achieved a certain level of independence in that he attended a day centre every day on his own and was involved in a relationship for more than 10 years with a woman with learning disabilities, PQ, who gave birth to their child in 2009. Although her disability was not as severe, nevertheless, PQ was unable to look after the child herself; the child was therefore cared for primarily by the maternal grandmother.

The application arose as a result of DE's parents' wish to have their son sterilised, arguing that it would allow him to regain his independence and that it was his wish not to have any more children. As he lacked the capacity to consent to the procedure, the matter came before the court in the form of an application by the NHS Trust for a declaration that he did not have capacity to consent and that it would be lawful in his best interests to undergo the procedure.⁵⁹

A, on the other hand, who was 28 years old when the case was reported had Down's Syndrome and was assessed as being on the "*borderline between significant and severe impairment of intelligence.*"⁶⁰ He was given a high level of care and supervision by his mother who brought an application to the High Court for a declaration that a vasectomy could lawfully be performed notwithstanding his inability to consent to it. She was concerned that if her health deteriorated, and A was moved to local authority care, that he might have a sexual relationship resulting in pregnancy. The application was refused on the basis that while cared for by the mother it was unlikely that A would engage in a sexual relationship and even if a pregnancy were to occur, it would have a minimal effect on A. The Court of Appeal dismissed the appeal finding that, balancing all the factors, it was not in his best interests to undergo the procedure. Before we examine the legal aspects of these cases in more detail it is worth exploring the dangers of implying that the right and freedoms of people with intellectual disability to form intimate relations should be limited because of society's unconscious fear of pregnancy as the outcome of the enjoyment of those rights.

Right to intimate relations

The rights of people with intellectual disability to enjoy intimate relations are well established in the literature and their sexuality was an integral part of normalization.⁶¹ People with intellectual disability have sexual needs and desires as well as the right to develop

intimate relationships.⁶² However despite the strides made and the clear statement in the Convention on the Rights of Persons with Disabilities, Gilmore and Malcolm point out that “*systemic issues and attitudinal barriers remain.*”⁶³

Shaw comments on how the sexuality of people with intellectual disability is a ‘*socially constructed phenomenon*’ and how although as a society we accept their rights to form sexual relationships that this acceptance comes at a price. That price is a prohibition on getting pregnant.⁶⁴ This analysis can be applied in DE’s case where his relationship with his sexual partner flourished until she became pregnant. Following the birth of the child the atmosphere in his home ‘*became discordant and strained.*’⁶⁵ His parents’ distress quite clearly had an impact on DE and his daily activities were altered so that he could no longer spend time alone with PQ.⁶⁶ He had also been prevented from meeting with her alone in accordance with a protection plan at an earlier stage of the proceedings which had caused him great distress.

Their relationship was described as ‘*enduring and loving.*’⁶⁷ When they had reconciled it was accepted that their relationship was an incredibly important feature in his life, King J commented, “*Dr Milnes told the court that from DE's perspective this relationship is very important and must carry great weight in the balancing exercise to be carried out by the court.*”⁶⁸ At the conclusion of the hearing the King J said:

“*The relationship has been sexual in the past and DE (and PQ) would like to, and should be permitted, to resume their sexual relationship.*”⁶⁹

Whilst the conclusion that DE has a right to continue and enjoy a sexual life like the non-intellectual disabled is surely correct, arguably what this really amounts to is a statement by the court that he can continue to have a sexual relationship but only on certain terms - those terms including that he is sterilised. The danger here is that in granting people with

intellectual disability a measure of conditional freedom, it reinforces the idea that they can enjoy sexual freedom but at a cost.

The Law

The cardinal rule is that medical procedures must be performed with the patient's consent.⁷⁰

The absence of consent can expose a medical professional to civil or criminal liability for battery.⁷¹ Voluntary sterilisations performed following free and informed consent given by the person requesting it are not controversial. Given the irreversible nature of these procedures the presence or absence of consent assumes fundamental importance.

Involuntary sterilisations are procedures performed on people with intellectual disabilities without their consent. The test of incapacity is set out under the Mental Capacity Act 2005⁷² ('MCA') and court authorisation for a non therapeutic sterilisation is necessary as it is designated a 'serious medical treatment.'⁷³ The applicant should contact the Official Solicitor before the application is made.⁷⁴ Sterilisation can only be lawful on those lacking capacity if it is judged to be in their best interests.

In *DE* it was accepted by the court that DE had capacity to consent to a sexual relationship but lacked capacity to consent to contraception.⁷⁵ The 'best interests' determination was central to both cases and we now examine the factors which influenced the court in arriving at their decisions.

Best interests - individual views

Involving the patient in the decision making process is clearly part of the legislative scheme. The best interest test is set out in section 4 MCA 2005: s4(4) states: the person making the determination must 'so far as reasonably practicable permit and encourage the person to

participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him'.

Further their viewpoints, beliefs and values are relevant to this determination: s4(6) states the person making the determination must, 'so far as is reasonably ascertainable', consider:

- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by her when she had capacity),
- (b) the beliefs and values that would be likely to influence his decision if she had capacity,⁷⁶

Clearly this model of decision making is intended to emphasise the patient's views. In this regard, DE told the care professionals in meetings that he would rather use a condom than undergo a vasectomy. However, King J concluded that he lacked capacity to consent and furthermore that his views on the issue would be treated '*with the utmost caution*'⁷⁷ which may be construed as meaning that they were treated with less weight. This begs the broader question: are the views of people with intellectual disability really taken into account and acted upon or are they merely being paid lip service?

Involving the patient in decisions affecting their health and wellbeing will undoubtedly be beneficial to them (see discussion in Donnelly)⁷⁸ as well as consistent with the ethical principle of obtaining consent to uphold principles of autonomy and self determination.

Baroness Hale explained this in *Aintree University Hospitals NHS Foundation Trust v James*:

"The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. ... But in so far as it is possible to ascertain

the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."⁷⁹

Donnelly argues that a preference stated by the patient should be considered and actions inconsistent with this should be subjected to thorough scrutiny.⁸⁰ In that regard the lesser weight apparently given to DE's views is arguably contrary to the spirit of the MCA. In *Re S*⁸¹ Marshall J commented that:

*"the statute now embodies the recognition that it is the basic right of any adult to be free to take and implement decisions affecting his own life and living, and that a person who lacks capacity should not be deprived of that right except in so far as is absolutely necessary in his best interests."*⁸²

Later in the judgment she adds: *"That situation carries great weight and effectively gives rise to a presumption in favour of implementing those wishes, unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this."*⁸³

It is illustrative that the sessions with DE wherein he had expressed a preference for condoms were dismissed by CH, the clinical psychologist, because he had, *inter alia*, *"just had a session in which the issue of pain immediately following a vasectomy was discussed."*⁸⁴ This is a very telling alarm bell. DE has a frank conversation where the drawbacks of the procedure are explained (i.e. the pain and discomfort) and he responds by saying he prefers condoms shortly afterwards. It is submitted that this is a response which is consistent with many of the general population and yet no-one would suggest that they be forced to undergo it. King J continues that *"Dr Milnes's final view is that if it is explained to DE that a vasectomy is foolproof in relation to 'no more babies', but that he might conceive with a condom he would go for the vasectomy."*⁸⁵ The danger is that professionals project their

viewpoints onto people with intellectual disability or the views of people with intellectual disability disappear into the mist under the weight of ‘medical-speak’. It is arguable whether the presumption in favour of respecting the patient’s preferences, spoken of by Marshall J, should have been set aside by the weight of the other evidence in this case.

There is another danger in the court’s approach in *DE* that medical professionals and courts may select patient’s views in ways that are consistent with their own.⁸⁶ Researchers claim that courts may not grasp the subjective state of the incompetent patient.⁸⁷ To quote Dresser: “*they sometimes construct a mythical, generalized competent person to inhabit the body that lies before them.*”⁸⁸ She argues: “*We should seek a more reciprocal relationship with these patients. Rather than making them the mirror of our own fears about debilitation and the end of life, we should attempt to ascertain their point of view, their perspective, on what is to be decided.*”⁸⁹ Although commentating about eliciting the patient’s view in relation to end of life treatments these sentiments surely can be applied in the sterilisation context.

Donnelly argues that the ‘participation model’ adopted under the MCA is in line with article 8 of the European Convention on Human Rights in its protection of the right to family and privacy interests.⁹⁰ The extent to which it is compatible with international proclamations in the Convention on the Rights of Persons with Disabilities (CIPD)⁹¹ will now be considered. Participation, inclusion and self-determination are at the heart of the paradigm shift articulated in Article 12 of the Convention. In affirming that persons with disabilities have legal capacity on an equal basis with others, Article 12(3) provides: “States shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

The essence of these provisions is that every person has the right to autonomous decision making and has the right to receive adequate support to make their decisions. This ‘paradigm

shift' replaces substitute decision-making systems with a supported decision-making model that upholds the autonomy, wishes and preferences of the individuals concerned. Safeguards may be required to ensure that this support respects the rights and preferences of the person concerned, that there are no conflicts of interest or undue influence, and that the support is proportional and tailored to the circumstances.⁹²

In the most recent sterilisation case, *Re DD*, the Court of Protection gave scant regard to the CRPD in their decision, but it is clear that international calls for a clearer framework which places the rights of the intellectually disabled at the centre of their decision making with a system of supported decision making would ensure that DE's wishes and preferences would be more clearly the focus.⁹³ Since there are concerns in some quarters which view coerced sterilisation as an act of violence, the participation model needs to be reinforced. Given that people with intellectual disability may still be able to consent,⁹⁴ it is submitted their consent or at least understanding should be present in the majority of procedures. The international framework of the CRPD has at its core that persons with disabilities should have equal access to voluntary sterilisation as well as other contraception which should be underpinned by full and informed consent. So the issue is not about the denial of these service to those who are able to freely consent or of not accepting the validity of this consent, once properly obtained, rather the danger is that we interfere with a person's bodily integrity with a forced procedure undertaken solely on paternalistic principles when the life or serious health of the person is not at risk.

As Goldhar argues people with intellectual disability are devalued which allows society to circumvent these individuals from the usual consent processes.⁹⁵

Best interests - interests of others

The MCA provides a framework for consulting carers and others as part of the best interest determination. Section 4(7) provides: He must take into account, if it is practical and appropriate to consult them, the views of- ...

(b) anyone engaged in caring for the person or interested in his welfare... as to what would be in the person's best interests...

Before considering the case law it is illustrative to consider the motivation of parents for seeking sterilisation for their offspring. There may be anxiety about their intellectually disabled child's sexuality; rooted in their ambivalent or restrictive attitudes about sex.⁹⁶ There may be concerns about menstrual management, inappropriate sexual behaviour, risk of sexual abuse, and pregnancy⁹⁷ Stansfield *et al* report "*For the men, the referrals were prompted because of 'transfer to adult care', 'latching on to pretty girls' and a 'long-term heterosexual relationship'...*"⁹⁸ They added: "*We hypothesize that request for sterilisation may be driven by a combination of a fear of the risks associated with the person's transition to adulthood, parental contraceptive attitudes, the requirement for a permanent solution to potential pregnancy and concern about who would care for any grandchild.*"⁹⁹

Interestingly this is borne out by *DE* where the court accepted that DE was "*significantly influenced by his parents.*"¹⁰⁰ The court set out what the consequences of another pregnancy for DE might have:

*"Not only would DE be upset, as he does not want another child, but so too would be his parents, which has a direct and significant impact on DE's well-being and happiness. The court is not directly concerned with the interests of FG and JK, but it is concerned at how their levels of tension and distress impact on DE's welfare and comfort and it is clear that the impact is considerable."*¹⁰¹

*“DE is very close to his parents; he loves and relies upon them. If they are upset he is upset. The court can take into account the benefits to FG and JK of DE having a vasectomy if it is a factor DE would consider if he had capacity. It is likely that DE would consider the benefit to his parents of relieving them of the anxiety and strain that they have been suffering and of which he has been very conscious.”*¹⁰²

*“DE's parents were deeply distressed by PQ's pregnancy and the birth of XY. Although they are, JK says, 'getting through it', they have obviously been traumatised by all that has gone on since PQ's pregnancy was discovered in 2010. Those events remain raw and JK exhibited an almost tangible fear of the consequences of a second pregnancy. They know their anxiety has an impact upon DE, I am sure they do their best to protect DE from it but they are only human and inevitably DE is acutely aware of their distress; this has had a significant impact upon his own emotional comfort and well-being.”*¹⁰³

We are also given glimpses of A's mother's reasons for the procedure in Thorpe LJ's judgment where it was evident that she disapproved of sex outside marriage and would oppose a day centre which *“adopted a permissive attitude to sexual intercourse.”*¹⁰⁴

In respect of the case law, in *Re F*¹⁰⁵ Lord Jauncey said, *“in the case of a long term incompetent, convenience to those charged with his care should never be a justification for the decision to treat.”*¹⁰⁶ Surely this is the correct position to adopt. The waters on relatives' interests had, however, been muddied prior to the MCA by a decision on bone marrow affecting an incompetent patient. In *Re Y (Adult Patient) (Bone Marrow Transplant)*,¹⁰⁷ a bone marrow donation was permitted from Y to her sister. Y, who was 25, was mentally and physically disabled. It is not immediately clear what the actual best interests of Y were served by the judgment as she would not stand to personally benefit. The court appeared to have taken a broader picture by promoting Y's relationship with her mother and sister as the main

rationale and suggesting that her mother may not visit as often if her sister fell ill and so Y would indirectly benefit.

In the sterilisation context, the courts have made clear in a series of cases that the interests of carers are not determinative; they can however “*indirectly be a factor.*”¹⁰⁸ A feature in DE was the recognition of the “*deep distress*” suffered by his parents at the birth of his first child and their trauma was somehow a factor to consider, albeit indirectly, in the best interests examination. In any case, DE’s child resided with its maternal grandmother and she bore the brunt of the care burden. It perhaps would have been interesting to hear the views of PQ and her mother. One cannot dispute the love and devotion of DE’s parents and their utmost good will. However which parent of a non intellectually disabled child has not had sleepless nights about their child falling pregnant or indeed the deep distress or trauma a pregnancy would cause, yet who would countenance their children be sterilised to reduce their anxiety?

In DE the court held that there were no missing ‘*pieces of the evidential jigsaw.*’¹⁰⁹ His quality of life would improve as the supervision levels would be reduced, and for King J, “*allowing DE to resume his long-term relationship with PQ and restoring to him his lost skills and independence*” (such as swimming or boarding a bus on his own) were important factors in determining his best interests.¹¹⁰ Although this argument has much force and no-one would seek to deny people with intellectual disability the process of integration and normalisation, another way of looking at this is that since the professionals¹¹¹ and family revoked his independence following the birth of his first child, they agreed to grant it again on condition that he was sterilised. In other words, one interpretation of this argument is that DE’s hard earned independence and skill development should be restored only on their terms.

Interestingly the Court of Appeal in *Re A* was clear that wider societal concerns arising from potential pregnancy including the protection of vulnerable women were not relevant to the

determination the A's best interests.¹¹² A key factor was that A's mother stated that she would not relax her supervision of A if a vasectomy were to be performed. Since he would not be free to enjoy a more relaxed regime, the balance was tipped against ordering the procedure.

When considering viewpoints and motivations of parents and carers in this context, the 'ethics of care' viewpoint provides an alternative to rights-based approaches. Herring argues the focus of legal and ethical responses should recognise interlocking mutually dependent relationships. He states: "*To harm a caregiver is to harm the person cared-for; to harm the person-cared for is to harm the caregiver. There should be no talk of balancing the interests of the caregiver and the person cared-for, the question rather should be emphasising the responsibilities they owe to each other in the context of a mutually supporting relationship.*"¹¹³

This would represent a shift from an individualistic towards a relational paradigm.¹¹⁴ The promotion of close relationships may underlie individual interests and this idea certainly accords with the judicial trend in asserting that best interest not be confined to purely 'medical' but to incorporate a '*wide range of ethical, social, moral, emotional and welfare considerations,*'¹¹⁵ which Herring argues could include '*obligations towards others.*'¹¹⁶

It is possible that care ethics gives a balanced view to take account of carers' interests as enhancing the individual's interests, and certainly it was beyond dispute that both A and DE were very close to and well cared for by their parents. Indeed it would be true to suggest that their families were '*at the centre of their interest.*'¹¹⁷

Care ethics may also provide a balance to the idea that the rights and interests of carers are "increasingly considered taboo."¹¹⁸ As Tobin and Luke explain: "*As recognised by the American Academy of Pediatrics, 'third parties have rightful interests' which must not be*

overlooked in the quest to atone for past sins which saw the interests of women and children with disabilities serve as a proxy for the interest of their carers. Furthermore, human rights law actually anticipates that the rights of others, including a carer's rights to family life, assistance in the provision of care and indeed their own health, may legitimately be considered when assessing the justification of sterilisation in this context”¹¹⁹

However, there are powerful counter-arguments in retaining the primacy of the individual's interests over carers, most notably at the heart of coerced sterilisations is the violation of bodily integrity.¹²⁰ Moreover it has been argued that care relationships are inherently an exercise of power, whether this power is exercised beneficially or otherwise, the aspect of force or coercion should not be overlooked.¹²¹

While arguments in favour of an ‘ethics of care’ approach have some force, in the ultimate analysis major irreversible surgical interventions cannot be justified on an individual by coercion. In uncompromising terms, the World Health Organisation announced in a recent interagency statement: *“in making a decision for or against sterilization, an individual must not be induced by incentives or forced by anyone, regardless of whether that person is a spouse, parent, other family member, legal guardian, health-care provider or public officer.”¹²²*

While giving primacy to carers' views is objectionable, another approach which would serve a possible relational model, might be to distinguish parents/carers from long term partners.

One of the striking features in *DE* was that he was in a long term relationship with PQ, whose views were never really considered. Perhaps meeting with DE and his long term partner, PQ, as a family unit, before the court hearing, was a better way forward on a model not miles apart from how a non-intellectually disabled couple would deal with their long term contraceptive needs. Such an enquiry arguably would be more in line with the objectives of

Article 12 of the CRPD, in supporting DE's will, preferences and interests. However, although this approach may well have worked here on these particular facts, it would not be appropriate in every case as coercion and undue influence could be hidden in long term relationships. For a couple planning reproductive choices outside the intellectually disabled setting, the law is designed to safeguard against oppressive or forced sterilisation through the legal framework of consent, although whether it does serve that purpose sufficiently is outside the parameters of this paper.¹²³

Promoting the least restrictive alternative

In *Re D Heilbron* noted: "*I cannot conceive of a more important step than that which was proposed in this case.*"¹²⁴ These sentiments underlie the enormity of the procedure on individuals. Arguably the proposed procedure should be the 'last resort' as well as being proportionate.¹²⁵ It is established that private life protected under the Article 8 of the European Convention on Human Rights includes choice about personal relationships with others and that sexual activity is "*a most intimate aspect of private life.*"¹²⁶ Any interference with privacy has to be proportionate to the legitimate aim.¹²⁷

It was accepted in court that having another child would be a distressing and traumatic experience for DE. It is also clear that a right to intimacy presupposes people with intellectual disability have equal rights to contraception, including sterilisation, as non-intellectually disabled do. The dilemma was powerfully summarised by the Australian Senate Committee who concluded: "*An outright ban of non-therapeutic sterilisation procedures without consent potentially denies the rights of persons with disabilities to access all available medical support on an equal basis with persons without a disability. It is a 'one size fits all' solution to a complex problem. An outright ban removes the focus from the needs and interests of the*

individual, placing it instead on generic notions of what is best for persons with disabilities as an homogenous group”¹²⁸

The question then arises of which method of contraception?

The MCA provides that decisions made on behalf of those lacking capacity must be the least restrictive of an individual’s rights and freedoms .¹²⁹ It stands to reason therefore that

alternative procedures should be considered, such as contraceptives and/or sex education.

Goldhar notes how some medical professionals have routinely ignored alternatives to

sterilisation. He argues that patients need to be allowed time to adjust to different options to

see what may work or what may not.¹³⁰ It could be argued that DE was not given such

opportunity to continue training with condoms. The court noted that he was learning how to

use a condom, that ‘*considerable progress*’ had been made¹³¹ and that, in time, his ‘*technique*

would improve with more training.’¹³² It is submitted that this course should have been

continued particularly in view of DE’s opinion that he would prefer to use condoms as

elicited by Dr Milnes and CH, a clinical psychologist.¹³³ They both downplayed his views

subsequently because, *inter alia*, CH suggested that he had “*just had a session in which the*

issue of pain immediately following a vasectomy” had been discussed.¹³⁴

Dr Milnes took the view that if the condom user has “*perfect technique and is very very*

careful,” the risk of a pregnancy over a 12- month period is 2%. However in relation to the

“*imperfect less than very very careful user*” the incidence of pregnancy jumps to 18%.¹³⁵ Dr

Milnes conceded that “*with regular clear instruction, DE would be as likely to use a condom*

as a person with capacity.”¹³⁶ Arguably it was incumbent on the court to allow his training to

continue. The principle of equal access would mean that DE should not have been treated less

favourably than the general population. No one would countenance compulsory sterilisations

for non intellectually disabled people for imperfect condom use, so arguably sterilising people with intellectual disability is morally and ethically dubious.

Lee and Morgan comment on how the House of Lords in *Re B* used facts to suit their view of how and whether the intellectually disabled person could cope with childbirth.¹³⁷ In her discussion of *Re F*, Shaw similarly argues that judges ‘tend to elevate medical opinions to the status of facts’.¹³⁸ It may be that the medical opinion was relied on too heavily to reach a decision on DE’s views and his feelings set aside too easily.

Interestingly DE’s initial consultant urological surgeon at the NHS Trust was of the view that the procedure was not in his best interests¹³⁹. This view was also shared by Dr Milnes, instructed by the Official Solicitor to provide an independent psychiatric report, who concluded in his first report that sterilisation was not in his best interests as there was “*a not insignificant risk of long term chronic pain.*”¹⁴⁰

The consultant “moderated” his view of the “*long term post operative problems*” (i.e. risk of chronic pain) at a subsequent hearing¹⁴¹ which led to Dr Milnes concluding that it *was* in DE’s best interests for a sterilisation to be carried out. A report from an independent consultant urologist commissioned by the Official Solicitor agreed with the revised opinion stating the “*likelihood of severe scrotal pain...at less than 0.5%.*”¹⁴²

In the medical literature, McCormack and Lapointe conclude in their research that the procedure is a safe method of contraception. However, they recognise that some patients feel long term pain, although they remark that this is ‘rare’.¹⁴³ Selikowitz and Schned suggested the phrase “late post-vasectomy syndrome” to describe persistent long term pain.¹⁴⁴ In their study, Myers et al state that the actual incidence of this syndrome has not been documented and note that reports range from 3-8%.¹⁴⁵ Chen and Ball note that while the pain settles in the majority of patients, it “persists in a small number despite treatment,” and in severe cases

further surgery is necessary.¹⁴⁶ In a survey of 172 patients who had undergone a vasectomy four years previously in Glasgow, McMahon et al found 33% had some pain, which 15% found troublesome and 9 patients (5%) had requested medical treatment for pain or swelling. They conclude that while a third of patients had some discomfort, a few patients developed severe pain which required further treatment. They argue that there is a need for informed consent about this risk of pain, uncommon though it might be.¹⁴⁷

Aside from medical effects, another question to consider is the long term psychological effects of having a sterilisation. Research has shown that low self-esteem follows from sterilisation performed forced on people without their consent¹⁴⁸ In one study it was found that forced sterilisation on people with intellectual disability, who lacked capacity, viewed the procedure as a ‘*reduced or degraded status*’ and this negative self image caused them to withdraw.¹⁴⁹ The assumption that people with intellectual disability may not respond negatively to being sterilised is perhaps rooted in viewpoints that they are somehow inferior to the general population.¹⁵⁰ This assumption has been discredited by researchers who demonstrate that people with intellectual disability have similar conceptions of sexuality and parenthood as non intellectually disabled people.¹⁵¹ These conceptions include the same ‘uniqueness’ and that preference that the potential to develop fully should be made available.¹⁵² Arguably this development should include the opportunity to inhabit a space which allows freedom of action and choice in reproductive matters in line with the CRPD. A troubling picture can also be seen in research undertaken by Carlson, Taylor, & Wilson about the sterilisation of men with intellectual disabilities in Australia.¹⁵³ They document one response from The Public Guardian of Western Australia:

“[they] outlined a number of anecdotal cases from the Public Guardian’s archives and commented on the lack of processes for facilitating informed decision-making. One young

man with Down syndrome was vasectomised to “protect against the possibility of getting a woman pregnant”. His family were unaware of the generally low fertility of men with Down syndrome. The young man involved was not aware of the operation or of its effect. In a second situation, a young man was told that unless he agreed to vasectomy, he could not marry his fiancé. He did not give informed consent and was apparently coerced into the sterilisation. He was reportedly disturbed by the outcome and needed months of counselling.”¹⁵⁴

They argue that for some men it may be difficult to explain the post surgical discomfort being experienced and how their behaviour may well be misunderstood as being difficult as a result of this discomfort.¹⁵⁵

Pregnancy and child birth can be a distressing experience and also cause psychological damage, so it is not advocated that anyone should be forced to have a child. The choice should not be ‘sterilisation’ or ‘no contraception’ presented in an all or nothing solution. Instead a genuine and real investigation into the least restrictive alternative and proportionality tests should ensure that other forms of non-surgical intervention are explored thoroughly for both sexual partners (just as would follow in a non intellectually disabled relationship) and then only if all else fails, or all is hopeless, should surgery be contemplated.

As there are reversible methods of sterilisation available then it follows from the least restrictive alternative principle that a reversible method is almost always to be preferred.

The central question becomes are there any non-coercive processes available to achieve the same outcome once the decision to sterilise is made?¹⁵⁶ Have all less restrictive measures been used and applied, especially non permanent? Underlying this discussion remains the central point that carers’ frustrations, time and anxieties regarding future pregnancies cannot

be used as reason to enforce an invasive non-therapeutic operation which carries significant physical and psychological risks. In DE's case, it boiled down to whether he could use the condom, or be taught to use it or indeed be entrusted to do so. It is not suggested his partner be required to use the morning after pill or have to undergo an abortion as this would be merely shifting the oppressive outcome onto women who already bear significant burdens of non consensual sterilisations in society.

The arguments about not trusting or that people with intellectual disability may not be responsible enough to carry out this practice is again dehumanising people with intellectual disability and counter to the shifts in social policy. In the final analysis this principle entails that the case-by-case individualised enquiry of each person with intellectual disability is continued and that the trajectory we have seen in *A Local Authority v K (by the Official Solicitor) and others* be welcomed as a reasoned way forward.

In this case an application for sterilisation on a 21 year old woman with Down's syndrome was refused by the Court of Protection. Cobb J held that there was a low risk of pregnancy, K was well supervised and that less invasive procedures ought to be tried. The court decided that sterilisation surgery would be disproportionate as there were less restrictive methods of contraception available.¹⁵⁷ This is the key in that DE also had an alternative which needed to be fully exhausted. Justice Cobb concluded: "*plainly risk management is better than invasive treatment, it is less restrictive. Moreover, I am persuaded by Dr. Rowlands that there are less restrictive methods of achieving the purpose of contraception than sterilisation, and that in the event of a need for contraception, these ought to be attempted.*"¹⁵⁸

Cobb J also set out the process to be followed in applications for non-therapeutic sterilisations adding, "*such a treatment decision is so serious that the Court has to make it.*"¹⁵⁹ This reminder makes clear the Court of Protection's central role is in protecting people

with intellectual disability, and it is submitted they should enforce the least restrictive alternative provisions robustly.

Moreover, unless there is clear evidence of a risk of sexual activity, it should never be countenanced as a ‘just in case’ measure. Is it right to carry out a surgical procedure which carries risks on a human being because of some possibility in the future?

In *DE* the court noted in following *Re A* that “*any benefit of treatment has to be balanced and considered in the light of any additional suffering or detriment the treatment option would entail.*”¹⁶⁰ King J recognised that in applying the ‘balance sheet’ approach¹⁶¹ the risk of ‘long term scrotal pain and/or discomfort,’ its non-therapeutic nature and the fact that it did not protect against STIs,¹⁶² were factors to weigh into any balancing exercise. Adopting the approach set out by the Court of Appeal it is submitted that perhaps greater weight could have been assigned in *DE* to the risk of long term pain/and or discomfort which he may feel after surgery.

Conclusion

It does seem that after the demise of eugenic reasoning, social policies of normalisation and care in the community provided new justification for sterilisations. It is ironic that modern arguments about promoting the sexual freedom of men with intellectual disabilities should be used as a justification to sterilise them. The fact that A would not have enjoyed more freedom while DE was likely to do so was used to justify the sterilisation in the latter’s case.

Deinstitutionalisation has also placed the burden of care onto parents who can only act within the context of their emotional and physical resources. Researchers have identified that there is a need for more specialist services in sex education and counselling for people with intellectual disability and their parents.¹⁶³

Family interests and their concerns, although well intentioned and motivated by compassion and good will, should never be allowed to trump the interests of people with intellectual disability. One does not wish to question the integrity of parents and their situation needs to be looked at sympathetically. However, it should always be questioned whether their decisions in this context are truly informed and whether access to counselling and support for alternatives might not be in order.¹⁶⁴

This trend is borne out by other studies cited above and suggests that it is incumbent upon the Court of Protection to enforce the 'least restrictive alternative' and proportionality mechanisms of the MCA robustly and that sterilisation should only be considered once all other avenues have been exhausted.

It is suggested that further research on the long term medical effects of sterilisation on men with intellectual disability needs to be undertaken, particularly the psychological effects. In the medical sphere with the continuing development of long term contraceptive techniques like progestin implants, surgical methods may well be reduced but further research is necessary.¹⁶⁵

It is also clear that a genuine participation model of decision making be adopted in keeping with international standards by UK courts to ensure that the views, wishes and interests of people with intellectual disability are genuinely respected. The outcomes in these cases can never justify the oppressive means to achieve them unless the life or serious health of the individual is at stake and the surgery is a proportionate response.

NOTES

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- ¹ [2013] EWCH 2562 (Fam).
- ² [2000] 1 FCR 193.
- ³ Jeff Goldhar, "Sterilization of Women with an Intellectual Disability - A Lawyer Looks at the Medical Aspects." (1990) 10 University of Tasmania Law Review 157, 157.
- ⁴ [2013] EWHC 242 (COP).
- ⁵ Goldhar; Alison Jane Stansfield, AJ Holland and ICH Clare, "The Sterilisation of People with Intellectual Disabilities in England and Wales during the Period 1988 to 1999" (2007) 51 Journal of Intellectual Disability Research 569; OHCHR and others, "Eliminating Forced, Coercive and Otherwise Involuntary Sterilization - an Interagency Statement" (2014) 3.
- ⁶ Stansfield, Holland and Clare. Stansfield et al undertook a survey into the outcomes of referrals to the Official Solicitor between 1988-1999. The males were aged 17, 26 and 41 and only one led to a court hearing reported as *Re A (Medical Treatment: Male Sterilisation)*.
- ⁷ Meera Roy, "A Case Note Follow-up of Women with Intellectual Disability Referred for Sterilization." (2010) 14 Journal of Intellectual Disabilities 43, 50.
- ⁸ Elizabeth Tilley and others, "'The Silence Is Roaring': Sterilization, Reproductive Rights and Women with Intellectual Disabilities" (2012) 27 Disability & Society 413, 418.
- ⁹ Miriam Carlson, Jill Taylor and Glenys Wilson, "Sterilisation, Drugs Which Suppress Sexual Drive, and Young Men Who Have Intellectual Disability" (2000) 25 Journal of Intellectual and Developmental Disability 91, 92.
- ¹⁰ Law Reform Commission of Canada, "Sterilization: Implications for Mentally Retarded and Mentally Ill Persons (Working Paper 24)" (1979) 41.
- ¹¹ Carol Hamilton, "Sterilisation and Intellectually Disabled People in New Zealand—still on the Agenda?" (2012) 7 Kotuitui: New Zealand Journal of Social Sciences Online 61, 70.
- ¹² Community Affairs References Committee, "Involuntary or Coerced Sterilisation of People with Disabilities in Australia" (2013) para 720. They noted however that "*These procedures may not be being performed in young men with disabilities, but it would be relatively uncommon for a sterilising procedure to be performed in a male of this age.*"[7.22]
- ¹³ OHCHR and others.
- ¹⁴ *Re D (A Minor) (Wardship: Sterilisation)* [1976] Fam 185.
- ¹⁵ Sterilisation "...involves the deprivation of a basic human right, namely, the right of a woman to reproduce, and therefore it would be, if performed on a woman for non-therapeutic reasons and without her consent, a violation of such a right." Ibid 193 per Heilbron J held in refusing to authorise a sterilisation on an 11 year old girl.
- ¹⁶ *Re B (A Minor) (Wardship: Sterilisation)* [1988] 1 AC 199. The House of Lords authorised a sterilisation on a 17 year old girl.
- ¹⁷ See Robert Lee and Derek Morgan, "Sterilisation and Mental Handicap: Sapping the Strength of the State" (1988) 15 Journal of Law and Society 229. See also discussion by Silver of the right to procreate in the American context: Michael G Silver, "Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History" (2003) 72 George Washington Law Review 862.
- ¹⁸ *Re DD (No 4) (Sterilisation)* [2015] EWCOP 4 [8]. A sterilisation was authorised on a 36 year old intellectually disabled woman.
- ¹⁹ M Bambrick and GE Roberts, "The Sterilization of People with a Mental Handicap: The Views of Parents" (2008) 35 Journal of Intellectual Disability Research 353, 353.
- ²⁰ A website screamed the following headline after the ruling: "Hitler Would Be Proud! Judge Justice Cobb Rules Mum of Six CAN Be Sterilised against Her Will..." <<http://www.uksocialservices.co.uk/2015/02/04/hitler-proud-judge-justice-cobb-rules-mum-of-six-can-be-sterilised-against-her-will/#more-126>>.
- ²¹ Desmond King and Randall Hansen, "Experts at Work: State Autonomy, Social Learning and Eugenic Sterilization in 1930s Britain" (1999) 29 British Journal of Political Science 77, 77.
- ²² Law Reform Commission of Canada Working Paper 24 24
- ²³ Ibid 25
- ²⁴ Glynis H Murphy, "Capacity to Consent to Sexual Relationships in Adults with Learning Disabilities" (2003) 29 Journal of Family Planning and Reproductive Health Care 148, 148.
- ²⁵ Goldhar 163.
- ²⁶ OHCHR and others 2; DJ Kevles, "Eugenics and Human Rights." (1999) 319 British Medical Journal (Clinical Research Ed.) 435, 435.

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- ²⁷ Law Reform Commission of Canada Working Paper 24 [26]
- ²⁸ 274 U.S. 200 (1927).
- ²⁹ Ibid 207; More than 70,000 people were sterilised in various states, the links between eugenics and sterilisation are explored in Silver.
- ³⁰ See Goldhar for more detail.
- ³¹ CK Harbour, Johns Hopkins and Pallab K Maulik, "International Encyclopedia of Rehabilitation History of Intellectual Disability Early History" [2013] International Encyclopedia of Rehabilitation 1 <<http://cirrie.buffalo.edu/encyclopedia/en/article/143/>>; *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.
- ³² King and Hansen 79.
- ³³ Ibid 80.
- ³⁴ Ibid 79–80.
- ³⁵ Ibid 90.
- ³⁶ Goldhar 169.
- ³⁷ King and Hansen 93.
- ³⁸ Cited in *ibid.* PRO, MH51/210, Confidential, Chairman's Memorandum, 8–9.
- ³⁹ Ibid 89.
- ⁴⁰ Melinda Jones and Lee Ann Marks, "Female and Disabled: A Human Rights Perspective and Law and Medicine" in Kerry Anne Petersen (ed), *Intersections: Women on Law, Medicine and Technology* (Dartmouth 1997) 49.
- ⁴¹ Elizabeth J Reed, "Criminal Law and the Capacity of Mentally Retarded Persons to Consent to Sexual Activity" (1997) 83 Virginia Law Review 799, 805.
- ⁴² Molly Ladd-Taylor, "Contraception or Eugenics? Sterilization and 'Mental Retardation' in the 1970s and 1980s" (2014) 31 Canadian Bulletin of Medical History 189, 200.
- ⁴³ Jones and Marks 49–71.
- ⁴⁴ Department of Health, "Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities" (2009). The report opens with the statement: "*People with learning disabilities are entitled to the same aspirations and life chances as other people*" and at p.35 "*the vision of Valuing People Now is that all people with learning disabilities are supported to become empowered citizens*"
- ⁴⁵ Tilley and others 423.
- ⁴⁶ John Tobin and Elliot Luke, "The Involuntary, Non-Therapeutic Sterilisation of Women and Girls with an Intellectual Disability - Can It Ever Be Justified?" (2013) 3 Victoria University Law Journal & Justice Journal 27, 30.
- ⁴⁷ European Union Agency for Fundamental Rights, "Involuntary Placement and Involuntary Treatment of Persons with Mental Health Problems" (2012). The United Kingdom ratified the CRPD on June 8, 2009
- ⁴⁸ Convention on the Rights of Persons with Disabilities 2006 General Assembly Resolution 61/106 Article 1(1).
- ⁴⁹ OHCHR and others; Linda Steele, "Submission to the Senate Community Affairs References Committee Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia" [2013] Faculty of Law, Humanities and the Arts - Papers.
- ⁵⁰ Lee and Morgan 239.
- ⁵¹ Tobin and Luke 38.
- ⁵² Ladd-Taylor 201.
- ⁵³ Goldhar 187.
- ⁵⁴ Linda Gilmore and Laura Malcolm, "'Best for Everyone Concerned' or 'Only as a Last Resort'? Views of Australian Doctors about Sterilisation of Men and Women with Intellectual Disability" (2014) 39 Journal of Intellectual and Developmental Disability 177, 185.
- ⁵⁵ Ibid 182.
- ⁵⁶ Community Affairs References Committee 2.38.
- ⁵⁷ *An NHS Trust v DE* [8].
- ⁵⁸ Ibid 9.
- ⁵⁹ Ibid 5.
- ⁶⁰ *Re A (Medical Treatment: Male Sterilisation)*.
- ⁶¹ M Aunos and MA Feldman, "Attitudes towards Sexuality, Sterilization and Parenting Rights of Persons with Intellectual Disabilities" (2002) 15 Journal of Applied Research in Intellectual Disabilities 285, 285.
- ⁶² Reed 805.
- ⁶³ Gilmore and Malcolm 177.

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- ⁶⁴ Josephine Shaw, “Sterilisation of Mentally Handicapped People: Judges Rule OK?” (1990) 53 *The Modern Law Review* 91, 98.
- ⁶⁵ *An NHS Trust v DE* [14].
- ⁶⁶ *Ibid* 15.
- ⁶⁷ *Ibid* 94.
- ⁶⁸ *Ibid* 66.
- ⁶⁹ *Ibid* 94.
- ⁷⁰ Emily Jackson, *Medical Law: Text, Cases, and Materials* (3rd edn, Oxford University Press 2013) 166.
- ⁷¹ *Chatterton v Gerson* [1981] QB 432; *R v Tabassum* [2000] 2 Cr App R 328.
- ⁷² s2 and s3 MCA 2005.
- ⁷³ Practice Direction 9E to the Court of Protection Rules 2007, and Para.6.18 and Paras.8.18-8.29 of the Mental Capacity Act 2005 Code of Practice.
- ⁷⁴ *A Local Authority v K (by the Official Solicitor)* [36].
- ⁷⁵ *An NHS Trust v DE* [35].
- ⁷⁶ Further guidance can be found in the Code of Practice which accompanies the MCA on the requirements set out in s4(4).
- ⁷⁷ *An NHS Trust v DE* [53]
- ⁷⁸ Mary Donnelly, “Best Interests, Patient Participation and the Mental Capacity Act 2005.” (2009) 17 *Medical Law Review* 1.
- ⁷⁹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 [76].
- ⁸⁰ Donnelly 10.
- ⁸¹ *Re S and Another (Protected Persons)* [2010] 1 WLR 1082.
- ⁸² *Ibid* 52.
- ⁸³ *Ibid* 57.
- ⁸⁴ *An NHS Trust v DE* [52].
- ⁸⁵ *Ibid*.
- ⁸⁶ Donnelly 9.
- ⁸⁷ Rebecca Dresser, “Missing Persons: Legal Perceptions of Incompetent Patients” (1993) 46 *Rutgers Law Review* 612.
- ⁸⁸ *Ibid*.
- ⁸⁹ *Ibid* 613.
- ⁹⁰ Donnelly 7.
- ⁹¹ UN Convention on the Rights of Persons with Disabilities (2006) General Assembly Resolution 61/106, 7.
- ⁹² OHCHR and others; Penelope Weller, “The Convention on the Rights of Persons with Disabilities and the Social Model of Health: New Perspectives” (2011) 3 *Journal of Medical Health Law* 74.
- ⁹³ *Re DD (No 4) (Sterilisation)* [102].
- ⁹⁴ *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819.
- ⁹⁵ Goldhar 160.
- ⁹⁶ D Chakraborti and AP Macdonald, “Contraception and the Mentally Handicapped.” (1984) 289 *British Medical Journal* (Clinical Research Ed.) 1095, 1096; Aunos and Feldman 287.
- ⁹⁷ Gilmore and Malcolm.
- ⁹⁸ Stansfield, Holland and Clare 575.
- ⁹⁹ *Ibid* 577.
- ¹⁰⁰ *An NHS Trust v DE* [41].
- ¹⁰¹ *Ibid* 63.
- ¹⁰² *Ibid* 92.
- ¹⁰³ *Ibid* 94.
- ¹⁰⁴ *Re A (Medical Treatment: Male Sterilisation)*, 205.
- ¹⁰⁵ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.
- ¹⁰⁶ *Ibid* 83.
- ¹⁰⁷ *Re Y (Mental Patient: Bone Marrow Donation)* [1997] Fam 110.
- ¹⁰⁸ *An NHS Trust v DE* [84].
- ¹⁰⁹ *Ibid* 87. Suggested by Thorpe LJ in *Re A (Medical Treatment: Male Sterilisation)*.
- ¹¹⁰ *An NHS Trust v DE* [95].
- ¹¹¹ following a protection plan earlier on in the proceedings.

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- ¹¹² *per* Dame Butler-Sloss at 203
- ¹¹³ Jonathan Herring, "Caregivers in Medical Law and Ethics." (2008) 25 *Journal of Contemporary Health Law and Policy* 1, 13.
- ¹¹⁴ I Gremmen and others, "Ulysses Arrangements in Psychiatry: A Matter of Good Care?" (2008) 34 *Journal of Medical Ethics* 77, 78.
- ¹¹⁵ *Local Authority X v MM* [2007] EWHC 2003 (Fam) [99] *per* Munby J.
- ¹¹⁶ Herring 30.
- ¹¹⁷ Anita Ho, "Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making" (2008) 22 *Scandinavian Journal of Caring Sciences* 128, 132.
- ¹¹⁸ Tobin and Luke 12.
- ¹¹⁹ *Ibid.*
- ¹²⁰ Community Affairs References Committee 5.93.
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