

**Medicine and Intersex: Legal and
Ethical Issues Surrounding Genital
and Gonadal Surgery**

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Candidate's Name: Melanie Newbould

Candidates School: School of Law

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Medicine and Intersex: Legal and Ethical Issues Surrounding Genital and Gonadal Surgery

ABSTRACT: This thesis deals with some of the legal and ethical issues that arise when an individual's genital and gonadal anatomy does not match what is perceived to be the biological (or sometimes culturally determined) norm. I focus on intersex individuals, particularly infants, who may undergo genital surgery, to 'normalise' genital anatomy. I compare this type of surgery to other forms of genital cutting on those too young to consent, male circumcision and female genital mutilation (FGM). I discuss how sex is complex and not yet fully understood; intersex challenges the idea that sex is a simple binary entity and the history of 'sex testing' in sport illustrates that there are, rarely, individuals for whom categorisation as biologically male or female is impossible. Gender is also a complex entity, but institutions such as medicine and the law still endorse a simple bipolar model of sex and gender. I argue that the assumptions on which medical practice in intersex is based are based on these simplistic gender norms. I argue that one form of intersex surgery, refashioning the clitoris, continues to be seen as a valid treatment option despite the paucity of outcome data and is not treatment for an illness but for an anatomical difference. At least some individuals who have had this procedure perceive that they have been harmed by it. Therefore I argue that the current medical and surgical approach to anatomical genital variation in intersex is ethically questionable. Furthermore it is possible to construct an argument that it is not in the best interests of the young child to undergo this procedure and that it therefore may be unlawful, even when carried out with parental consent. I also argue that, if FGM is unlawful, as it is, then other analogous procedures, such as clitoral surgery for intersex and male circumcision for non-medical reasons should similarly be unlawful. Male circumcision is held to be lawful in England at present, but the English courts have not considered genital surgery in intersex infants. If they did, then the logical conclusion ought to be to proscribe it. I argue that documents such as driving licences and passports should permit a neutral gender and that birth certification ought to permit registration without specifying sex for intersex infants. It is possible that at least some of this may come about in the future, since a recently published report from the House of Commons Women and Equalities Committee on Transgender Equality has suggested change in the current situation, one indication of the current rapid pace of change in this area of Law. I argue that education about intersex and sex and gender diversity is important for healthcare professionals and for everyone.

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PREFACE

BACKGROUND: I am a consultant paediatric histopathologist at the Royal Manchester Children's Hospital and hold the degrees of B. Sc., M. B., B.S., and the Fellowship of the Royal College of Pathologists. In 2001 I completed the M. A. in Healthcare Ethics and Law in the University of Manchester. In 2009, I decided to attempt the PhD in Bioethics and Medical Jurisprudence at the University of Manchester as a part time student.

As part of my studies I have attended and presented papers at the following conferences and meetings -:

- **30 March-1 April 2010** - Socio-Legal Studies Association Annual Conference, University of the West of England, Bristol, UK. Conference on *Gender, Sexuality and Law*. I gave a paper entitled 'Intersex, society and the law'.
- **14th-16th June 2010** – I attended a Conference at Uppsala University called *Is medical ethics in the best interests of the patient*– I gave a paper entitled - 'Infantile surgery for intersex: is it in the best interests of the child?'
- **1st -2nd September 2010** I attended the *Concepts of Health* Conference at the University of the West of England I gave a paper entitled 'Is there any validity in the Concept of a Disorder of Sex Development'. A volume of essays was produced from this conference (H. Carel & R. Cooper (eds.), *Health, Illness & Disease* (Durham: Acumen Publishing Limited, 2013). Chapter 6 of this thesis, 'Intersex, medicine and pathologisation' was written for this volume.
- **10th March 2011** I presented an early version of the 'Infantile Surgery for Intersex: are the parents always right?' at the ISEI

seminar. The paper that I eventually wrote on this topic is presented in chapter 7 of this thesis.

- **9th April 2011** – I attended a conference *Sexuality and legal Transformation* at the University of Westminster organised by PECANS (Postgraduate & Early career Scholars). I gave a paper entitled *Should infantile genital surgery for ‘disorders of sex development’ be restricted in the manner of the ‘Colombian’ model?*
- **30th March 2012**- I attended a Workshop *Bodies of Law and Law and the Body* at Westminster University, London. I gave a paper called ‘What is the point of sex?’ This was really an early stage in considering the question of intersex and athletics. This eventually became the paper ‘What do we do about women athletes with testes?’, which forms Chapter 8 of this thesis.
- **18th May 2012** –I attended the *21st Century Body* – symposium at University College, London. I gave a paper on ‘Biology, Sex and Sport’.
- **June 2012** – I attended the 11th World Congress of Bioethics in Rotterdam, I gave a paper entitled ‘Do we need sex?’ Again this was thinking about women, testes and sport.
- **22nd April 2014** - North West Gender Conference 2014: *Constructions of Gender in Research - Lancaster University, George Fox Building*, I gave a paper entitled ‘Sport, Cheating and Bodies’.

- **29th October 2014** - *I attended the Manchester School of Law Annual Postgraduate Research Conference Wednesday. I gave a paper entitled 'Parallel Rivers' on the two very different strands of literature concerning intersex (the medical and the social/ethical/legal) and the lack of any cross reference between them.*
- **7th-8th September 2015** – 9th Postgraduate Bioethics Conference, *Binaries in Bioethics: what role should they serve?* I gave a paper entitled 'Women, testes and sport'.

In 2014, I also wrote a book chapter, part of which dealt with the science of sex development in humans and also with the range of gonadal pathologies that may occur in intersex conditions (Newbould, MJ, 'Germ cell tumours of the ovaries and dysgenetic gonads' in N Wilkinson (ed.), *Pathology of the Ovary, Fallopian tube and Peritoneum* (London: Springer, 2014), 289-326.) This is relevant to my work as a paediatric histopathologist, but it did also enable me to look in depth at the some of the scientific background of intersex.

I have occasionally presented papers at the PhD studies days. I have also presented some of this research at Grand Rounds at the Royal Manchester Children's hospital.

CHAPTER 1

INTRODUCTION: THE ISSUES.

I am a medical consultant in paediatric and perinatal pathology. Before I started to research the topic of intersex, I thought that it was a simple matter to decide what sex someone is, though I was aware that sex and gender do not always exactly correlate. I thought that it was *normal and natural* for a woman to have certain well-defined anatomical and physiological characteristics and I thought that it was *normal and natural* a man might also have other, distinctly different, anatomical and physiological characteristics. I thought that some people were anatomically normal and others not and I believed that intersex people have a *disorder of sex development*, a medical condition, which implies that there might be a medical treatment to correct the *disorder*. I thought that the current standard model of treatment for intersex was medically appropriate, though I was aware that there were activists who questioned this, but believed they were wrong and did not understand anatomy and physiology in the same way that doctors do.

Before starting this research I did not question the idea that gender might, in some way, be biological. I did not question the existence of a biological gender identity. I believed that scientific studies might hold the clue to what gender is and thought that the brain might be the site where gender is determined.

In this work I originally set out to examine some of the legal and ethical questions that arise when a person's genital and gonadal anatomy does not conform to what is perceived as the biological or, in some cases, societal norm. My initial research focused on intersex individuals, and in particular infants, who frequently have genital and gonadal anatomy that is sometimes considered to be 'ambiguous' and not formed in a way considered 'normal'. It is therefore not uncommon for those with these

conditions to undergo surgery to 'normalise' genital anatomy during infancy. Surgery raises questions concerning the lawfulness and the ethics of such interventions. Examining the evidence and the literature relating to surgery on intersex infants, several other sets of questions became pertinent: genital cutting for ritual, cultural or even cosmetic reasons and surgery on athletes (intersex women or trans women) who wished to compete at a high level as women. Broader questions are also raised. For example, the existence of intersex challenges the notion that sex is strictly bipolar. Though most individuals fit into the two major poles, a small but significant minority do not.

Intersex also challenges the idea of what is normal and what is abnormal and what constitutes illness. Intersex individuals may have anatomical features or combinations of anatomical features that are unusual and this raises the question as to whether this should be regarded as an 'illness'.

Intersex in infants.

One of the commoner states included in the umbrella term 'intersex' is congenital adrenal hyperplasia. 'Biologically'¹ female fetuses with this condition become virilised in utero and are born with variably masculinized genitalia. There are other much less common conditions in which 'biologically' female neonates may also be born with atypical masculinized genitalia. It is the solution to this problem that has most frequently led to ethical debate. Once it became technically feasible to operate and refashion the genitalia of infants in the 1950s, because of technical advances in surgery and medicine, it became accepted medical practice to 'normalise' anatomy. This is not life saving surgery (though some of the hormonal replacement therapy given to intersex children with

¹ Implying that the individual has chromosomes, gonads and internal genitalia that are all of the type that usually are found in human females (46 XX chromosomes, ovaries, uterus).

adrenal insufficiency may be essential²) but it is carried out to change the child's appearance to something considered more normal. This was initially considered an urgent matter to be completed as soon as possible after the child was born, because it was an important factor determining the type of parental response to the child, which in turn was considered to influence gender development.³ Though no longer felt to be urgent, genital surgery continues to be carried out to try to make little girls (who are too young to give their own consent) appear more normal.^{4, 5}

Creating or correcting a problem?

I shall show how such a view is now contested and, it could be argued, in certain cases such surgery is unlawful. The appearance of the child's genitalia may be of importance to the parents of the child concerned, but the problem with early surgery is that it exposes the child to physical harm for no *medical* gain and may expose him or her to later

² Such as immediate hormone replacement for those who lack the enzymes necessary for the production of mineralocorticoid hormones in the salt-losing form of congenital adrenal hyperplasia. Ieuan Hughes writes 'To imply that a mutation in the *CYP21* gene resulting in 21-hydroxylase deficiency and leading to a life threatening cause of ambiguous genitalia (congenital adrenal hyperplasia) is a *variant* or a *difference*, not a *disorder*, is akin to suggesting that atheromatous plaques in the coronary arteries resulting in a myocardial infarct is not a cardiovascular disorder', IA Hughes, 'The quiet revolution' (2010) 24 *Best Practice & Research Clinical Endocrinology & Metabolism* 159-162. But no one is arguing that the resulting potentially fatal hormone deficiency resulting from the gene mutation is not a serious illness, it is the ambiguous genitalia (an effect of the stimulation by abnormal hormone levels) that, it is argued, constitutes a *variant* or *difference* rather than a *disorder*.

³ J Money & AA Ehrhardt, *Man & Woman, Boy & Girl* (Baltimore: Johns Hopkins Press, 1972) 12.

⁴ The standards for treatment are set out in IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

⁵ Surgery continues to be a valid option some years after publication of the standards referred to in n 4, above. See for example, R Sturm, B Durbin-Johnson & EA Kurzrock E, 'Congenital adrenal hyperplasia: current surgical management at Academic medical centers in the United States' (May 2015) 193 (5) *Journal of Urology* 1796-1801.

psychological harm; it is an imposition of societal and parental values on the child and it is this that makes it ethically and, perhaps, legally questionable. Of course, there are powerful reasons why parents may wish their child to have normal appearing genitalia, thinking that the child will have to face a life of teasing or bullying unless 'normal'. Surgery performed on intersex infants is grounded in a notion of gender and sex that closely links both of these to genital anatomy, a view that is no longer held universally⁶ though, as I will discuss throughout this work, it remains a commonly-held view. Surgery can cause physical harm to the child, because of scarring, but, also, surgical intervention as a young child may prove a problem for those who wish to transition gender as adults. The surgery is irreversible and some consider it mutilating.⁷ However, the situation is far from simple and many adult patients with (and without) intersex conditions also choose to 'normalise' their genitalia. The need to be perceived as normal is powerful.

Other forms of genital cutting: do they serve the same purpose?

In evaluating this situation it became apparent that it is not only intersex individuals who may be submitted to genital surgery as infants or young children. In some societies it is common to perform some forms of genital cutting, varying in extent and circumstance, often on children unable to consent. I will argue that all such procedures require ethical analysis and, in some circumstances, are legally questionable. There is no law that deals specifically with surgery for intersex in this country. The statutes and case law in England and Wales deal with other forms of

⁶ As in the Gender Recognition Act 2004, which will be considered further in Chapter 5. (See page 128) .

⁷ For example, K Karkazis, *Fixing Sex: intersex, medical authority and lived experience* (Durham: Duke University Press, 2008) 229. Many adults who had surgery as children consider that their bodies are now ugly and disfigured – 'When they separated my labia, they left too much skin. I've compared myself to other women, and it looks like they just ran the scalpel down and sewed them'

genital cutting – both female genital mutilation and male circumcision. Therefore it may be helpful to consider whether there are any analogies between intersex surgery, considered therapeutic, and other non-medical forms of genital cutting.

I will argue that other forms of genital alteration take place to modify appearance in order to conform to some external standard of normality. Like genital surgery for intersex individuals it serves to fashion genitalia into a form deemed acceptable to the community in which the child lives. Again the situation is complex, because individuals have a strong desire to belong to and to pass as normal in their society and genital cutting may act as a mark of belonging. Families wishing their son to undergo ritual circumcision may fervently wish that he is accepted as a member of that society and may consider that he is disadvantaged if he does not belong.

Therefore surgery for intersex and other forms of genital cutting have in common that they may be carried out following consent of those with parental responsibility who consider that they are consenting to something that will help the child in his or her future life.

Intersex in adolescents and adults.

It is not only infants who may be forced to have surgical intervention. Not all individuals with intersex states/*disorders of sex development* are detected at birth.⁸ Intersex conditions can be diagnosed in individuals who have passed infancy; the presentation to the medical team may occur because of failure to enter the menarche,⁹ virilisation¹⁰ in a girl at

⁸ SF Ahmed, JC Achermann, W Arlt, AH Balen, G Conway, ZL Edwards, S Elford, IA Hughes, L Izatt, N Krone, HL Miles S O'Toole, L Perry, C Sanders, M Simmonds, AM Wallace, A Watt & D Willis, 'UK Guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development' (2011) 75 *Clinical Endocrinology* 12-26.

⁹ The first menstrual period.

puberty or delayed puberty in a boy.¹¹ Detection may occur following testing for high testosterone amongst female competitors in elite athletic events, sometimes identifying non-suspecting individuals.¹²

All of the above are situations in which an individual may need to have surgical intervention in order to pass as what is held to be normal in a society or group to which she belongs.

Pace of change

An exciting aspect of this research is that in the past three years or so there has been a marked acceleration in the pace of change in attitudes towards matters such as sex and gender in general and also, to some extent, towards intersex surgery. In England, the recent report by the House of Commons Women and Equalities Committee on Transgender Equality¹³ and the various changes in gender law around the world that I will discuss later in this thesis provide some evidence of this. Though, as yet, there has been no change in English law concerning genital surgery in intersex, there is increasing recognition of the ethical problems with the publication of relevant international Human Rights Instruments in recent years. For example, the European Union (EU) Agency for Fundamental

¹⁰ This is a description of the effects of hormones such as testosterone on an individual, usually someone who is otherwise phenotypically female. The effects include deepening of the voice and the development of facial and body hair in the pattern usually associated with a phenotypic male.

¹¹ Ahmed & others, above, n 8.

¹² P Fénichel, F Paris, P Philibert, SG Hiéronimus, L Gaspari, J-Y Kurzenne, P Chevalier, S Bermon, N Chevalier & C Sultan, 'Molecular diagnosis of 5 α -reductase deficiency in 4 elite young female athletes through hormonal screening for hyperandrogenism' (2013) 98 (6) *Journal of Clinical Endocrinology and Metabolism* E1055-E1059.

¹³ House of Commons Women and Equalities Committee, 'Transgender Equality' 14th Jan 2016
<http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf>
Accessed 22/05/2016.

Rights (who provide advice to Member States and EU Institutions ¹⁴) suggested in 2015 that changes to birth certification and legal documents would be a step forward for intersex people. Further it was suggested that surgery should be avoided unless the individual concerned consents to it. ¹⁵ Therefore there may be many more changes to come in the near future.

¹⁴ European Agency for Fundamental rights. <http://fra.europa.eu/en/about-fra>
Accessed 22/05/2016

¹⁵ FRA Focus, 'The fundamental rights situation of intersex people'
<http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf>
Accessed 22/05/2016.

I will now briefly outline the content of this thesis.

The format of the Doctorate in Biomedicine and Medical Jurisprudence consists of a number of published or publishable papers (forming chapters 6,7 and 8 of this thesis), with further chapters to discuss background and other issues (chapters 1-5) followed by the conclusions.

Chapter 2: Background: biology, sex, gender and medicine.

This is an introduction to the topics of biological sex and intersex. I discuss the rationale behind the development of the classic treatment for intersex. Because of a belief that social learning was the major factor in acquisition of gender, surgical correction of unusual genitalia was considered mandatory in order that social cues would be appropriate to facilitate this. I discuss the present day position as far as genital and gonadal surgery for intersex individuals is concerned. I mention the paucity of scientific data on the results of intersex treatment and I move on to question whether there should be recognition of more than two sexes. Next, I provide a succinct account of some aspects of gender relevant to intersex.

Chapter 3: Ethical and Legal Background.

This chapter uses three case scenarios to examine some ethical and legal issues encountered during the life of an intersex child from birth to adolescence. The issues include giving information at delivery and during the process of diagnosis, assigning of the gender to the child, legal birth certification and some aspects of the ethics and law concerning intersex surgery on infants (including parallels with other forms of genital cutting). I also discuss some aspects of the management of gender dysphoria in intersex.

Chapter 4: Philosophical Approach.

In this chapter I look at case scenarios in the context of philosophical approaches to medicine. I look at a biostatistical theory of disease, a normativist theory of health and a type of phenomenological approach to illness and examine how these approaches assist in our understanding of intersex. I discover that phenomenological approaches in particular can assist in understanding some aspects of intersex that other approaches fail to highlight.

Chapter 5: Legal Approach.

I look at the development of gender law in England from the 1970s onwards, from the definition of gender as an individual's biological sex at birth in *Corbett v Corbett*¹⁶ to the Gender Recognition Act 2004. I discuss a recent report recommending further change to gender law in England.¹⁷ I discuss some aspects of the law relevant to genital surgery on infants and children for intersex, comparing it to other forms of genital cutting. I discuss how, though there are some analogies as well as differences between surgery for intersex, male circumcision and female genital mutilation, the law concerning them in England is very different; only female genital mutilation is unlawful.¹⁸ I also discuss how there may be future change, since bodies such as the World Health Organisation, United Nations and agencies of the European Union have in recent years recognised the vulnerability of those with intersex conditions to surgical intervention when they are too young to consent.

¹⁶ *Corbett v Corbett* [1971] P 83

¹⁷ House of Commons Women and Equalities Committee, *Transgender Equality*, above, n 13.

¹⁸ Female Genital Mutilation Act 2003.

Chapter 6: Intersex, medicine and pathologisation. ¹⁹

I look at some aspects of intersex, including the changes brought about by the introduction of a protocol for medical management in 2006, when the term 'disorder of sex development' was introduced into medical discourse in place of the term 'intersex'. I discuss the need to be normal and some of the problems of cosmetic genital surgery. I argue that medical intervention may not 'normalise' those with intersex conditions but make them more aware of their differences.

Chapter 7: When parents choose gender: intersex, children and the law. ²⁰

I discuss the issue of parental consent for medical treatment for their child, focusing on the intersex child and the problems of deciding what is in the child's best interests. I consider the law concerning other examples of controversial treatments for children, such as other forms of genital cutting and sterilisation procedures to identify any parallels.

Chapter 8: What do we do about women athletes with testes? ²¹

I examine the rules concerning athletic competition whereby intersex women (and trans women) with functioning testicular tissue must undergo gonadectomy if they are to compete as women. I consider if this is actually 'fair' in the context of the sport of athletics, since other characteristics that confer athletic ability, such as muscle type or height

¹⁹ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180.

²⁰ M Newbould, 'When parents choose gender: intersex, children and the law' Accepted for publication in *Medical Law Review* 2016 (forthcoming).

²¹ MJ Newbould, 'What do we do about women athletes with testes?' (6/11/15) *Journal of Medical Ethics* doi:10.1136/medethics-2015-102948. Accessed 22/05/2016.

are not eliminated in this way. There have been recent changes in the rules, published after publication of this paper, so I discuss the changes elsewhere, mainly in Chapter 9.

Chapter 9: In conclusion

I conclude by considering that my thesis has highlighted three broad topics: first, there are the fundamental matters of biology, medicine and law that serve to emphasise the binary nature of human sex differentiation. My second broad topic is more focused on specific areas of medicine concerned with intersex where I consider that past and current practice may be viewed as unethical. The third topic I deal with in my conclusions concerns my recommendations for change in medicine, law and more generally.

CHAPTER 2:

BACKGROUND: BIOLOGY, SEX, GENDER AND MEDICINE.

Intersex is an area in which it is necessary to understand something of the basic biology and medicine in order to be able to understand the ethical and legal arguments. This background is also important as it helps to place intersex into the wider context relating to sex and gender. This is therefore a long chapter that covers some relevant aspects of biology, medicine and science. It includes information about the approach taken, both historically and currently, by healthcare professionals to intersex.

In order to illustrate intersex briefly, I will start by discussing what happens at the present time following the birth of an intersex baby. Unless there is already an index case with a known gene or structural malformation to act as a marker in a family, it is unlikely that a diagnosis of intersex will be made using antenatal ultrasound scans. It is also unlikely that it will be possible to distinguish between normal male genitalia and atypical female genitalia using this imaging technique. Though I will also be dealing with intersex beyond infancy, the neonate seems a sensible place to start. It is only possible to recognise the young infant as intersex if the genitalia are unusual in form. Though this is frequently so, it is not true for all intersex individuals, hence the occasional diagnosis of an adolescent or adult as intersex, as mentioned in Chapter 1.

First things

When a baby is born the first question that is often asked of the attending midwife concerns the baby's sex. As far as I am aware, in most societies, sex is viewed as a matter of fundamental importance and

determines how the world will respond to that individual. In most countries, it is essential to know the child's sex to complete birth certification. At birth, the child will need to be categorised into male or female. This applies to all babies following birth but may be problematic for an intersex child. It may be necessary to involve expert help and to delay deciding until some preliminary investigations such as the hormonal profile and karyotype have been carried out. These may or may not give some clues as to the child's underlying biology, but will in any case take time to evaluate. This is likely to be a shocking and difficult situation for the family concerned and I discuss this further in Chapter 3.

Sex and intersex

This is a succinct introductory account to this matter. The problems with intersex arise in part because for many people it is simply a given that a person will be male or female. Though it is considered a matter of common sense and beyond argument that we mammals are easily categorised into either male or female sex, in fact determination of biological sex is extremely complex. Basically, there is no one biological character at the genotypic level or at the phenotypic level that can be said to be an exclusive determinant of either the male or the female sex.

Mammalian sex differentiation involves many stages, so it is not surprising to learn that, at times, there are variants from the usual situation. There are four biological criteria that one might use to determine mammalian sex; the chromosomes (XX for females, XY for males),¹ the gonad type (ovary or testis), the internal anatomy and the external genitalia.² Though in humans the presence of the Y-chromosome is established at the point of conception, depending on whether a Y-chromosome bearing or an X-chromosome bearing sperm

¹ SF Kemp, 'The role of genes and hormones in sexual differentiation' in SE Sytsma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006) 2.

² Kemp, above, n 1, 3.

fertilises the ovum (which is always X-bearing), this is certainly not all there is to sex development. The gonadal type (either ovary or testis) and the hormones it produces are important in determining what internal and external anatomy the individual will manifest.³ To some extent the gonad type develops independently of the chromosomal complement. In early embryonic life the gonad can potentially develop into either ovary or testis. Initially, there is a balance in the microenvironment so that it does not develop into either.⁴ Differentiation into a testis or an ovary occurs when either the testicular or the ovarian pathway is instigated and the other is suppressed.⁵ This is a complex and dynamic process, as much of the genome is under transcription at this stage (indeed, it appears that half the genome is active in the gonad at this time)⁶ and many genes are expressed in a sexually dimorphic way. There is therefore far more to forming a testis than possession of a Y-chromosome and there is far more to forming an ovary than possession of XX sex chromosomes. Development of either gonad requires a very complex network of gene products forming the microenvironment. I also discuss this process in Chapter 6 (see page 161 onwards). Despite the complexity, the majority of individuals end up with chromosomes, gonads, internal and external anatomy that are either all female or all male. In an intersex person, one or more of these entities is of male type and the others are of female type.⁷ In the current medical terminology, intersex states are known as a 'disorders of sex

³ Kemp, above, n 1, 3.

⁴ M Cools, KP Wolffenbuttel, SLS Drop, JW Oosterhuis & LHJ Looijenga, 'Gonadal development and tumour formation at the crossroads of male and female sex determination' (2011) 5 *Sexual Development* 167-180.

⁵ SC Munger & B Capel, 'Sex and the circuitry: progress toward a systems-level understanding of vertebrate sex determination' (2012) 4 *WIREs Systems Biology and Medicine* 401-412.

⁶ Munger & Capel, above, n 5.

⁷ Kemp, above, n 1, 5-6.

development'.⁸ I discuss the introduction of this term in chapter 6 (page 173).

There are many possible variants and so there are many hundreds, if not thousands, of different intersex conditions, many of which remain unexplained at the genetic and molecular level. Whilst approximately 30 genes have been identified that seem to be involved in the process of human sex development, more than half of the described intersex conditions do not involve any of them, suggesting that there must be many other genes and processes that play a part that have yet to be discovered.⁹ Estimates of the prevalence of intersex vary, from around 1.7% down to 0.018%, depending on what is included in the definition, but it occurs more frequently than many realise.¹⁰ In fact the birth prevalence of anatomically unusual genitalia (which is not the same as the birth prevalence of intersex, though there will be many individuals who are included in both groups) may be as high as one in 300, though cases in which even an experienced neonatologist cannot identify genital sex at birth are much less frequent, estimated at one in 5000.¹¹

⁸ See for example V Pasterski, P Prentice & IA Hughes, 'Impact of the consensus statement and the new DSD classification system' (2010) 24 *Practice & Research Endocrinology & Metabolism* 187-195.

⁹ Munger & Capel, above, n 5.

¹⁰ L Sax, 'How common is intersex? A response to Anne Fausto-Sterling' (2002) 39 *The Journal of Sex research* 174-178.

¹¹ SF Ahmed, JC Achermann, W Arlt, AH Balen, G Conway, ZL Edwards, S Elford, IA Hughes, L Izatt, N Krone, HL Miles S O'Toole, L Perry, C Sanders, M Simmonds, AM Wallace, A Watt & D Willis, 'UK Guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development' (2011) 75 *Clinical Endocrinology* 12-26.

Classic treatments for intersex

One might well infer [...] a girl must be made up of rather simple stuff and a boy or man is only capable of living as male if his penis is functional¹²

Corticosteroid hormone replacement therapy for babies born with congenital adrenal hyperplasia was developed in 1950.¹³ This condition, described in Chapter 1, was very important in the development of medical and surgical treatment of intersex. The initial 'standard treatment protocol' for intersex was developed in the 1950s and was based on the pioneering ideas of John Money. He was working in Baltimore and observed that, in the society of the time, parents treated girls and boys very differently¹⁴ and he believed that this was the most influential factor in gender development.¹⁵ Children were rewarded for what was perceived by parent, peers and society to be appropriate masculine or feminine behaviour and thereby learned how to behave, so that there was a strong social element to the acquisition of gender.¹⁶ This was known as 'gender socialization hypothesis'.¹⁷ His theories were not directly influenced by, but to some extent tied in with, the more general theories put forward by Bandura. Initially looking at the development of aggression, Bandura had shown that children probably

¹² WG Reiner, 'Prenatal gender imprinting and medical decision making: genetic males with severely inadequate penises' in SE Sytsma (ed), *Ethics and Intersex*. (Dordrecht: Springer, 2006) 153-164, 159.

¹³ J Money & AA Ehrhardt, *Man & Woman, Boy & Girl* (Baltimore: The Johns Hopkins University Press, 1972) 97.

¹⁴ Money & Ehrhardt, above, n 13, 117-145.

¹⁵ Money & Ehrhardt, above, n 13, 145.

¹⁶ G Siann, *Gender, sex and sexuality* (Hove: Psychology Press, 1994) 65.

¹⁷ K Karkazis, *Fixing Sex: intersex, medical authority and lived experience* (Durham: Duke University Press, 2008) 52.

learned by observing the behaviour of adults.¹⁸ Bandura later developed what is known as social learning theory in which 'psychological functioning is explained in terms of a continuous reciprocal interaction of personal and environmental determinants'.¹⁹ For the Baltimore group, because it was thought that children learned both by imitation and in response to cues from those around them, early genital surgery for the child followed by treatment with appropriate hormones was deemed important.²⁰ If the child looked appropriate for a gender, it was felt to be more likely that parents and peers would interact in a manner appropriate to that gender. I will discuss gender again later in this chapter. Social factors continue to be seen as important in the development of gendered behaviour. I discuss the early medical model for treatment of intersex in more detail in my papers 'Intersex, medicine and pathologisation'²¹ and 'When parents choose gender'.²² I will discuss some very basic points in what follows.

There were problems with the approach of the Baltimore team. Then (as now) there were (and are) rather narrow views as to what was and is appropriate for each gender. Management in Baltimore was centred on penile size.²³ For John Money, a baby without a penis must be reared as a female. The sex of rearing was based pragmatically on the genital

¹⁸ A Bandura, D Ross & SA Ross, 'Transmission of aggression through imitation of aggressive models' (1961) 63 *Journal of Abnormal and Social Psychology* 575-582. Children observed adults behaving aggressively towards a doll and then were observed in order to establish if they had learned this behaviour.

¹⁹ A Bandura, *Social learning theory* (Upper Saddle River, NJ: Prentice-Hall Inc, 1977) 11-12.

²⁰ Money & Ehrhardt, above, n 13, 97.

²¹ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180. (In this thesis, see chapter 6, 168).

²² Newbould, M., 'When parents choose gender: intersex, children and the law', accepted for publication in *Medical Law Review* (2016). (In this thesis, see Chapter 7, 202).

²³ Money's threshold for raising a child as a boy was an infantile penis length of 1.9cm. See Karkazis, above, n 17, 101.

appearance, or how the genitalia could be made to appear. In the case of a small penis, the structure might be deemed 'too small' (meaning that it was not thought likely to function as a 'copulatory organ'). If this was the case, then the child was castrated and reared as a girl.²⁴ The general rule was that, for boys, the ability to have heterosexual intercourse was of prime importance, but fertility was less important. For girls, on the other hand, sexual functioning in the sense of orgasm was not held to be of much importance. It was, however, important that they were able to take part in heterosexual intercourse so a vagina was constructed where necessary. For females, fertility was deemed very important. It was never even considered that a girl might have a use for a phallus capable of penetration and an enlarged clitoris was removed (clitoridectomy).²⁵

The phallogocentric treatment model was brought into question by the case of David Reimer, which refuted the existence of a simple relationship between genital anatomy, social cues and gender.²⁶ David had male genitalia at birth and XY chromosomes at birth and was, therefore, unequivocally biologically male by any currently measurable criteria. He was born in August 1965.²⁷ At 8 months of age, he lost his penis in an accident during circumcision.²⁸ His distraught parents contacted John Money who suggested that the child would do best if he were brought up as a girl²⁹ and he had sex reassignment including gonadectomy. He was known as Brenda from July 1967.³⁰ However, in fact, at the time that the change (to Brenda) took place, David was aged nearly two years,

²⁴ Karkazis, above, n 17, 56-57.

²⁵ Karkazis, above, n 17, 56-57.

²⁶ J Colopinto, *As nature made him: the boy who was raised as a girl* (New York: Harper Perennial, 2000) (Kindle edition).

²⁷ Colopinto, above, n 26, 9.

²⁸ Colopinto, above, n 26, 12-14.

²⁹ Colopinto, above, n 26, 50.

³⁰ Colopinto, above, n 26, 52.

so a little beyond the 18-month limit that Money usually imposed. His life was widely cited as an example of successful gender acquisition through 'gender socialization'. In reality, by 1980, Brenda had re-transitioned to David.³¹ David subsequently married and had an adopted family.³² John Money never produced any long-term follow-up studies on David Reimer and in 1987 he was continuing to reiterate the importance of his discovery that boys with an absent penis or early penis loss must be brought up as girls.³³ He considered that this was his major contribution to medicine.³⁴ John Money's influence may have led to the widespread medical acceptance of the importance of early genital surgery in intersex infants.³⁵ David Reimer was one of his most celebrated and well-known cases.

David's story eventually appeared in the medical literature and non-medical press, though this was 17 years or so after David had transitioned to live as a male. In 1997, a paper by Milton Diamond and Keith Sigmundson described the events of David Reimer's teenage and adult years, revealing that David had rejected the female upbringing that Money and his family had chosen for him.³⁶ Also in 1997, Colopinto wrote an essay for *Rolling Stone* on the case³⁷ and his book was later published.³⁸ The book is not a medical text but a sensationalist account

³¹ Colopinto, above, n 26, 204

³² Colopinto, above, n 26, 194.

³³ Colopinto, above, n 26, 203.

³⁴ Colopinto, above, n 26, 203.

³⁵ A Davidian, 'Beyond the Locker room: changing narratives on early surgery for intersex children' (2011) 26 *Wisconsin Journal of Law, Gender and Society* 1-22.

³⁶ M Diamond & HK Sigmundson, 'Sex reassignment at birth: long-term review and clinical implications' (1997) 15 (3) *Archives of Pediatrics & Adolescent Medicine* 298-304.

³⁷ J Colopinto, 'The true story of John/Joan' (11/12/1997) *Rolling Stone* 54-97.

³⁸ Colopinto, *As nature made him: the boy who was raised as a girl*, above, n 26.

of the events, but nonetheless it did provide useful information. There was no response from John Money about the revelations and it is uncertain as to whether he had previously known about the outcome. David's personal story ended sadly; tragically, he killed himself in his thirties.³⁹

The events of this case did not necessarily imply Money was wrong about everything and undoubtedly he was right about many aspects of the care of intersex children. He was wrong that life as a male is impossible with a small or absent penis. The work of William Reiner, a psychiatrist who worked with a group of children with cloacal extrophy and related malformations demonstrated that boys with a small or absent penis could develop a secure male identity. Children with cloacal extrophy have chromosomes, internal genitalia and external genitalia all of one sex type so it is not an intersex condition but, because of a severe congenital malformation (in which the pelvic organs including the bladder are located externally on the lower abdominal wall), the penis is absent or small in boys. The children with an XY karyotype and testes would, under the Money protocol, be reared as females. In a series of sixteen cases, Reiner found two children were raised as boys but fourteen had been brought up as girls. Eight of those reared as girls (so over half of them) later decided to transition to male, but the small number reared as boys continued to live as males into adulthood.⁴⁰ So the lack of a functioning penis does not make a boy any less male. This was known previously in any case – many children are born with neurological conditions that impair sexual function and it has never been suggested that they should be raised as female. One of the very important matters that Reiner recognised was the value of an evidence base in managing intersex patients.⁴¹

³⁹ Colopinto, *As nature made him: the boy who was raised as a girl*, above, n 26, 286.

⁴⁰ Reiner, above, n 12, 158.

⁴¹ Reiner, above, n 12, 158.

As time went on, further problems emerged with this simplistic model of intersex treatment. As discussed in 'When parents choose gender' (Chapter 7),⁴² in the 1990s intersex adults, who had received treatment in infancy, started to question aspects of their treatment, particularly early clitoral surgery. Also around this time, scholars from the humanities and social sciences started to consider the implications of and problems associated with the Baltimore treatment protocol for intersex. Writers such as Kessler,⁴³ Fausto-Sterling,⁴⁴ Dreger,^{45,46} and Preves⁴⁷ discussed intersex management critically. The critical and questioning atmosphere so generated led to discussion amongst specialist paediatric surgeons and endocrinologists managing intersex conditions. Ultimately this led to the consensus statement published in 2006⁴⁸ discussed briefly in 'When parents choose gender' (Chapter 7).⁴⁹

Surgery in intersex

Although surgery on intersex infants and young children is no longer performed in all cases it is still lawful in England for parents to consent to

⁴² Newbould, 'When parents choose gender: intersex, children and the law', above, n 22. (In this thesis, see chapter 7, 203).

⁴³ S Kessler, 'The medical construction of gender: Case management of intersexual infants' (1990) 16 *Signs* 3-26.

⁴⁴ A Fausto-Sterling, 'The five sexes: why male and female are not enough' (1993) 33 *The Sciences* 20-24.

⁴⁵ A Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge Mass: Harvard University Press, 1998).

⁴⁶ A Dreger, *Intersex in the Age of Ethics* (Hagerstown: Maryland University Press, 1999).

⁴⁷ S Preves, 'For the sake of the children: destigmatising intersexuality' (1998) 9 (4) *Journal of Clinical Ethics* 411-420.

⁴⁸ IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

⁴⁹ Newbould, 'When parents choose gender: intersex, children and the law', n 22. (In this thesis, see chapter 7, 203).

such surgery as discussed in my paper⁵⁰ (Chapter 7). This very possibility is, I argue, ethically problematic, because there is nothing inherently pathological in having ambiguous genitalia, or even with having an ambiguous, non-binary sex.

Feminizing surgery has been modified over the years. The basic aim has always been to reduce clitoral size and, eventually, to build a vagina.⁵¹ However, clitoral reduction surgery has evolved from clitoridectomy (amputation) to, initially, clitoral recession in the early 1990s.⁵² This consisted of dissection of the corpora cavernosa (the very vascular erectile tissue), which was attached to the underside of the pubic bone. Though the rationale was to preserve the clitoral nerve supply, in fact this procedure could result in pain and often required further surgery. This operation is no longer performed.⁵³ The procedure most frequently carried out now is clitoral reduction (sometimes called clitoroplasty), involving dissection and removal of part of the clitoral corpora, but with the aim of retaining the vascular and nerve supply.⁵⁴ A problem is that it is still not clear what effect this has on sexual functioning since, as noted at the end of this chapter, good outcome studies are lacking.⁵⁵

⁵⁰ Newbould, 'When parents choose gender: intersex, children and the law', n 22. (In this thesis, see chapter 7).

⁵¹ SM Creighton, L Michala, I Mushtaq & M Yaron, 'Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same' (2014) 5 *Psychology and Sexuality* 34-43.

⁵² Creighton & others, above, n 51.

⁵³ Creighton & others, above, n 51.

⁵⁴ Creighton & others, above, n 51.

⁵⁵ Creighton & others, above, n 51.

Surgery to remove gonads⁵⁶

This is also part of the medical treatment for intersex disorders. The medical rationale is that the gonads in many intersex states (in both girls and boys) have a variable potentiality to develop malignant germ cell tumours.⁵⁷ A further reason is that they will produce hormones, which may have unwanted effects (for example, the presence of testes in a girl may, at puberty, result in undesirable virilisation because of the effects of testosterone⁵⁸). Often, the decision to remove gonads may be delayed until the child is sufficiently mature to be able to take part in the decision making process.

In some cases the diagnosis will not have been apparent until the child reaches adolescence and will present at this time because of failure to start periods or virilisation in a girl or failure to undergo puberty in a boy (though often boys will have presented earlier because of concerns regarding undescended testes). There are major problems for the child and her family when diagnosis is late. There may have been no previous indications that the child had a problem. Suddenly, it is discovered that the girl child has either XY chromosomes, has testes or both and will not be fertile (in the absence of reproductive technology). A boy may be found to have no testes, a uterus and XX chromosomes. Sometimes, the child has a malignant germ cell tumour at presentation.⁵⁹ Diagnosis can therefore be a great shock and I discuss this in Chapter 4.

⁵⁶ Gonadectomy is the name for surgery to remove gonads of any sort; the term orchidectomy refers to removal of testes and oophorectomy to removal of ovaries.

⁵⁷ LHJ Looijenga, R Hersmus, BHCGM de Leeuw, H Stoop, M Cools, JW Oosterhuis, SLS Drop & K Wolffenbuttel K, 'Gonadal Tumours and DSD' (2010) *24 Best Practice & Research: Clinical Endocrinology and Metabolism* 291-310.

⁵⁸ For example, deepening of the voice (which is a permanent effect even if testosterone is subsequently lowered), increased body and facial hair growth.

⁵⁹ Looijenga & others, above, n 57. Germ cell refers to the type of cell forming the tumour. See Newbould MJ, 'Germ cell tumours of the ovaries and

As I will discuss in detail in Chapter 8, ‘What can we do about women athletes with testes?’⁶⁰ diagnosis may also be made following testing for elevated testosterone in elite women athletes.⁶¹ Until the end of 2015, gonadectomy was a requirement for intersex athletes with testes entering women’s events.⁶² Trans women also had to undergo gonadectomy before competing as women, leading to potential conflict between these rules and the Gender Recognition Act 2004 in England.⁶³ In November 2015, the rules changed.⁶⁴ Trans gender athletes can now compete in gender categories on the basis of self-declared gender without the need for surgery, as long as they fulfil regulations regarding blood testosterone level, which I explain in Chapter 9.

Though, in medicine, it is accepted without question or controversy that gonadectomy forms a part of appropriate medical treatment in intersex, there is a growing movement against this practice. The WHO has

dysgenetic gonads’ in N Wilkinson (ed), *Pathology of the Ovary, Fallopian tube and Peritoneum* (London: Springer, 2014) 289-326.

⁶⁰ MJ Newbould, ‘What do we do about women athletes with testes?’ [6/11/15] *Journal of Medical Ethics* doi:10.1136/medethics-2015-102948. Accessed 22/05/2016. (In this thesis, see chapter 8, 229).

⁶¹ P Fénichel, F Paris, P Philibert, SG Hiéronimus, L Gaspari, J-Y Kurzenne, P Chevalier, S Bermon, N Chevalier & C Sultan, ‘Molecular diagnosis of 5 α -reductase deficiency in 4 elite young female athletes through hormonal screening for hyperandrogenism’ (2013) 98 (6) *Journal of Clinical Endocrinology and Metabolism* E1055-E1059.

⁶² IOC addresses eligibility of female athletes with hyperandrogenism. www.olympic.org/medical-commission?articleid=124006 (accessed 12/04/2014)

⁶³ Statement of the Stockholm consensus on sex reassignment in sports. <http://apps.fims.uwo.ca/NewMedia2008/page1772927.aspx> (accessed 12/04/2014)

⁶⁴ International Olympic Committee, ‘IOC Consensus Meeting of sex reassignment and hyperandrogenism, November 2015’. http://www.olympic.org/Documents/Commissions_PDFfiles/Medical_commission/2015-11_ioc_consensus_meeting_on_sex_reassignment_and_hyperandrogenism-en.pdf Accessed 31/01/2016.

recently published a paper on forced sterilisation and has recognised that intersex individuals form a group that are especially vulnerable to this.⁶⁵

What are the results of intersex treatment?

There are anecdotal single reports, such as those individuals who gave accounts to Dreger.⁶⁶ The most common theme in such literature is that:

(m)any adult intersexuals report feeling deeply ashamed and abused by their medical treatments'⁶⁷.

I discuss this aspect in my paper 'Intersex, medicine and pathologisation', Chapter 6.⁶⁸ However, there have been relatively few large outcome studies on the general well-being of individuals with intersex diagnoses so there is a paucity of available information. Indeed, Sarah Creighton, a gynaecologist involved in intersex points out that a longitudinal study including a large number of individuals with DSD, in order to look at results of different treatment protocols, would be more or less impossible to organise.⁶⁹ Funding for most UK studies is granted for a number of years only and resources are not available for the type of work that such a large-scale long-term research would involve, particularly since intersex

⁶⁵ WHO 'Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement' 2014
http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf
7 Accessed 23/05/2016

⁶⁶ A Dreger, *Intersex in the Age of Ethics*, above, n 46.

⁶⁷ M Holmes, *A Perilous Difference* (Selinsgrove: Susquehanna University Press, 2008) 148.

⁶⁸ Newbould, 'Intersex, medicine and pathologisation', above, n 21. (In this thesis, see chapter 6, 180).

⁶⁹ SM Creighton, JA Greenberg, K Roen & DL Volcano, 'Intersex practice, theory and activism' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 249-260.

is not an issue that involves a high proportion of the population (unlike cancer or heart disease).⁷⁰

Crouch and Creighton note that there is actually very little objective data on the results of feminising genital surgery and even the few studies that there are often give very few details as to how assessment of patient satisfaction was made.⁷¹ The few surgical outcome studies that there are suggest that many outcomes are not satisfactory. It does appear that those women who had undergone childhood surgery experience a higher rate of orgasmic and sexual problems than those who did not have genital surgery.⁷² For example, one study of fifty-seven XY individuals with intersex disorders subjected to feminising surgery discovered that almost half expressed dissatisfaction with the results of surgery. Seventy per cent of this group reported physical sexual problems. This suggests that, in this group of patients at least, treatment protocols may need to change.⁷³ In a recent article for the British Medical journal (September 2015), Creighton and her team reiterated that there are no reliable long-term studies of outcome following early surgery.⁷⁴ The small studies that there are demonstrate a high rate of problems such as diminished genital sensitivity, and difficulty with orgasm.⁷⁵ Most girls had to have multiple

⁷⁰ Creighton & others, above, n 69.

⁷¹ NS Crouch & SM Creighton, 'Long-term functional outcomes of female genital reconstruction in childhood' (2007) 100 *British Journal of Urology International* 403-406.

⁷² CL Minto, LM Liao, CR Woodhouse, PG Ransley & SM Creighton, 'The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study' (2003) 61 *Lancet* 1252-1257.

⁷³ B Köhler, E Kleinemeier, A Lux, O Hiort, A Grütters, U Thyen & the DSD Network Working group, 'Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: results from the German clinical evaluation study' (2012) 97 *Journal Of Clinical Endocrinology and Metabolism* 577-588.

⁷⁴ L-M Liao, D Wood & SM Creighton, 'Parental choice on normalizing cosmetic genital surgery' (2015) 351 *British Medical Journal* h5124.

⁷⁵ Liao & others, above, n 74.

further operations in order to facilitate menstrual flow or vaginal intercourse.⁷⁶

It might be thought that in view of the uncertainty regarding outcome, it might be best to abandon infantile genital surgery for intersex children before they can make the decision for themselves. The situation is complex, however. Creighton notes that adult women DSD patients who come to her clinic are themselves very 'traditional in their aspirations' and want to achieve what they view as normality.⁷⁷ Women, including those with exclusively female sexual partners, want to have what they view as 'normal' genitalia and they wish to have a vagina by which they can achieve heterosexual sexual intercourse. Even when fully informed that clitoral reduction may lead to a loss of sensation and inability to have orgasm, many will choose to try surgically to achieve a normal appearance.⁷⁸ It is however, perhaps, a different matter when the patient has herself chosen to undergo surgery but the matter is far from simple. The need to be normal is discussed further in the paper 'Intersex, medicine and pathologisation.'⁷⁹

I will now discuss some of the background regarding sex and gender. These are enormous topics and this is a brief account dealing with only some of the areas that are most relevant to intersex.

Should we recognise two sexes or more?

According to the World Health Organisation:

Sex refers to the biological and physiological characteristics that define men and women. Gender refers to the socially

⁷⁶ Liao & others, above, n 74.

⁷⁷ Creighton & others, 'Intersex practice, theory and activism', above, n 69.

⁷⁸ Creighton & others, 'Intersex practice, theory and activism', above, n 69.

⁷⁹ M Newbould, 'Intersex, medicine and pathologisation', above, n 21. (In this thesis, see chapter 6, page 178).

constructed roles, behaviours, activities and attributes that a given society considers appropriate for men and women.⁸⁰

This appears to suggest that it should be a simple matter to say what sex someone is. I will start by further discussing the problems of defining two easily distinguishable sexes by considering the implications of a well-known essay written in the 1990s. In the forgoing accounts of sex, I have explained that it is not always easy to describe biological sex in terms of male or female. So in view of the existence of many intersex states, might one solution be to devise a system of more than two sexes?

In 1993, Anne Fausto-Sterling published her classic essay on the topic of 'The five sexes: why male and female are not enough'⁸¹. She initially proposes the introduction of three further terms to describe biological sex: 'herms' (who possess both ovaries and testes) 'ferms' (who have ovaries and male external genitalia) and 'merms' (who possess testes with female genitalia). She goes on to say that 'sex is a vast, infinitely malleable continuum that defies the constraints of even five categories'⁸² and this is perhaps the more accurate way to look at the biological evidence (and seems to refute what she said in the preceding section of the paper about having a system of five distinct sexes).

Further, Morland in his essay 'Why five sexes are not enough' makes the point that Fausto-Sterling starts her discussion by telling the story of Levi Sudyam, who in 1843 was subjected to medical examination because there were questions regarding his eligibility to vote at a local election by the law pertaining at the time (in Salisbury, Connecticut) which permitted only men to vote.⁸³ He had a phallus (and so was declared eligible to

⁸⁰ World Health Organisation. <http://www.who.int/gender/whatisgender>
<http://www.who.int/gender-equity-rights/understanding/gender-definition/en>

⁸¹ Fausto-Sterling, above, n 44.

⁸² Fausto-Sterling, above, n 44.

⁸³ I Morland, 'Why five sexes are not enough' in N Giffney & M O'Rourke (eds), *The Ashgate Research Companion to Queer Theory* (Farnham: Ashgate Publishing Company, 2009) 34-48.

vote) but was also reported to have a vaginal opening and to menstruate. As Morland notes, Levi did not claim to be a 'Herm', rather he claimed and was granted privileged male status, which carried the ability to vote in national and local elections. I am not trying to allege that this was a deliberate choice on his part, but it happens that his identification as a male did render him politically important. He therefore became part of the *binary* system of sex and *gender*. I discuss gender further on in this chapter. Therefore, though Fausto-Sterling is correct that biological sex is infinitely more complex than is acknowledged, there is a difference between 'identifying intersex and identifying *as* intersex'.⁸⁴ The problem is, as most theorists would now concede, that the *gender* categories male and female carry implications regarding permitted freedoms and privileges and are not neutral. For Levi, life as a man meant he was permitted to help choose those who governed him.

It is notable though that, in 2000 when Fausto-Sterling revisited 'The Five Sexes',⁸⁵ she started her paper with a description of Cheryl Chase, someone who did accept her intersex identity, addressing the Lawson Wilkins Pediatric Endocrine Society on the topic of genital ambiguity in newborns. Fausto-Sterling noted 'as if from nowhere, intersexuals are materializing before our very eyes'⁸⁶ She did, however, note that whilst some people had found her suggestion disturbing, she had brought the topic into wider discourse and helped the way for those who did wish to identify as intersex. However, as I discuss later *legally speaking* there is no way of registering a newborn infant as anything other than male or female in England at the present time.

The answer to the question 'Should there be two sexes or more?' is therefore complex. Biologically speaking, there are more than two sexes – there are an infinite number of possible permutations of sex. However,

⁸⁴ Morland, above, n 83, 40.

⁸⁵ A Fausto-Sterling, 'The Five Sexes, Revisited' (2000) 40 (4)*The Sciences* 18-23.

⁸⁶ Fausto-Sterling, 'The Five Sexes, Revisited', above, n 85.

in England, there are two legally recognised *genders*; in practice, it is difficult to live outside this binary structure, as discussed later in this chapter and in Chapters 3, 5 and 9.

Distinction between sex and gender

Since the 1930s, anthropologists such as Margaret Mead had realised that the meaning of the terms 'man' and 'woman' was variable and dependent on social factors.⁸⁷ John Money was one of the first to apply this type of thought to medical practice. In addition to his pioneering work on medical and surgical treatment for intersex infants, he also was influential in many other clinical areas concerning sex and gender. For Money gender was what was acquired by the child's upbringing in the family environment and social world.⁸⁸ In the 1950s he used the term *gender role* to mean:

[N]ot only the private and introspective self recognition of being he or she, but also the public evidence of that self-recognition in the presence of others.⁸⁹

Later, he used 'gender role' to mean the public presentation of an individual as a man or a woman. The individual's self-representation as male or female (their internal conviction)⁹⁰ was termed 'gender identity' by Robert Stoller.⁹¹

Socialisation begins in infancy and everything that surrounds us from our earliest years serves to reiterate our position in society in terms of

⁸⁷ H Moore, 'Understanding sex and gender', T Ingold (ed), *Companion Encyclopedia of Anthropology: humanity, culture and social life* (Routledge, 1994) 813

⁸⁸ Money & Ehrhardt, above, n 13, 15.

⁸⁹ J Money, *A First Person History of Pediatric Psychoendocrinology* (New York: Kluwer Academic, 2002) 35.

⁹⁰ Money & Ehrhardt, above, n 13, 15.

⁹¹ R Stoller, 'A contribution to the study of gender identity' (1964) 45 *The International Journal of Psychoanalysis* 220-226.

gender. This was recognised by Simone de Beauvoir, as early as 1949. Famously, she stated 'one is not born, but rather becomes, woman'.⁹² From the 1970s onwards, the idea that sex and gender were separate became widely accepted, particularly by feminist writers who argued that social institutions such as gender generated and perpetuated social inequality.⁹³ For example, the anthropologist Gayle Rubin asks:

what is a domesticated woman?' She answers 'A female of the species. [...] A woman is a woman. She only becomes a domestic, a wife, a chattel, a playboy bunny, a prostitute, or a human Dictaphone in certain relations.'⁹⁴

So an individual's role in social interactions may be malleable and dependent on social circumstances.

The 'gendered brain'

This is a very succinct account of an enormous area of research and theory. Since it was relevant to the development of intersex treatment I have already referred to Money's theory of the development of gender, in which, he considered that learning from social cues was very important. He was aware from the 1960s that girls with congenital adrenal hyperplasia showed 'tomboyism' and 'very little interest in infant care and feminine associated clothing and toys'.⁹⁵ This was interpreted as 'masculine' behavior and it is frequently observed in girls with congenital adrenal hyperplasia; I discuss this in more detail below. Overall, Money thought that gender acquisition was a complex matter with biology also possibly playing a role in some circumstances but that the social cues

⁹² S de Beauvoir, *The Second Sex* (C Borde & S Malovany-Chevalier (trs), Vintage Books, London) (Kindle edition) First published 1949, Chapter 1, lines 1-2, loc 6047.

⁹³ A Fausto-Sterling, *Sexing the Body* (New York: Basic Books, 2000) 3.

⁹⁴ G Rubin, 'The Traffic in Women. Notes on the political economy of sex' in RR Reiter (ed), *Toward an Anthropology of Women* (New York: Monthly Review Press, 1975) 157-210, 158.

⁹⁵ See Money, above, n 89, 43.

were most important. This is similar to some theories of gender acquisition of the present day in which it is considered that the genetic make-up of the individual interacts with cultural influences and the individual's experiences and this leads ultimately to the gender expressed by the individual.⁹⁶

There are also other theories that hold that gender is part of an individual's genetic make up and that sex-typical behaviour is hard-wired and innate.⁹⁷ The influential academic psychologist, Simon Baron-Cohen, for example, considers that:

females on average have a stronger drive to empathize while males on average have a stronger drive to systemize.⁹⁸

However, scientific evidence for an *innately* gendered brain is difficult to obtain. In practice, it is more or less impossible to exclude social factors when testing some aspect of behaviour since all children exist in a social environment. The earlier the testing, the more likely it is that innate factors in isolation are under investigation⁹⁹ but this rather severely limits what can be tested. Nonetheless, some psychologists (including Baron-Cohen's group) consider that they have demonstrated sex differences in behaviour of male and female neonates (only one to two days old). For example, one study showed that when given the choice of a face and a mechanical mobile, male infants looked for a longer time at the mobile, where as females favoured the face.¹⁰⁰ The meaning of this is uncertain

⁹⁶ LJ Rogers, 'Sex differences are not hardwired' in JA Fisher (ed), *Gender and the science of difference* (New Brunswick: Rutgers University Press, 2011) (Kindle edition) chapter 2.

⁹⁷ Rogers, above, n 96, loc 370.

⁹⁸ S Baron-Cohen, MV Lombardo, B Auyeung, E Ashwin, B Chakrabarti & others, 'Why Are Autism Spectrum Conditions More Prevalent in Males?' (2011) 9 (6) *PLoS Biol* : e1001081. doi:10.1371/journal.pbio.1001081 Accessed 24/05/2016.

⁹⁹ Rogers, above, n 96, loc 420.

¹⁰⁰ J Connellan, S Baron-Cohen, S Wheelwright, A Batki & J Ahluwalia, 'Sex differences in human neonatal social perception' (2000) 23 *Infant Behaviour & Development* 113-118.

and it is difficult to extrapolate from this the implication that we are born with a male or female brain. There are many other studies and I just cite an example here.

Looking at older individuals, human brain function shows sexual dimorphism. It can be shown that there are differences of perception between males and females.¹⁰¹ The brains of men do seem to show structural and functional differences to those of women;¹⁰² for example, men have been demonstrated to have better motor and spatial abilities.¹⁰³ They also have more connections within each cerebral hemisphere and more connections within the cerebellum. Women have better memory and social cognition skills in the test environment and more connections between the cerebral hemispheres.¹⁰⁴ Ingalhalikar & others concluded from their study involving 949 young people that:

male brains are structured to facilitate connectivity between perception and coordinated action, whereas female brains are designed to facilitate communication between analytical and intuitive processing modes.¹⁰⁵

Some studies have revealed subtle differences in small areas of the brain of trans women in comparison to men at post mortem and this area in trans women had the same structure as in other women.^{106, 107} However,

¹⁰¹ Rogers, above, n 96, loc 370.

¹⁰² MM Ingalhalikar, A Smith, D Parker, TD Satterwaite, MA Elliott, K Ruparel, H Hakonarson, RC Gur & R Verma, 'Sex differences in the structural connectome of the human brain' (2014) 111 *Proceedings of the National Academy of Sciences* 823-828.

¹⁰³ Ingalhalikar, above, n 102.

¹⁰⁴ Ingalhalikar, above, n 102.

¹⁰⁵ Ingalhalikar, above, n 102.

¹⁰⁶ FPM Kruijver, J-N Zhou, CW Pool, MA Hofman, G Gooren & DF Swaab, 'Male-to-female transsexuals have female neuron numbers in a limbic nucleus' (2000) 85 (5) *The Journal of Clinical Endocrinology and Metabolism* 2034-2041.

many researchers feel that the truth is not that there are rigid sex differences but that:

human brains are composed of 'mosaics' of features, some more common in females compared with males, some more common in males compared with females, and some common in both females and males. Our results demonstrate that regardless of the cause of observed sex/gender differences in brain and behavior (nature or nurture), human brains cannot be categorized into two distinct classes: male brain/female brain.

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Another important point is that any differences that might be demonstrated between male and female brains or between the brains of trans women and men are not necessarily innate. Lawrence suggested that the findings pertaining to trans women could be related to hormone therapy given as treatment rather than to any intrinsic structural factors.

¹⁰⁹ It does seem that there is functional and structural organisation of the human nervous system continuously throughout life – 'experience-dependent plasticity'¹¹⁰. This is perhaps to be expected from the way in which people are able to acquire skills such as musical performance, dancing, taxi-driving, juggling. Humans seem to have a brain that shows considerable plasticity in response to environmental situations. For these reasons it is difficult to prove that there is such a thing as an

¹⁰⁷ J-N Zhou, MA Hofman, LGJ Gooren & DF Swaab, 'A sex difference in the human brain and its relation to transsexuality' (1995) 378 *Nature* 68-70.

¹⁰⁸ Concluded from a study using MRI imaging of 1400 brains. D Joel, Z Berman, I Tavor, N Wexler, O Gaber, Y Stein, N Shefi, J Pools, S Urchs, DS Margulies, F Liem & J Hanggi, 'Sex beyond the genitalia: the human brain mosaic' (Published online before print November 30, 2015) *PNAS* doi: 10.1073/pnas.1509654112 Accessed 24/05/2016.

¹⁰⁹ A Lawrence, 'A critique of the brain-sex theory of transsexualism' (2007) http://www.annelawrence.com/brain-sex_critique.html accessed 24/05/2016.

¹¹⁰ C Fine, R Jordan-Young, A Kaiser & G Rippon, 'Plasticity, plasticity and plasticity....and the rigid problem of sex' (November 2013) 17 (11) *Trends in Cognitive Sciences* 550-551 <http://dx.doi.org/10.1016/j.tics.2013.08.010> Accessed 24/05/2016.

innately male or female brain. Cordelia Fine uses the term 'neurosexism' to describe the way in which any apparent differences in male and female brain physiology are considered to indicate inherent gender differences.

¹¹¹ Overall, there is no definitive evidence for innate gender.

The information from science seems to fit best with a complex theory of gender acquisition; rather than the simple hard-wired brain or the simple social learning, perhaps it is more accurate to say that:

The circuits of your brain are quite literally a product of your physical, social and cultural environment, as well as your behaviour and thoughts. What we experience and do creates neural activity that can alter the brain, either directly or through changes in gene expression. ¹¹²

So that gender comes into our brain by the interaction between our innate biology with everything that we experience in the world outside. Neither factor is the sole determinant.

Development of gender

In young vertebrates, it is clear that there are 'sensitive periods' when experiences have a particularly profound effect on the young mammal, for example, the 'imprinting' experience of young birds. ¹¹³ Much less is known about the 'sensitive periods' in the young human, though it is likely that they do exist. ¹¹⁴ It therefore seems probable that multiple factors (some genetic, some hormonal and some environmental) will contribute to the patterns of neural connectivity and to the development of cerebral functioning. For the purposes of managing intersex children, the timing

¹¹¹ C Fine, *Delusions of Gender* (London: Icon Books, 2010) xxvii

¹¹² Fine, above, n 111, 236

¹¹³ Rogers, above, n 96, loc 527- loc 551.

¹¹⁴ Rogers, above, n 96, loc 543.

of gender acquisition is of importance even if the factors influencing it are uncertain. Young infants start to respond differently to males and females in the first few months of life in length of gaze fixation¹¹⁵ and by the end of the first year of life they can associate objects into gender categories.¹¹⁶ For example, in one study the infants' gaze time was shorter when shown an image of a male face paired with a football and longer if that face was paired with a frying pan.¹¹⁷ This was interpreted as demonstrating that infants were able to distinguish a novel association from one that is more familiar, suggesting that young infants approaching one year of age are to form some sort of understanding of complex social categories, including those related to expectations surrounding gender. Around the start of their third year, children start to be aware of themselves as boys or girls.¹¹⁸ By the time they are three years of age both sexes are culturally aware of activities that might be considered gender appropriate.¹¹⁹ For example, by the age of 24 months, girls associate females with activities such as putting on make up, vacuuming, and holding a baby, and men with fixing a car and shaving, something boys are able to do a few months later.¹²⁰ However, children do not seem to see gender as a permanent state of being initially, but learn this gradually over the first 3-7 years.¹²¹ One matter that may of importance

¹¹⁵ A Fausto-Sterling, *Sex/gender; Biology in a social world*, above (New York: Routledge, 2012) (Kindle Edition) chapter 5, loc 830

¹¹⁶ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 830.

¹¹⁷ GD Levi & RA Haaf, 'Detection of gender-related categories by 10 month old infants' (1994) 17 *Infant Behavior and Development* 457-459.

¹¹⁸ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 852.

¹¹⁹ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 852.

¹²⁰ D Poulin-Dubois, LA Serbin, JA Eichstedt, MG Sen, & CF Beissel, 'Men don't put on make-up: toddlers' knowledge of the gender stereotyping of household activities' (2002) 11 (2) *Social Development* 166-181.

¹²¹ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 852.

for families with an intersex child is that it is not yet clear at which age gender 'identity' can be reliably assessed in practice.¹²²

Therefore the developmental information suggests that knowledge of gender role develops gradually over the first years. In fact John Money also understood gender was gradually acquired, though he considered that the latest time at which one could alter genital anatomy and assign a child to the gender appropriate to the acquired anatomy was 18 months of age.¹²³ By that time, he considered that the social conditioning that the child had received was likely to have resulted in a rigid future in one of the two genders.¹²⁴ In this he may well be correct. The factors involved in forming gender are really not known and there is very little research into some of them. For example, as Anne Fausto-Sterling points out, other than the situation of absent penis in males, (referred to previously) there is still very little objective data about the influence of external genitalia (which Money considered of major importance) in the development of a masculine or feminine (or other) body image.¹²⁵ This is an area on which there has been very little written in recent years.¹²⁶ It has been neglected on the assumption that it is unimportant.

Gender non-conformity, gender dysphoria and trans individuals

As I explain in the following section, dissatisfaction with the gender assigned at birth does sometimes occur in both intersex and non-intersex

¹²² Hughes & others, above, n 48.

¹²³ Money & Ehrhardt, above, n 13, 13.

¹²⁴ Money & Ehrhardt, above, n 13, 13.

¹²⁵ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, Loc 893.

¹²⁶ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, Loc 893.

individuals.¹²⁷ The account given here is extremely brief and detailed consideration of the enormous literature on this topic is outside the scope of this work. 'Gender nonconformity' refers to the 'extent to which a person's gender identity, role or expression differs from the cultural norms prescribed for a particular sex'.¹²⁸ This is not the same as gender dysphoria, though gender non-conforming individuals may feel gender dysphoric at some time.¹²⁹ The term gender dysphoria describes the condition in which a person experiences discomfort or distress because there is a mismatch between their biological sex (or assigned gender) and the gender of their inner experience.^{130, 131} For some, this feeling will be sufficiently strong for them to decide to live permanently in a gender role other than that to which they were assigned at birth (usually referred to as being trans gender) and many will go to any lengths necessary to have a body that conforms to the gender in which they live.¹³² One possible medical treatment is therefore to undergo surgical treatment and hormonal therapy to bring the body into line with the gender identity.¹³³ These *transsexual* individuals will be either trans men (a biological female who lives as a man) or trans women (vice versa).

¹²⁷ In those who do not have an intersex condition, gender assigned at birth will be based on biological sex. I use the term 'biological sex' in line with common usage. Earlier in this chapter I discussed how this is actually a complex entity and it can be difficult to identify the sex of some individuals. Nonetheless, most individuals do have an identifiable biological sex.

¹²⁸ The World Professional Association for Transgender Health (WPATH), 'Standards of Care for the Health of Transsexual, Transgender and Gender Nonconforming People' http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926 5 Accessed 24/05/2016.

¹²⁹ The World Professional Association for Transgender Health, above n 128, 5.

¹³⁰ NHS website <http://www.nhs.uk/conditions/Gender-dysphoria/Pages/Introduction.aspx>

¹³¹ The World Professional Association for Transgender Health, above, n 128, 5.

¹³² The World Professional Association for Transgender Health, above, n 128, 5.

¹³³ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, Loc 919.

The prefix cis- has now entered the general language and means someone who has a gender congruent with his or her biological sex. For example, a cis woman is someone living as a woman who was assigned to the female sex at birth and was born with female biology. This word was originally used in academic writing and the purpose of using it in everyday discourse is to avoid pathologising trans individuals, since it avoids the idea that one group is 'normal' and the other group – the 'trans' individuals- are in some way different and pathological.^{134,135} Those with gender dysphoria choosing to live in line with their self-identified gender may generate considerable controversy, because such individuals do not subvert the binary structure of gender and sex in society. Rather, in the opinion of some feminist scholars, they reinforce it.¹³⁶ Many trans individuals wish to participate and 'pass' in a two-gender system, just as intersex persons may wish to do¹³⁷. As I mention below it is not easy to live outside the binary gender system.

Most trans gender individuals are straightforwardly male or female (genetically and biologically) by the criteria currently available. It is very rare for a trans gender individual not previously known to be intersex to

¹³⁴ E Shapiro, *Gender Circuits: Bodies and identities in a technological age* (Abingdon: Routledge, 2015) 70-71.

¹³⁵ However, cis-gendered is a controversial term for many reasons. See P Elliot, *Debates in Transgender, queer, and Feminist Theory.*, (Farnham: Ashgate Publishing Limited, 2010) 152. Detailed discussion of this aspect of gender is outside the scope of this thesis. The debates often centres around how a woman should be defined and who should have access to or be allowed to volunteer at certain 'safe' woman only spaces, such as rape crisis centres. For example, see Elliott, above, n 135, 12. The use of the terms cis women and trans women imply that both groups are *women*, and this implies that all should have access to the same spaces and same rights in law, whereas some feminist scholars prefer to emphasise that there should be 'recognition of similarities, not sameness' and 'a recognition and respect for differences', see Elliott, above, n 135, 152.

¹³⁶ S Preves, *Intersex and Identity* (New Brunswick: Rutgers University Press, 2003) 45-46.

¹³⁷ Holmes, above, n 67, 15.

be diagnosed as such after revealing themselves as trans gender.¹³⁸ The reason why some people are trans gender is unknown and there is no unequivocal scientific evidence for an innate biological explanation. As I discuss in the section on 'gendered brain', any similarities in the brains of non-trans women and trans women might be explained by the remarkable plasticity that the brain can manifest, rather than be indicative of an innately gendered structure. The concept of *lived gender* can be helpful when considering adults and the way in which they interact with the world. This encompasses:

the reality and materiality of the body's sex, both medically and biologically, the individual's psychological or social gender as perceived by the individual in question, and the imposition of gender norms on the body and psyche from external sources.

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In other words where it comes from does not matter, gender is how the individual chooses to live and interact with society. For some modern theorists such as Judith Butler, gender is a *doing*, a *performance*, rather like a drag act;¹⁴⁰ there is no inner essence of our being that is gendered. The law in England permits individuals to change gender from that assigned at birth to that with which they identify and to live permanently in the role of the acquired gender for all purposes.¹⁴¹ They can do this whether or not they have any surgical or medical treatment.¹⁴² The Gender Recognition Act 2004 is further discussed in Chapter 5.

¹³⁸ The World Professional Association for Transgender Health, above, n 128, 70.

¹³⁹ S Matambanadzo, 'Engendering sex: Birth certificates, biology and the body in Anglo American Law' (2005) 12 *Cardozo Journal of Law and Gender* 213-245.

¹⁴⁰ J Butler, *Undoing gender* (New York: Routledge, 2004) 209, 213-4.

¹⁴¹ Gender Recognition Act 2004 s 2 (1) (c).

¹⁴² Gender Recognition Act 2004. There is no requirement for any specific medical or surgical treatment.

Gender and intersex

It seems that for intersex children the sex of upbringing is the best predictor of adult gender.¹⁴³ Whilst most intersex people will not develop gender dysphoria, some do and it is more prevalent in intersex individuals than in the general population.^{144, 145} In the most recent (2013) edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, the definition of gender dysphoria was altered to indicate distress regarding *assigned gender* rather than biological sex.¹⁴⁶ This means that intersex individuals can be included. As discussed previously, for intersex infants, biological sex may be difficult to define so they are *assigned* a gender in early life for the purposes of birth certification and entry into the social group.

Gender dysphoria in the intersex population does show a number of specific features in comparison to the trans gender population in general.¹⁴⁷ For example, it is most frequent in intersex individuals assigned female at birth, but is more common in biological males in those who do not have an intersex condition.¹⁴⁸ As early as the late 1960s, it was postulated that antenatal exposure to androgenic hormones affected subsequent behaviour.¹⁴⁹ Milton Diamond had also observed this.¹⁵⁰

¹⁴³ P Cohen-Kittens, 'Psychological long-term outcome in intersex conditions' (2005) 64 (supplement 2) *Hormone Research* 27-30.

¹⁴⁴ Hughes & others, above, n 48.

¹⁴⁵ HFL Meyer-Bahlburg, 'Introduction: gender dysphoria and gender change in persons with intersexuality' (2005) 34 (4) *Archives of sexual Behaviour* 371-373.

¹⁴⁶ AL Lawrence, 'Gender assignment dysphoria in the DSM-5' (2014) 43 *Archives of Sexual Behaviour* 1263-1266.

¹⁴⁷ Lawrence, above, n 146.

¹⁴⁸ Meyer-Bahlburg, above, n 145.

¹⁴⁹ Money, above, n 89, 43.

¹⁵⁰ M Diamond, 'A critical evaluation of the ontogeny of human sexual behaviour' (1965) 40 *Quarterly Review of Biology* 147-175.

Sometimes, individuals brought up as girls will ultimately transition to live as males, though which individuals will do this is not easily predicted by any measurable biological parameter such as the level of androgen in the blood in infancy.¹⁵¹ It is actually difficult to test any theories about the part played by androgen exposure and to define such effects in any detail¹⁵² and there is as yet no direct evidence or any idea as to what metabolic pathway might be involved.¹⁵³ Cordelia Fine suggests that the influence of androgens may not be the result of biological factors in isolation but social factors may also be important. She points out that raised androgens levels are not the only difference between these girls and girls who are not intersex. The intersex girls often have atypical genitalia, they take hormone therapy and are under medical surveillance; all these factors may affect social interactions with those peers and family.¹⁵⁴ Though mechanisms by which androgens may influence brain development (whether directly or indirectly) have been postulated,^{155, 156} as yet these are just proposals and concrete scientific evidence for any of them is lacking, certainly in the human.

Gender is problematic

For intersex people and for many others besides, gender may pose difficulties. Morgan Holmes points out that gender always generates

¹⁵¹ Hughes & others, above, n 48.

¹⁵² Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 691.

¹⁵³ Fausto-Sterling, *Sex/gender; Biology in a social world*, above, n 115, loc 743.

¹⁵⁴ Fine, above, n 111, 119-122

¹⁵⁵ MM McCarthy, AP Auger, TL Bale, GJ De Vries, GA Dunn, NG Forger, EK Murray, BM Nugent, JM Schwarz & ME Wilson, 'The epigenetics of sex differences in the brain' (2009) 29 (41) *Journal of Neuroscience* 12815-12823.

¹⁵⁶ MM McCarthy, LA Pickett, JW VanRyzin & KE Kight, 'Surprising origins of sex differences in the brain' (2015) *Hormones and Behaviour* <http://dx.doi.org/10.1016/j.yhbeh.2015.04.013> Accessed 25/05/2016

trouble and that, whilst intersex is troubling, this does not always imply that the intersex are more troubled than others or that 'doing' gender is anymore difficult for them than it is for others.¹⁵⁷ One major problem for all is that defining one's gender always implies a number of relationships with other gendered individuals in society. It may imply entitlement to a set of privileges or alternatively it may imply the opposite. As discussed earlier in this chapter, the intersex individual, Levi Sudham, identified as a man and claimed his right to vote, rather than as a woman, which would have precluded this privilege.

Some problems arise because gender role, like sex, is still seen by many as a binary entity. There is now a growing awareness of non-binary gender categories in western countries – such as gender queer¹⁵⁸ and gender fluid or, perhaps, gender neutral. However, it is still not necessarily easy for those who wish to live in one of these categories to find help in gender clinics where the more conventional request concerns a wish to live either as male or female.¹⁵⁹ In medicine, as in society in general, gender is largely seen as a bi-polar entity. Everyone must lie at one or other arm of the dichotomy. Whilst it is true that some cultures have long recognised and continue to recognise a third gender role, this does not mean that such individuals are considered to hold equal rights to others in that culture.^{160, 161} Therefore recognising a third sex/gender does not mean that all the problems are immediately solved for those that

¹⁵⁷ Holmes, above, n 67, 13-14.

¹⁵⁸ B Donnatone & K Rachlin, 'An intake template for transgender, transsexual, genderqueer, gender non-conforming and gender variant college students seeking mental health services' (2013) 27 *Journal of College Student Psychotherapy* 200-211.

¹⁵⁹ L Olson, 'A case of cis regret' http://www.huffingtonpost.com/lola-olson/a-case-of-cis-regret_b_7020598.html
Accessed 26/05/2016.

¹⁶⁰ G Kalra, 'Hijras: the unique transgender culture of India' (2012) 5 (2) *International Journal of Culture and Mental Health* 121-126.

¹⁶¹ S Farran, 'Pacific perspectives: fa'afine and fakaleiti in Samoa and Tonga: people between worlds' (2010) 31 *Liverpool Law Review* 13-28.

do not fall easily into the roles of male or female. However, legal recognition might form a base from which other reforms follow. I discuss this further in Chapter 5.

In the next chapter I will move on to discuss a range of issues, both legal and ethical, that touch the life of an intersex person from the time of birth through to adolescence.

CHAPTER 3:

ETHICAL AND LEGAL BACKGROUND

The chosen subject of my research, which is broadly an evaluation of ethics and law relating to the medical approach to intersex, invites consideration of multiple legal and ethical issues. It is impossible to write about all of the possible issues in this thesis. Therefore I have been selective about what I have chosen to cover in this and the next two chapters (that is, in chapters 3, 4 and 5).

In this chapter, I use case scenarios concerning various stages in the life of an intersex individual from birth to adolescence. For each scenario I will try to uncover some of the ethical and legal issues that arise in the situation illustrated, so that I provide an overview of the most important concerns. I am not going to deal with issues concerning adults with intersex in this chapter. Though these are just as important, I have to be selective. However, I do deal with some selected issues concerning adults, such as the need to be normal in Chapter 6 ('Medicine, intersex and pathologisation'¹) and the problem of athletics in chapter 8 ('What do we do about women athletes with testes?'²).

In Chapter 4 (Philosophical Approach), I also use case scenarios to consider in depth whether or not intersex should be regarded as a disease or illness. I look at three theories concerned with the epistemology of disease and illness. This type of analysis is of vital importance when it comes to deciding how those who are biologically neither male nor female should be viewed, not only in the narrower

¹ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180. (In this thesis, see chapter 6, 178).

² MJ Newbould, 'What do we do about women athletes with testes?' [6/11/15] *Journal of Medical Ethics* doi:10.1136/medethics-2015-102948. Accessed 22/05/2016. (In this thesis, see chapter 8, 229 onwards)

contexts of medicine and law, but also in general. If it cannot be shown that some aspects of intersex are disease/illness, this carries implications regarding the encounters with medicine. I thought when I started this research that the approach taken in Chapter 4 was theoretical, in contrast to the overview of more practical questions covered in Chapter 3. However, I realised that this very theoretical approach could have a clinical application and I end Chapter 4 by discussing this.

In Chapter 5 (Legal Approach), I examine two areas forming the legal bedrock underlying consideration of intersex. First, some aspects of change in gender law in England between the early 1970s and the present. Secondly, I look at case law and statute concerning genital surgery in children in England and elsewhere, considering male circumcision and female genital mutilation in addition to intersex surgery.

In chapter 3, I will start by mentioning the problems that might arise when communication fails in a clinical situation.

Scenario 1

This is a similar scenario to that presented in my paper ‘when parents choose gender’ (Page 194, Chapter 7). At a birth centre, under midwife-led care a baby is born. This is the first child of a stable relationship. The pregnancy, labour and delivery have been uncomplicated and no abnormalities have been identified on antenatal scanning. Though the baby cries at birth, and the child is placed in contact with the mother’s skin, the midwife is silent and says nothing. The parents have noted that the baby appears to have male genitalia. On questioning by the father, a few seconds later, she seems flustered and is reluctant to tell them that they have a little boy. After indicating that the baby is in excellent general condition, she goes to get help. Nothing is said about the baby’s sex. Eventually after quite a while, several people appear, including a paediatrician, who explains that, whilst there is no doubt that the baby seems healthy and well grown, the health care professionals are having a little difficulty in deciding what sex the baby is because the baby has what are called ‘ambiguous genitalia’. This is devastating for the parents. They are, of course, relieved that their baby is alive and appears healthy– but they have already started to worry about what they tell others in the family and others in their social circle, all of whom are waiting for news regarding the safe delivery. They are told that the baby will need to undergo tests and will need to be placed under the care of a specialist team of paediatricians at the regional tertiary centre which is likely to be located in a big city and so can require, for some parts of the UK, a journey of substantial length. It may be that transfer of that child to that centre as an inpatient will be needed, adding to the difficulty and distress experienced by the family.

Giving Information at delivery

The scenario demonstrates the difficulties that may arise when health care professionals are faced with a comparatively rare event. The requirement for the medical team to ensure families are fully informed, so that parents are able to fulfil their parental responsibilities in relation to authorising treatment, is a key legal and ethical issue in the context of intersex births (and all births where families are called upon to make crucial decisions). This scenario illustrates that implementing a principle of full disclosure may be simple in theory but harder to act on in practice, as I shall explain.

As discussed elsewhere, very atypical genitalia may involve around 1 in 5000 of the population, though lesser degrees occur much more frequently.³ In the UK births can occur in many places outside the tertiary centres, as described in this scenario, so many of the healthcare professionals at the delivery may never have encountered this situation previously. This scenario is unusual but not vanishingly rare, though it may be that local birth units will encounter this situation only once in a generation. Initially, those at the birth may find it difficult to communicate with the child's parents, leading to confusion and distress.⁴ The carers themselves may find they are frightened and uncertain what to do. Many parents may be completely unaware that intersex exists prior to the birth of their child.⁵ Therefore communication in the first days of life may still be difficult or impossible and this can be extremely harmful for the

³ SF Ahmed, JC Achermann, W Arlt, AH Balen, G Conway, ZL Edwards, S Elford, IA Hughes, L Izatt, N Krone, HL Miles S O'Toole, L Perry, C Sanders, M Simmonds, AM Wallace, A Watt & D Willis, 'UK Guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development' (2011) 75 *Clinical Endocrinology* 12-26.

⁴ C Sanders, B Carter & L Goodacre, 'Searching for harmony: Parents' narratives about their child's genital ambiguity and reconstructive genital surgeries in childhood' (2011) 67 (10) *Journal of Advanced Nursing* 2220-2230.

⁵ Sanders & others, above, n 4.

families concerned. In Karkazis' study of family's experiences⁶ there are multiple examples of the trauma suffered by parents when health care professionals found classification of their newborn child (as either male or female) difficult or impossible.⁷ Early problems in communication can create lasting negative memories for the families concerned.⁸ Also, post traumatic stress disorder is increasingly recognised in parents following a diagnosis of intersex in their child, though this is most marked when the child also has an associated problem such as salt-wasting.^{9,10} The problem is that although this is a time at which poor communication can worsen an already devastating situation, this is not the fault of those healthcare professionals at the delivery, who are not necessarily going to be experienced in the care of the intersex infant. Possibly the only way to counter this is to ensure that all (healthcare professionals *and* others) are educated in the fact that intersex exists and perhaps even have a protocol for how to handle the communication. There is no easy solution to this difficult problem.

The next stage: the diagnosis

A definitive genetic diagnosis is not attained for every child but it is likely that in the first few weeks of life the multidisciplinary team caring for the child will be able to place most intersex children into one of several broad

⁶ K Karkazis, *Fixing Sex: intersex, medical authority and lived experience* (Durham: Duke University Press, 2008).

⁷ Karkazis, above, n 6, 184-185.

⁸ Sanders & others, above, n 4.

⁹ Many intersex conditions are associated with abnormal steroid hormone synthesis; some of the hormones are present in excess compared to normal and others are deficient. In some conditions, the hormones that are deficient are those responsible for maintaining sodium and potassium levels in the body. In their absence, sodium can be lost – hence 'salt-wasting'.

¹⁰ V Pasterski, K Mastroiannopoulou, D Wright, KJ Zucker & IA Hughes, 'Predictors of posttraumatic stress in parents of children with a disorder of sex development' (2014) 43 *Archives of Sexual Behaviour* 369-375.

categories based on genotype, hormone levels and anatomy.¹¹ In order to illustrate some of the issues encountered in care of the young infant, I will assume that the child has a 46, XY karyotype, ambiguous genitalia (more female appearing than male), a small vagina, no uterus and internal gonads (probably testes). If gene testing shows a specific finding, for example a mutation in *HSD17β3*, then this will carry implications for the specific diagnosis, future progression and prognosis.¹² It enables prediction of the most probable gender in later life and also carries implications for possible medical complications such as future development of gonadal neoplasia. It is also of some significance for the child's parents and other family members, since the gene responsible for this condition is inherited in an autosomal recessive fashion.¹³ Though the need for multiple investigations involves casting the child in the role of a patient and the child's intersex state will be framed as a medical 'problem',¹⁴ it is also an essential part of the process, enabling parents to know as much as possible regarding their child's future.

Information sharing with families in the early stages

Discussion with parents cannot be avoided but at times in the past a matter that has affected practice in this area is how far comprehensive information has been and should be provided. John Money advocated

¹¹ The process of doing this is given in a number of papers such as Ahmed & others, above, n 3.

¹² Ahmed & others, above, n 3.

¹³ An *autosomal* condition is a state resulting from a mutation of a gene or genes on the first 22 non sex chromosomes. Genes come in pairs. One gene in each pair comes from the mother, and the other gene comes from the father. *Recessive* inheritance means both genes in a pair must be abnormal to cause disease. People with only one defective gene in the pair are called carriers and do not have the disease. However, they can pass the abnormal gene to their children. If a child is born to parents who both carry the same disease-causing autosomal recessive change (mutation), the child has a 1 in 4 chance of inheriting the abnormal gene from both parents and developing the disease. He or she has a 50% (1 in 2) chance of inheriting one abnormal gene, making that child a carrier.

¹⁴ I discuss the problems that arise from this approach in Chapter 4 and Chapter 6.

discussion between physicians and families regarding their child's intersex state.¹⁵ However, the information that he suggested giving them was, perhaps, not entirely full or accurate, as I will now explain. He indicated to families that the child had a 'true' sex and that the medical care was going to 'finish' what nature had failed to complete. In order to minimise ambiguity of social cues, the family were not necessarily fully informed or involved in the decision-making regarding what the 'true' sex was. They were not informed that these were decisions made by doctors and not biological necessities.¹⁶ In the present day, it is probable that in the first week or so of life the child with unusual genitalia will, at some point, be identified as intersex and will come into the care of experienced clinicians. At this point there will be opportunities for communication.

In the present era it is unlikely that the truth, as far as it is known by the team looking after the child, will be withheld from parents. Information sharing and psychological support is now an important part of early management.¹⁷ Full disclosure of information is ethically important in order that the family can make fully informed autonomous decisions regarding their child's future. If any intervention is planned then there is a legal requirement to disclose all information available, including possible complications arising from the intervention.¹⁸ It is possible, perhaps probable, that multiple medical investigations will be needed to provide as full a picture as possible and it is because of this that there may be a delay and a need for involvement of a clinical psychologist experienced in this very specialised area to help the family cope with the gradual acquisition of knowledge about their child.¹⁹

¹⁵ Karkazis, above, n 6, 59.

¹⁶ Karkazis, above, n 6, 59.

¹⁷ Ahmed & others, above, n 3.

¹⁸ See *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

¹⁹ Ahmed & others, above, n 3.

The gender assigned at birth for the purposes of upbringing

One of the first important decisions is to assign a gender to the child. This approach might be considered unethical as it is giving the child a future chosen by others, limiting options and depriving him or her of the right to make autonomous decisions about these matters. As I explain though, in Chapter 4, (when discussing scenarios 5 (page 112) and 6 (page 113)) this can be a great help to the child's parents. The gender to be assigned to the child will be dependent, according to the still current 2006 consensus statement on 'the diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, the potential for fertility'²⁰ and, perhaps more controversially, 'views of the family, and sometimes the circumstances relating to cultural practices.'²¹ This might suggest that the child's best interests are not always at the centre of the decision-making process. The current protocols therefore still seem to be based on the idea that the child is assigned a gender and might be moulded medically and surgically so that he or she possesses the anatomical characteristics appropriate to that gender. I discuss this further in the next section.

In the example that I have chosen prediction of gender is not straightforward. At birth the genitalia are not fully virilised and, in the past, children with *HSD17β3* were often brought up as females, perhaps with clitoral surgery. It is one of the situations in which the penis might have been deemed 'inadequate' for a male upbringing under the early protocols. However, these individuals become increasingly virilised at puberty²² and 60% of those assigned to the female gender at birth will

²⁰ IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

²¹ Hughes & others, above, n 20.

²² This phenomenon occurs in several intersex states. These conditions are more common in Papua New Guinea where they were studied extensively – For

eventually transition to live as males.²³ The problem is that making this diagnosis takes time. Obviously this is going to be a difficult and worrying time for the parents, and following the diagnosis they have to make major decisions that will impact on the life of their child. They need to adjust to the situation and consider what truly is in the best interests of their child. The demands of birth certification can limit the time available, as the birth must be registered in six weeks in England. By then, the decision must be made as to whether to register as a girl or a boy.

The birth of the baby – birth certification

The discussion above has shown that in many cases there are significant practical problems in assigning gender soon after birth. The binary model does not fit this child and placing into a gender category soon after birth may not be in his/her best interests. However, in many jurisdictions and in many aspects of law it is assumed that sex and gender are binary. This binary view of sex and gender is apparent from the first days of an infant's life. When a baby is born one of the first questions asked is whether the child is a boy or a girl. In addition to the needs of the parents and the child's wider family, legal requirements must be fulfilled. The child's birth must be registered²⁴ (under the Births and Deaths Registration Act 1953) during the first forty-two days of the child's life. The sex (and name) of the child must be entered on the birth certificate.

²⁵ The criteria for determining the sex of a child at birth are not defined in

example, J Imperato-McGinley, RE Peterson, T Gautier & E Sturia, 'Androgens and the evolution of male-gender identity among male pseudohermaphrodites with 5 alpha-reductase deficiency' (1979) 300 (22) *New England Journal of Medicine* 1233-1237.

²³ Hughes & others, above, n 20.

²⁴ See Gov.uk, 'Registering a birth' <https://www.gov.uk/register-birth/overview>

²⁵ *Sheffield and Horsham v United Kingdom* [1998] 3 FCR 141 concerns the difficulties encountered by two different transsexual women both of whom wished to amend the sex recorded on their birth certificates, prior to the Gender

the Act. This is generally held to be the biological criteria (chromosomal, gonadal and genital) as laid down by Ormrod J in *Corbett v Corbett* in 1970.²⁶ The 1953 Births and Deaths Registration Act provides for the correction by the Registrar of clerical errors or factual errors. The official position is that an amendment may only be made if the error occurred when the birth was registered or if the individual decides to follow the path available under the Gender Recognition Act 2004, discussed in Chapter 5. Only in cases where the apparent and genital sex of a child was wrongly identified can a change in the initial entry be made. It is necessary for that purpose to adduce medical evidence that the initial entry was incorrect. In England it is not possible to register a child as being other than male or female at the present time.

However, some jurisdictions do not impose a strict binary classification of sex at birth certification. Germany permitted the registration of babies as indeterminate sex from 2013.²⁷ The problem with the German system is that where sex is difficult to identify at birth following medical examination, the child must be registered as intersex; the system is obligatory and medically supervised.²⁸ In the Australian states of Victoria and New South Wales, birth certificates do not have to specify sex.²⁹ This is not a mandatory obligation. If the English system permitted birth registration as neither male nor female, it might help families during the difficult early stages of their intersex child's life. It would give them time to think about a strategy for the child's upbringing and it may make it easier to forego surgical intervention. Not having to register as male or female may also

Recognition Act 2004. The judgment involved a discussion of the criteria used for recording of the child's sex on the certificate at 148, para 28-30.

²⁶ *Corbett v Corbett* [1971] P 83

²⁷ S McBain, 'India's supreme court recognizes a third gender' (16/04/2014) *New Statesman* <http://www.newstatesman.com/world-affairs/2014/04/india-s-supreme-court-recognises-third-gender> Accessed 26/05/2016

²⁸ M Travis, 'Accommodating intersexuality in European Union Anti-Discrimination law' (March 2015) 21 (2) *European Law Journal* 180-199.

²⁹ Travis, above, n 28.

make it possible to try to delay making any major decisions and to see how the child develops in the first two years or so of life. However, reform of birth certification would only help the situation if a really sound and credible alternative to surgical intervention is on offer in the form of consistent psychosocial follow-up. Whilst this is stated to be mandatory in all the protocols, in practice the services that actually are available may not be optimal, a point made by Liao, Wood and Creighton in their recent editorial article in the *British Medical Journal*.³⁰

Infancy – the possibility of surgical intervention

The scenario that I discussed above was one where the medical team might advise, in view of the evidence, that the child is assigned a male gender. Surgical augmentation for an infant assigned to the male gender with an 'inadequate' penis is not yet a routine treatment option and therefore is unlikely to be offered; the techniques of phalloplasty (the surgical construction of a male phallus) are not sufficiently advanced.³¹ I will therefore consider an alternative scenario -:

³⁰ L-M Liao, D Wood & SM Creighton, 'Parental choice on normalizing cosmetic genital surgery' (2015) 351 *British Medical Journal* h5124.

³¹ PA Lee, AB Wisniewski, L Baskin, MG Vogiatzi, E Vilain, SM Rosenthal & C Houk (2014) 'Advances in diagnosis and care of persons with DSD over the last decade' *International Journal of Pediatric Endocrinology* <http://www.ijpeonline.com/content/2014/1/19> , 5. Accessed 26/05/2016.

Scenario 2:

This scenario also involves the birth of a baby. At the birth, the baby once again has 'ambiguous genitalia' and as in scenario 1 (page 61), it is difficult to identify sex at birth. However in this case, initial tests show a baby who has a deficiency of adrenal hormones. This can be replaced simply by taking a small daily dose of replacement therapy,¹ though this will be an essential lifelong treatment; life without adrenal cortical hormones is severely shortened. This is therefore a relatively non-controversial medical treatment. Once this aspect of the child's physiology is normalised, other investigations can be organized. The early tests may show that the child has a 46, XX karyotype, a uterus and ovaries. The baby most probably has a form of congenital adrenal hyperplasia (CAH). The most frequent gene anomaly associated with this involves a mutation in CYP21A2 which is inherited in an autosomal recessive pattern.

Ref: 1. Ahmed & others, above, n 3. This paper describes the effects of a mutation in CYP21A2.

Most children with the features described in scenario 2 are assigned to a female gender. They have the same potentiality for fertility as other females and in 90% of cases or so live as females throughout life.³²

Though the hormone deficiency is easily treated, it can be an additional source of trauma and anxiety for the parents to learn that their child does have a potentially serious 'medical' condition, in addition to the atypical genitalia.

As discussed throughout this thesis, this is one of the medical situations in which, in the past, the child was frequently subjected to genital surgery

³² Hughes & others, above, n 20. This means that 10% do NOT live as females throughout life.

if her genitalia resembled male genitalia and, though less frequent, this form of surgery may still take place today. Medical care is seen as enabling her to pass as a sexed individual of her gender with appropriate genital anatomy. I quote the following in my paper 'Intersex, medicine and pathologisation'³³ :

to remake the body in the social image of that gender. Such efforts at 'correction' not only violate the child but lend support to the idea that gender has to be borne out in singular and normative ways at the level of anatomy.³⁴

This can be applied to all forms of genital surgery/cutting/circumcision, whether for medical or non-medical reasons. All are ways in which the individual is re-made anatomically in line with a gender standard appropriate to the culture in which he or she exists. In the next section, I will consider why I believe that there are parallels between surgery for intersex and other forms of genital cutting. This is important because the different forms of genital cutting/surgery are characterized in a very different way in English law and the validity of the very different legal approaches should therefore be open to question.

Parallels with intersex surgery - Background to other forms of genital cutting.

Genital cutting involving both sexes is a practice that has taken place for many millennia in many societies and may involve both males and females. There are several theories why these procedures are so widespread. As Bettelheim pointed out (discussing the male child) 'circumcision [...] is one of the most widely distributed human customs',³⁵

³³ Newbould, M., 'Intersex, medicine and pathologisation', above, n 1. (In this thesis, see chapter 6, 174-5).

³⁴ J Butler, *Undoing gender* (New York: Routledge, 2004) 63.

³⁵ B Bettelheim, *Symbolic Wounds* (New York: Collier books, 1962) 15.

practised at puberty in some cultures and sometimes in infancy.³⁶ In the US, non-medical circumcision remains a common cultural practice.³⁷ Whilst it might seem that these practices are carried out for a number of purposes (for example many male circumcisions are carried out as part of religious observance), both male and female forms might be seen as confirming membership of some sort of gender group. Some initiation ceremonies for boys seem to emphasise masculinity with the implication that henceforth the boy must live as a true man.³⁸ Thomson (who considered the situation primarily in Anglo-American culture) noted that even in infant circumcision there is 'a move to look at circumcision as sexing the infant male body',³⁹ both because there is 'an understanding of the foreskin as feminised flesh'⁴⁰ and because of the way in which pain and risk have a 'role in defining the male body, masculinity and male privilege'.⁴¹ Similarly female genital mutilation is seen, in some cultures at least, as enhancing femininity and beauty by removing those tissues that have a more male appearance,⁴² a reason that is not dissimilar to the

³⁶ In 1999, for example, 85% of newborn males in the US were subjected to circumcision, though the rate has since fallen. Figures from the American Academy of Pediatrics Task Force, 'Circumcision, Circumcision Policy Statement' (1999) 103 *Pediatrics* 686, quoted in M Thomson, *Endowed. Regulating the male sexed body* (New York: Routledge, 2008) 19.

³⁷ JS Svoboda, 'Circumcision of male infants as a human rights violation' (2013) 39 (7) *Journal of Medical Ethics* 469-474.

³⁸ Though this is by no means universal and the situation is in reality very complex. Bettelheim quotes many examples of ceremonies that seem to be a means whereby the male makes himself more like a female. For example, there are extensive forms of circumcision called 'sub incision' in which the penile urethra is opened from the meatus back to the junction with the scrotum forming a vagina-like wound. See Bettelheim, above, n 35, 17 see Bettelheim, above, n 35, 106.

³⁹ Thomson, above, n 36, 18.

⁴⁰ Thomson, above, n 36, 18.

⁴¹ Thomson, above, n 36, 18-19.

⁴² For example, CJ Walley, 'Searching for 'Voices': feminism, anthropology, and the global debate over female genital operations' (1997) 12 (3) *Cultural Anthropology* 405-438.

rationale for performing clitoral surgery in girls with congenital adrenal hyperplasia. Therefore it might be argued that there is common ground between intersex surgery and other forms of infantile genital cutting. Though differing in detail and extent, all forms of infantile genital surgery involve the removal of 'healthy tissue from the body of a child who is unable to give consent'⁴³ and all forms are done because it is deemed necessary for the genital anatomy to conform to an externally determined norm, which is at least in part culturally determined and which confirms membership of a gender group.

Basic legal considerations

There is a very different approach in law to the three forms of genital surgery discussed here. The Female Genital Mutilation Act 2003 makes surgery carried out on the genitalia of a child or woman of any age unlawful even if the subject has freely given consent, unless carried out for by a doctor or midwife for *medical* reasons.⁴⁴ Oddly, 'medical' in this context includes *cosmetic* procedures; the Department of Health website used to have a section on labial and vaginal surgery for such reasons.⁴⁵ Circumcision for non-medical reasons on a male child is seen as lawful⁴⁶ providing both parents (if there are two and both hold parental responsibility) give consent. The child may give consent himself if he is competent to do so. I will discuss some of the legal arguments used

⁴³ M Fox & M Thomson 'Cutting it: surgical interventions and the sexing of children' (2005) 12 (8) *Cardozo Journal of Law and Gender* 81-97.

⁴⁴ Female Genital Mutilation Act 2003 s1 (2), (3).

⁴⁵ Department of Health website - <http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/CosmeticSurgery>, accessed 24/10/2010 . This link no longer works, perhaps not surprisingly.

⁴⁶ Lord Templeman in *R v Brown* [1993] 2 All ER 75. Mentioned in passing only. He does not seem to say that the circumcision involves males only.

further in Chapter 5 and Chapter 7.⁴⁷ As discussed earlier in this chapter, surgery carried out on the intersex child (which may, sometimes, be more extensive and have greater implications for future sexual and reproductive functioning than either of the above) continues to be considered as legitimate medical treatment carried out on someone who is ill.⁴⁸ I discuss this further in my paper 'When Parents choose gender',⁴⁹ (Chapter 7) and in Chapter 5

The different approach taken by the law here seems strange because procedures that do show analogies (explored further in Chapter 5), whether regarded as surgery or genital cutting, are associated with very different ethical and legal considerations. These seem to relate to context or motivation, rather than the procedures themselves.

Problems with the different approach to different forms of genital cutting

Whilst at first sight it might seem a reasonable state of affairs that Female Genital Mutilation is unlawful, but other forms of genital surgery/circumcision are lawful, there are problems. It might be argued that it is inappropriate to ever perform appearance-altering surgery on those who cannot consent to it so that it is unacceptable to ever carry out male circumcision (or genital surgery for intersex). All individuals should be permitted to make their own autonomous decisions about such matters. Therefore it might be suggested that such procedures (intersex surgery and male circumcision) might be deferred until the person concerned is able to give consent. This is not yet the situation in law and

⁴⁷ Chapter 5, 143. Also see Newbould MJ, 'When parents choose gender: intersex, children and the law' Accepted for publication in *Medical Law Review* (2016). (In this thesis see chapter 7, 215, 219).

⁴⁸ See for example Liao & others, above, n 30.

⁴⁹ MJ Newbould, 'When parents choose gender: intersex, children and the law', above, n 47. (In this thesis, see chapter 7, 191 onwards).

the different forms of genital surgery/cutting are construed very differently.

One problem is that all types of male circumcision are considered together and seen as uniform and all forms of female genital cutting are similarly considered together and seen as uniform,⁵⁰ but each category includes different types of procedure and there is overlap. As pointed out by Michael Thomson:⁵¹

while female genital cutting is referred to as mutilation and is constructed as morally and legally unacceptable within a civilized society, male circumcision is characterised as a standard and benign medical practice.⁵²

Female genital mutilation is widely regarded as ‘barbaric and crippling’⁵³ as indeed it is. Infibulation, the most severe form, consists of narrowing of the vaginal orifice by cutting the labia minora and/or the labia majora with or without excision of the clitoris.⁵⁴ This results in a tiny opening for the passage of menstrual blood and urine; the wound is reopened when the girl is married, but is sometimes closed again following the birth of each child.⁵⁵ It is, presumably, a way of trying to ensure that offspring will be those of the legitimate husband. However, procedures included differ

⁵⁰ Fox, & Thomson, above, n 43.

⁵¹ Thomson, above, n 36, 18.

⁵² Thomson, above, n 36, 18.

⁵³ BD Earp, ‘Female genital mutilation (FGM) and male circumcision: Should there be a separate ethical discourse?’ *Practical Ethics*. University of Oxford. Available at: https://www.academia.edu/8817976/Female_genital_mutilation_FGM_and_male_circumcision_Should_there_be_a_separate_ethical_discourse. DOI: 10.13140/2.1.3530.4967. Also found at http://oppenheimer.mcgill.ca/IMG/pdf/Female_genital_mutilation_separate_discourse_.pdf Accessed 26/05/2016.

⁵⁴ Earp, above, n 53.

⁵⁵ B Shell-Duncan, ‘The medicalisation of female ‘circumcision’: harm reduction or promotion of a dangerous practice?’ (2001) 52 *Social Science & Medicine* 1013-1028.

considerably in extent and some are less extensive than the clitoroplasty for intersex infants. In Indonesia and Malaysia there is a form of female genital cutting in which the clitoris is subjected to a small cut that causes minor bleeding, but no permanent alteration in anatomy.⁵⁶ In some cultures the common procedure is removal of the prepuce of the clitoris only.⁵⁷ Elsewhere in the world female genital cutting may involve removal of the clitoris and the labia minora.⁵⁸ It is not merely the extent of a procedure that determines the harms that result from it; the conditions under which it is performed are also of importance. In many cases, FGM will be carried out by a traditional practitioner outside of a clinical setting, in contrast to the situation for the intersex child.

Male circumcision also frequently takes place outside of the clinical setting. There are multiple forms of male circumcision differing in extent and potentiality for serious harm. The original ancient Jewish form was relatively minor, involving removal of the over-hanging tip of the foreskin only.⁵⁹ The common modern procedure is much more extensive, involving removal of one third to one half of the highly sensitive foreskin.⁶⁰ There are more extensive forms. For example, the subincision procedure of Australia involves opening the urethra from the glans to the scrotum, causing potential problems with urination.⁶¹ It is true that adverse medical consequences occur relatively rarely following standard male circumcision but, as in the case of all surgical procedures (whether carried out by a surgeon or a 'traditional practitioner'), death is an

⁵⁶ Shell-Duncan, above, n 55.

⁵⁷ Though there is some doubt as to whether this procedure does in fact exist, see Shell-Duncan, above, n 55.

⁵⁸ R Cerny Smith, 'Female Circumcision : bringing women's perspectives into the international debate' (1992) 65 *Southern California Law Review* 2449-2504.

⁵⁹ Earp, above, n 53.

⁶⁰ Earp, above, n 53.

⁶¹ Earp, above, n 53.

occasional consequence.^{62, 63, 64} Some circumcised men feel that they have been harmed and there is a support group for them, NORM UK (now operating as 15square).⁶⁵ It is frequently stated that male circumcision is not associated with any loss of sexual function,⁶⁶ but this may be erroneous, since removal of the foreskin has been associated with a loss of penile sensory function in some studies.⁶⁷ Some traditional initiation ceremonies involving male circumcision are associated with a relatively high mortality and morbidity.⁶⁸ It is therefore not the benign procedure that many believe it to be. Though the comparison of intersex surgery and female genital mutilation is made fairly frequently, Fox and Thomson point out that there is some

⁶² Thomson cites the case of a child who died with disseminated *Herpes simplex*, thought to have been contracted from the practitioner. Thomson, above, n 36, 25.

⁶³ Circumcision Information and Resource pages, <http://www.cirp.org/library/death/> contains information on deaths relating to circumcision. Accessed 28/05/2016.

⁶⁴ See also the case of Goodluck Caubergs, discussed further in Chapter 5, A Fogg, 'Male Circumcision: let there be no more tragedies like baby Goodluck' <http://www.guardian.co.uk/commentisfree/2012/dec/17/male-circumcision-baby-goodluck> Accessed 28/05/2016.

⁶⁵ NORM UK (currently operating as 15Square) <http://www.15square.org.uk> Accessed 28/05/2016.

⁶⁶ That was the view taken by the Law Commission, for example - Law commission Consultation Paper No. 139, *Criminal Law, Consent in the Criminal Law* (1995) Can be found at -: https://sexualitymatters.files.wordpress.com/2013/01/cp139_pt09.pdf Accessed 30/05/2016) para 9.2.

⁶⁷ For example, Memorandum submitted by Norm UK to Human Rights joint Committee of UK Parliament – www.publications.parliament.uk/pa/jt200809/jtselect/jtrights/157/157we37.htm accessed on 14/11/2010 - no longer available 28/05/2016 Here the medical evidence for the adverse effects of male circumcision – these include reduced penile sensation, and a risk of premature ejaculation and erectile difficulties.

⁶⁸ For example see AD Smith, 'Thousands face agony or death after Zulu king's circumcision decree' (17/01/10) *The Observer* <https://www.theguardian.com/world/2010/jan/17/circumcision-zulu-south-africa-hiv> Accessed 29/05/2016.

justification for considering male circumcision in the same context.⁶⁹ All of these genital procedures on minors do have common features, but the approach taken by the law in England is very different.

The family of a child with atypical genitalia will be faced with the decision as to whether to consent to surgery to refashion her genitalia. Before making their choice they have to consider whether the procedure would be in her best interests or not. I present evidence in this thesis (for example, the small outcome studies relating to genital surgery discussed in chapter 2) to suggest that genital surgery is not necessarily in the child's best interests, raising the possibility that surgery might be unethical and, it could be argued, unlawful. In any case, it is obligatory to discuss the findings of the outcome studies, possible complications and likely need for multiple further surgeries with families before any decisions are made in accordance with the Supreme Court decision in *Montgomery v Lanarkshire Health Board*.⁷⁰ However, in practice the decision is not likely to be a simple one and I will now discuss some of the difficult issues the family will have to consider.

Best Interests?

The *UN Convention on the Rights of the Child* holds that:

[p]arents or [...] legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.⁷¹

This basic principle is much harder to apply in practice. Trying to decide how to act in the child's best interests is one of the most complex and

⁶⁹ Fox & Thomson, above, n 43.

⁷⁰ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

⁷¹ UN Convention on the Rights of the child, Article 18, <http://www.unicef.org.uk/UNICEFs-Work/UN-Convention> Accessed 28/05/2016.

difficult issues in medical care for the intersex child. Parental concern is likely to be focused on how best to make that child's future life easier.

The question facing those with parental responsibility is:

to leave the child alone, and let her be potentially subjected to teasing, ridicule, and inconvenience because of the difference? Or is it to allow surgery to normalize the difference and alter forever the body and, thus, in significant ways, the identity the child was born with.⁷²

A problem with much of the writing (particularly where clitoroplasty is concerned) is that it is polarised into either emphasising the clinical need for (and good results of) surgery or else it emphasises the ethical problems associated with parental consent to this surgery, suggesting that it is inappropriate ever to operate on those too young to give their consent. However, as pointed out by Murray,⁷³ genitalia that have *not* undergone surgery are never just neutral and natural, but always carry cultural values and beliefs. She points out that there is a dearth of scholarship dealing with parental experience, but what there is at times describes parents failing to live up to what they consider themselves to be the 'ideal' and detailing their awareness of their own limitations to deal with the situation.⁷⁴ In one sense Money's protocol and, to some extent, the consensus statement are treating 'parental and social anxiety about gender ambiguity'.⁷⁵ Indeed it is extremely difficult to separate the parental feelings about their own existence in a world, where gender is

⁷² PS Miller, 'Toward truly informed decisions about appearance-normalizing surgeries' in E Parens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (Baltimore: Johns Hopkins University Press, 2006) 211-266, 217.

⁷³ S Murray, 'Within or beyond the binary/boundary' (2009) 24 (60) *Australian Feminist Studies* 265-274.

⁷⁴ E Feder, ' "In their best interests": Parents' experience of atypical genitalia' in E Parens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (Baltimore: Johns Hopkins University Press, 2006)189-210, 190, 204-206.

⁷⁵ Murray, above, n 73, 267.

narrow and binary, from their concern for their child. There is thus always a tension in the parental decision making process. The physicians and surgeons caring for the child also carry their ideas regarding sex and gender with them. Surgeons may firmly believe that the child will be traumatised by life if permitted to live with what is perceived as '*abnormal genitalia*'.

The reasons usually given for choosing the surgical option is that it is considered by parents and by the medical team to be in the *child's* best interests.⁷⁶ Though it is extremely difficult to separate the best interests of the child from those of the parent; certainly for the next fifteen years or so, it is likely they will be living in the same environment and circumstances. In most circumstances there is no one who is better placed to decide for their child. Therefore the parents are forced to choose what they feel is best for the child, but this depends a great deal on their experience and understanding of the society in which they live.

One argument often used by parents in this situation is that surgery may free their offspring from the difficulty of having to deal with other people's possible future reactions to the child's perceived abnormality.⁷⁷ In Katrina Karkazis' view this is essentially surgery performed on an infant because it is believed that *future onlookers* may experience discomfort,⁷⁸ though the reasons usually given for the surgery are that it protects *the child* from the embarrassment of being the object of the gaze of those onlookers. Some parents feel that if they make the decision for surgery on their intersex child, it then means that the child does not have to make this decision when an adolescent,⁷⁹ something that is perceived as a potential burden. In some cases they felt that it would help the child

⁷⁶ Karkazis, above, n 6, 201.

⁷⁷ Karkazis, above, n 6, 202.

⁷⁸ Karkazis, above, n 6, 202.

⁷⁹ Karkazis, above, n 6, 202-203.

develop a gender identity appropriate to other biomedical characteristics present:

we chose surgery [...] because we did not want her to grow up questioning her sexual identity. We felt that she should look like a female, so we chose the clitoroplasty and the vaginoplasty.⁸⁰

There is evidence from the accounts given by parents who were against early surgery that the problems resulting from the reactions of peers are exaggerated.⁸¹ However, for whatever rationale, genital surgery continues to be carried out. A parent may ask:

[w]hat sort of parents would subject their child to life as a hermaphrodite?⁸²

One of the jobs that a parent must fulfil is to accommodate the child to the world as it is. Genital surgery may be presented to those with parental responsibility as a means to achieve this end.⁸³

Perhaps one way forward is to encourage parents to try to identify more fully with their child and try to imagine what they might feel in years to come; this is extremely difficult. Suzanne Kessler asked a group of college students to imagine that they were the parents of a child with unusual genital anatomy.⁸⁴ Almost all of them told her that they would request early normalising genital surgery for their child. When she asked them if they themselves had the atypical genital anatomy, they took a different view and a majority stated that, unless it were painful or life threatening, they would not personally have wanted their parents to

⁸⁰ Karkazis, above, n 6, 203, who took her information from an internet forum for parents of children with congenital adrenal hyperplasia.

⁸¹ Karkazis, above, n 6, 202.

⁸² Feder, above, n 74, 205.

⁸³ Feder, above, n 74, 205.

⁸⁴ S Kessler, *Lessons from the Intersexed* (New Brunswick, Rutgers University Press: 1998) loc 1327.

consent to surgery to 'correct' the appearance.⁸⁵ Though we have already discussed the fact that many women will eventually consent to 'normalising' surgery⁸⁶ (discussed in Chapter 2), the difference is that this is a part of their *self*-determination. Kessler's work is open to criticism, since it deals with hypothetical situations that may not translate fully to real life circumstances, but it is interesting that students in this artificial situation did view matters differently whether they were imagining themselves a parent or a child. Perhaps discussions exploring this aspect would help all parents finding themselves in this situation. Perhaps a greater period of time to get to know their child and to think about the future might help. As mentioned previously, this is where changes in birth certification could prove helpful, providing the appropriate psychological support is available.

Whether the child received surgical or medical intervention, the child will grow, with his or her family and become more aware of his or her position in the circumstances in which he or she lives. This raises the problem of how families start to involve children in discussion.

Disclosure and withholding of information within families

As I discuss below, there is evidence that the secrecy and lack of information whilst growing up has added to the trauma experienced by many intersex individuals. In John Money's era, the fact that families were not given full information about their child as it became available meant that the child could not be informed at an appropriate stage. But even when parents were fully aware of the procedures undertaken on their child, communication was difficult. David Reimer, for example, was not told his history whilst living as a girl through his childhood, and only

⁸⁵ Kessler, above, n 84.

⁸⁶ SM Creighton, JA Greenberg, K Roen & DL Volcano, 'Intersex practice, theory and activism' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 249-260.

learned the truth in his teens.⁸⁷ Families have frequently found discussion of intersex difficult and continue to do so. In one small study from Hamburg the median age at which the 44 adults in the study were informed of their diagnosis was 15 years of age. Whilst there were some examples of children receiving age appropriate information from their earliest years, in some cases it was only as adults that they found out anything about their intersex state.⁸⁸ Other studies have shown similar findings.⁸⁹ One study from a tertiary referral centre in London carried out in 2010 revealed that even amongst those diagnosed within the last 30 years only half of families had discussed diagnosis with their intersex child by 15 years of age. This study looked at individuals aged between 16 years and 62 years, so it is possible that the intersex diagnosis could have been made as early as 1948 for a few of the older participants, but those diagnosed in the late 1990s were also included. It remains to be seen if families subjected to the 2006 protocol will find discussion easier. Whilst there are ethical issues around the child's right to know about their medical state, particularly if, say, there is a parental desire for the child not be informed,⁹⁰ the next paragraph illustrates some of the consequences of non-disclosure.

The absence of knowledge regarding their intersex state may prove harmful for at least some children. There are accounts in the literature of the suffering caused to children when family discussion about an intersex

⁸⁷ A Davidian, 'Beyond the Locker room: changing narratives on early surgery for intersex children' (2011) 26 *Wisconsin Journal of Law, Gender and Society* 1-22

⁸⁸ L Brinkmann, K Schuetzmann & H Richter-Appelt, 'Gender assignment and medical history of individuals with different forms of intersexuality: evaluation of medical records and the patient's perspective' (2007) 4 *The Journal of Sexual Medicine* 964–980.

⁸⁹ L-M Liao, H Green, SM Creighton, NS Crouch & GS Conway, 'Service users' experiences of obtaining and giving information about disorder of sex development' (2010) 117 (2) *British Journal of Obstetrics and Gynaecology* 192-199.

⁹⁰ CM Cole & E Kodish, 'Minors' right to know and therapeutic privilege' (2013) 15 (8) *American Medical Association Journal of Ethics* 638-644. To consider this issue further is outside the scope of this thesis.

diagnosis seemed to be off limits, perhaps because parents feared that the information itself was too disturbing.⁹¹ Some children were told nothing of the surgery that they were to undergo, even if they were in the early teenage years at the time.⁹² Some describe the horror of having to undergo multiple medical examinations, sometimes with an audience of medical students and trainee doctors, which was a major source of pathologisation of the experience of being intersex.⁹³ I discuss this further in Chapter 6, (my paper ‘Intersex, medicine and pathologisation’.⁹⁴) Modern protocols suggest that, ideally, experienced psychologists should continue to work with the family, facilitating family relationships and helping information sharing between parents and children.⁹⁵ As I mentioned above this important aspect of medical care is not always freely available.⁹⁶ The child and the family need to be viewed as individuals who have different requirements. There is also a major role for local support groups who can help both the intersex child and the family, giving information and peer support.⁹⁷ Such groups now also provide important feedback for the clinical team, helping to shape future policy.⁹⁸

Information sharing in the wider family members and social circle is a further matter requiring thought. In the early days of John Money’s protocol, it was considered important that those in the child’s social environment were unaware of his or her intersex state, in order to

⁹¹ Karkazis, above, n 6, 219-220.

⁹² Karkazis, above, n 6, 221.

⁹³ Karkazis, above, n 6, 223.

⁹⁴ Newbould, ‘Intersex, medicine and pathologisation’, above, n 1.

⁹⁵ Ahmed & others, above, n 3.

⁹⁶ Liao & others, ‘Parental choice on normalizing cosmetic genital surgery’, above, n 30.

⁹⁷ Ahmed & others, above, n 3.

⁹⁸ Ahmed & others, above, n 3.

facilitate social learning and appropriate gender acquisition by the elimination of ambiguous social interactions.⁹⁹ In current management protocols, it is not considered mandatory to give those apart from the immediate family detailed information. The 2006 Consensus states:

the healthcare team should discuss with the parents what information to share in the early stages with family members and friends.¹⁰⁰

Parents might choose to reveal very little if they wished. This is, though, the same situation as pertains in any issue affecting any family member, whether it concerns healthcare or not.

It might be difficult to withhold information regarding the assigned gender to those in the child's social circle. In general, it is usual for parents to disclose the sex of a newborn infant to their wider family and to their community. This information is therefore almost always known to all of those who interact with him/her. Teachers, playmates and anyone else with whom the child interacts will usually be in possession of this information. Occasionally parents of a non-intersex child have chosen not to reveal his or her sex to peers and other family members in order to avoid societal pressures to conform to gender stereotypes.¹⁰¹ This may prove unsuccessful since it is extremely difficult, if not impossible, to stop young children from demonstrating the gendered behaviour (that some might consider stereotypical) and interactions with peers, making gender apparent from around 2 years of age.¹⁰² Therefore, though an admirable attempt at avoiding rigid gender stereotypes, this approach is

⁹⁹ Brinkmann & others, above, n 88.

¹⁰⁰ Hughes & others, above, n 20.

¹⁰¹ R Alleyn, 'Couple raise child as 'gender neutral' to avoid stereotyping' (20/01/2012) <http://www.telegraph.co.uk/news/9028479/Couple-raise-child-as-gender-neutral-to-avoid-stereotyping.html> Accessed 28/05/2016.

¹⁰² DE Cutas & S Giordano, 'Is it a boy or a girl? Who should (not) know children's sex and why?' (11/12/2012) *Journal of Medical Ethics* Online First: 11 December 2012 doi:10.1136/medethics-2011-100415 Accessed 28/05/2016.

probably doomed to failure. Cutas and Giordano suggest that a more fruitful way to promote gender tolerance in children may be to promote parental education for all. This might equip families to provide a social environment for their child in which gender differences are promoted and championed.¹⁰³ In almost all cases, the child's sex of upbringing will be an important factor in his or her existence in the social world from the very earliest time and it is difficult to conceal. This applies to intersex children, just as it does to others.

As the intersex individual grows, there is also the question of how much information they themselves choose or feel they are able to share with others. In the study by Liao et al referred to above¹⁰⁴ it was notable that many of the intersex participants themselves found sharing information with others difficult, even those with whom they were intimately connected. For example, 16% of adults had shared no information regarding their intersex state with a partner and 37% had not discussed it with a sibling who also had the same intersex condition.¹⁰⁵ All this seems to suggest that there is some way to go before intersex can be discussed openly. Of course the decision to tell those around them is entirely the decision of the intersex individual, unless it is likely that others are affected. The next section concerns a circumstance in which the child's condition does potentially affect others in the family.

Some intersex states are genetically determined

The two case scenarios referred to so far in this chapter both concerned children with intersex states associated with genetic mutations. Both of the conditions described involve conditions associated with autosomal recessive inheritance. Therefore, this is significant also for other family members who might also carry the gene mutation. This information

¹⁰³ Cutas & Giordano, above, n 102.

¹⁰⁴ Liao & others, 'Service users' experiences of obtaining and giving information about disorders of sex development', above, n 89.

¹⁰⁵ Liao & others, 'Service users' experiences of obtaining and giving information about disorders of sex development', above, n 89.

carries important implications and it might be argued that all those in the wider family who might benefit from the knowledge of the genetic mutation have a right to know. Many ethical issues arise and only a very succinct and selective discussion is possible here. It is important that the implications of disseminating the knowledge through the family are explored, before the information is actually shared. The issues to be balanced are the parents' and child's right not to have their genetic information disseminated against the relative's right to know – or perhaps their right not to be told, if this is what they wish.¹⁰⁶ It is possible to share information with others who may benefit from knowing it even in the absence of consent if doing so may avoid serious harm. Advice from the GMC¹⁰⁷ and Royal Colleges indicates that it can be justifiable to share genetic information with other family members in this situation,¹⁰⁸ though it is probably rare¹⁰⁹ for people to fail to agree to share genetic information. Such discussion would require input and facilitation from those skilled in genetic counselling.

Knowledge of one's genetic status may enhance people's control over what kind of children they will have. Detailed discussion regarding this is outside the scope of this thesis but, in brief, there are ethical issues regarding the decision not to have intersex children. If, as I will argue further in chapter 4, there are no sound epistemological reasons to

¹⁰⁶ This is a large and complex topic. Detailed discussion is outside the scope of this current thesis – see for example M Parker & A Lucassen, 'Concern for families and individuals in clinical genetics' (2003) 29 *Journal of Medical ethics* 70-73.

¹⁰⁷ General Medical Council *Confidentiality* (2009) http://www.gmc-uk.org/Confidentiality_English_1015.pdf 48902982.pdf, paragraphs 36-37.

¹⁰⁸ The Royal College of Pathologists, The Royal College of Physicians, *Consent and confidentiality in clinical genetic practice: Guidance on genetic testing and sharing genetic information* (2011) http://www.bsgm.org.uk/media/678746/consent_and_confidentiality_2011.pdf, 20-21.

¹⁰⁹ The incidence of those not wishing to share genetic information with other family members is unknown. See The Royal College of Pathologists, The Royal College of Physicians, above, n 108.

consider at least some aspects of intersex as illness, then it may follow that selecting children on the basis that they do not carry the relevant intersex gene, may be regarded not as a selection in favour of 'healthy' children, but, rather, selection of the children that the parents prefer to have. Selection of non-intersex children might be seen as similar to sex selection for non-medical reasons.

For couples that carry one copy of the abnormal recessive gene each, prenatal diagnosis¹¹⁰ might be feasible. This leads to the possibilities including termination of pregnancy, of prenatal treatment and of pre-implantation diagnosis of embryos. I cannot discuss termination of pregnancy further here, since this is a highly complex topic that needs detailed consideration that is outside the scope of this work. Pre-implantation genetic diagnosis is also an enormous and complex subject raising many legal and ethical matters that lie outside the scope of this thesis.¹¹¹ Prenatal treatment also has been suggested, but again is too large a topic to be discussed fully in this thesis.¹¹²

Even if those in the family of a child with a mutation associated with intersex have no plans to use the information for any of the techniques mentioned above, it remains useful information. Prenatal diagnosis can

¹¹⁰ This would be carried out by gene testing following chorionic villous sampling.

¹¹¹ There is some discussion on its potential use in intersex. For example R Sparrow, 'Gender eugenics? The ethics of PGD for intersex conditions' (2013) 13 (10) *American Journal of Bioethics* 29-38.

¹¹² See LB McCullough, FA Chervenak, RL Brent & B Hippen, ' "Transgressive bioethics": letter of concern from bioethicists about the prenatal administration of dexamethasone' (2010) 10 (9) *American Journal of Bioethics* 35-45. The discussion concerns giving potentially toxic dexamethasone to pregnant women who are at risk of having a child with congenital adrenal hyperplasia. All pregnant women who have had a previous child with CAH would receive dexamethasone and only 1 in 8 of the pregnancies would be expected to involve a female fetus affected with CAH. Because of the low proportion of those who might 'benefit' and because the perceived 'benefits' are more normal genitalia, less masculine behaviour and less homosexuality in those who do 'benefit', ethical concerns have been raised. See A Dreger, EK Feder & H Lindemann, 'Still Concerned' (2010) 10 (9) *American Journal of Bioethics* 46-48.

give families time to prepare and to think about how they plan to bring up their child.

Surgery in the intersex individual past infancy: ethical and legal issues.

I will now consider a further brief clinical scenario. This involves the child described in scenario 2 (page 70) during the teenage years (possibly aged fifteen or so). This child is now likely to be competent to consent to surgery in accordance with *Gillick v West Norfolk and Wisbech Area Health Authority*.¹¹³ The judgment in *Gillick* held:

That the parental right to control a minor child deriving from parental duty was a dwindling right which existed only in so far as it was required for the child's benefit and protection; that the extent and duration of that right could not be ascertained by reference to a fixed age, but depended on the degree of intelligence and understanding of that particular child and a judgment of what was best for the welfare of the child; the parents' right to determine whether a child under 16 should have medical treatment terminated when the child achieved sufficient intelligence and understanding to make that decision itself.¹¹⁴

¹¹³ *Gillick Respondent v West Norfolk and Wisbech Area Health Authority First Appellants and Department of Health and Social Security Second Appellants* [1986] AC 112.

¹¹⁴ *Gillick Respondent v West Norfolk and Wisbech Area Health Authority First Appellants and Department of Health and Social Security Second Appellants* [1986] AC at 113-114.

Scenario 3 –:

The family of the child with CAH described in Scenario 2 (page 70) decided that they did not wish the child to undergo genital surgery. They decided that, though initially assigned to the female gender (on the advice of medical staff and following much thought and discussion by the family) and registered as female at the time of birth certification, they would be prepared for the child to wish to change and live as a male during the teenage years if that seemed to be appropriate. Having read about CAH, they were aware that this sometimes happens. They were also aware that it is difficult to predict from the results of physiological testing which individuals will eventually wish to transition. ¹ The whole family worked with a clinical psychologist from the birth onwards and the child, aged 15 years, is now sure that he wishes to spend his life as a male.

*Ref:1. AB Dessens, FME Slijper & SLS Drop, 'Gender dysphoria and gender change in chromosomal females with congenital adrenal hyperplasia' (2005) 34 (4) *Archives of Sexual Behaviour* 389-397.*

Gillick therefore implies that even when aged under 16 years, the child may have sufficient understanding of his or her condition and any surgical procedures or medical treatment required to be able to give his or her own consent. Involvement of clinicians skilled in assessment of gender dysphoria are essential in this situation and detailed assessment over time is needed before any plans are made to change an individual's birth assigned gender.^{115, 116} However, the criteria for gender reassignment

¹¹⁵ The World Professional Association for Transgender Health (WPATH), 'Standards of Care for the Health of Transsexual, Transgender and Gender Nonconforming People' (2012)

differ for those with intersex states in comparison with those who have gender dysphoria but are not intersex.¹¹⁷ In intersex, transition from the gender assigned at birth may take place over wide age range, from soon after starting school to middle adulthood.¹¹⁸ Therefore teams of health care professionals looking after intersex individuals need to be very flexible in their approach and not apply very rigid criteria. Early transition (even prior to puberty) may be the best option for those with severe gender dysphoria. Hormonal and, perhaps, surgical, treatment may sometimes be needed in intersex states to maintain life in birth assigned gender and therefore transition can be easier to effect before these have been necessary.¹¹⁹ For example, during the teenage years, vaginoplasty may be required in a girl with very virilised genitalia and an absent or very short vagina; this type of surgery is complex and carries risks (including the development of neoplasia in the newly formed structure) so that it is performed when the girl is able to participate in the decision making process, rather than in infancy.¹²⁰ If transition to male is contemplated that it would be best to avoid any complex feminising surgery such as vaginoplasty.

Legal and ethical issues may arise because the individual in this scenario has a uterus and ovaries and is likely to be fertile as a female but he could not be fertile as a male (with currently available reproductive

http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926 68-71. Accessed 28/05/2016.

¹¹⁶ HFL Meyer-Bahlburg, 'Gender monitoring and gender reassignment of children and adolescents with a somatic disorder of sex development' (2011) 20 *Child & Adolescent. Psychiatric Clinics of North America* 639-649.

¹¹⁷ The World Professional Association for Transgender Health, above, n 115, 71.

¹¹⁸ Meyer-Bahlburg, above, n 116.

¹¹⁹ Meyer-Bahlburg, above, n 116.

¹²⁰ Hughes & others, above, n 20.

technologies ¹²¹). If the individual was adamant that he wanted to undergo hysterectomy (surgical removal of the uterus) and oophorectomy (surgical removal of the ovaries) before the age of 18 years, to prevent menstruation and the feminising effects of ovarian hormones, then the procedure might be considered to constitute sterilisation of a minor. As I discuss in Chapter 7, the law in England and Wales has stipulated that, following *Re B* ¹²² all cases involving sterilisation of a person under 18 years *for contraceptive purposes* must be considered by the courts prior to the procedure taking place. This is when the procedure is to be carried out primarily for sterilisation, rather than a ‘medical’ reason such as a tumour. The situation described here, gender dysphoria,¹²³ might be considered ‘medical’ and it is questionable as to whether it is mandatory for the medical team to approach the courts before undertaking hysterectomy. The medical team certainly could obtain court approval in order to dispel any doubts as to the lawfulness of the procedure. It would be absolutely mandatory to involve the individual, both with and without his family, in detailed discussions to ensure that he understands the implications of undergoing hysterectomy and oophorectomy and the resulting loss of fertility. Storing ovarian tissue may be an option or even storing oocytes for a post pubertal individual,¹²⁴ though both techniques are in the relatively early stages of

¹²¹ Though theoretically, it is possible to generate male or female cells from stem cells. See J Kehler, K Hübner, S Garrett & HR Schöler, ‘Generating oocytes and sperm from embryonic stem cells’ (2005) 23 (3) *Seminars in Reproductive Medicine* 222-233.

¹²² In *Re B (A Minor) (Wardship: Sterilisation)* [1988] AC199 at 202.

¹²³ In the WPATH, *Standards of Care*, above, n115. Section XV deals with Gender Dysphoria in people with disorders of sex development (intersex). Previously in WPATH standards, intersex was considered to be such a special case in terms of epidemiology, presentation and, possibly, aetiology that the term ‘Gender Identity Disorder – Not Otherwise Specified’ was used, rather than ‘Gender Dysphoria’, to describe those intersex individuals who felt distress because of a mismatch between their ‘inward gender’ and the gender of upbringing assigned to them. However it is now considered appropriate to use the term ‘Gender dysphoria with a disorder of sex development (DSD)’ to describe this condition.

¹²⁴ Meyer-Bahlburg, above, n 116.

development and there are only relatively small numbers of successful pregnancies achieved following freezing of either oocytes or ovarian tissue.¹²⁵ Following hysterectomy, ethical and legal issues might be raised by the techniques required for reproduction in the individual under discussion, but consideration of these is outside the scope of this thesis.

Legal gender transition would, in England and Wales, take place in accordance with the Gender Recognition Act, 2004 on attaining 18 years of age. Though the majority of intersex individuals wish to live as either male or female, there are a few people who wish to identify as intersex, such as Norrie, the person at the centre of the Australian case, *NSW Registrar of Births, Deaths and Marriages v Norrie* [2014].¹²⁶ In England and Wales, as the law stands, there is no possibility of legal recognition as neither male nor female, but this may be changing in the future following the House of Commons Women and Equalities Committee report on transgender equality.¹²⁷ Some jurisdictions do permit a third sex/gender option on legal documentation. Very recently, France has recognized a third sex category,¹²⁸ by allowing a 64 year old to use the term 'gender neutral' on official forms, though an appeal has been lodged by the Court on the grounds that this is not mentioned in the French Legal code.¹²⁹

¹²⁵ Human Fertilisation & Embryology Authority, 'Freezing and storing eggs' <http://www.hfea.gov.uk/46.html#8> Accessed 28/05/2016.

¹²⁶ *NSW Registrar of Births, Deaths and marriages v Norrie* [2014] HCA 11

¹²⁷ House of Commons Women and Equalities Committee, Transgender Equality, 14th Jan 2016 <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf> Accessed 28/05/2016.

¹²⁸ C Cauterucci, 'France now recognises a 'neutral gender' – but its just as narrow as the first two' (15/10/2015) *Outward* http://www.slate.com/blogs/outward/2015/10/15/france_s_new_third_gender_is_just_as_narrow_as_the_first_two.html Accessed 28/05/2016

¹²⁹ H Samuel, 'French court sets EU precedent by recognizing 'gender neutral' person' (14/10/2015) *Telegraph*

There are other jurisdictions that recognize a legal third gender outside Europe. In Australia, there has been considerable reform over the years. In 1979, the Family Court of Brisbane annulled a marriage on the basis that it was between a woman and an intersex man and considered him neither male nor female, and thus outside the category of persons able to marry legally, though with the added complication that his wife had not been aware of the husband's biology prior to the marriage.¹³⁰ Since that time, there has been progress in the recognition of sex and gender outside the binary categorization of male and female in several Australian courts. Australia first permitted intersex as a description of sex on passports in 2003.¹³¹ Anti-discrimination law was introduced in 2013 (the Sex Discrimination Amendment (Sexual Orientation, Gender identity and Intersex Status) Act. Since the decision in *NSW Registrar of Births, Deaths and Marriages v Norrie* [2014]¹³² the Registrar in that state has been permitted to record an individual's sex as 'non-specific'. In Canberra, Australia, (the ACT or Australian Capitol Territory) the law permits trans people to change the sex on their birth certificate, as in England, but there it is also possible to change the sex given to a third category, 'X', so that people are able to officially live as intersex or androgynous.¹³³ From 2014, India allowed registration as a third gender on official documents.¹³⁴ Other countries now offer passports with a third possible gender option, including New Zealand (from 2012), Nepal,

<http://www.telegraph.co.uk/news/worldnews/europe/france/11932162/French-court-sets-EU-precedent-by-recognising-gender-neutral-person.html> Accessed 28/05/2016

¹³⁰ *In the Marriage of C and D (falsely called C)* (1979) 28 ALR 524.

¹³¹ Travis, above, n 28.

¹³² *NSW Registrar of Births, Deaths and marriages v Norrie* [2014] HCA 11.

¹³³ K Lawson, 'Canberra's transgender and intersex community heartened by change to birth certificate laws' (20/03/2014) *The Canberra Times* <http://www.canberratimes.com.au/act-news/canberras-transgender-and-intersex-community-heartened-by-change-to-birth-certificate-laws-20140320-35420.html> accessed 28/05/2016.

¹³⁴ McBain, above, n 27.

Uruguay¹³⁵ and Bangladesh (from 2011).¹³⁶ Nepal permitted registration as a third gender on its census since 2007 and Pakistan allowed this on identity cards from 2011.¹³⁷ Recognition can be regarded as a first step towards equality or non-discrimination, though as discussed in Chapter 2, even in countries where a third gender is recognised this does not necessarily mean equal opportunities and treatment in practice.

Intersex adults

This work has focused mainly on the management of intersex in infants but intersex adults may also face multiple ethical issues and legal problems. However, I have to be selective and I am not going to discuss them further in this chapter. I discuss the issue of the need to conform to a notion of normality in Chapter 6 ('Intersex, medicine and pathologisation'¹³⁸), a matter that is very relevant to intersex adult women. Genital cosmetic surgery in order to appear normal is a frequent procedure in this group as discussed in Chapter 2.¹³⁹ The problem that intersex women with testes have until recently been required to undergo gonadectomy in order to compete as women in elite athletics is discussed in Chapter 8 ('What do we do about women athletes with testes'¹⁴⁰).

¹³⁵ R White, 'Preferred private parts: importing intersex autonomy for *MC v Aaronson*' (2013) 37 *Fordham International Law Journal* 777-821.

¹³⁶ McBain, above, n 27.

¹³⁷ McBain, above, n 27.

¹³⁸ Newbould, 'Intersex, medicine and pathologisation', above, n 1. (In this thesis, see chapter 6, 178).

¹³⁹ Creighton & others, above, n 86.

¹⁴⁰ Newbould, '*What do we do about women athletes with testes?*', above, n 2. (In this thesis, see chapter 8, 229 onwards).

I will now move to Chapter 4, where I discuss some philosophical theories of medicine, looking particularly at intersex from these different viewpoints.

CHAPTER 4:

PHILOSOPHICAL APPROACH

Notions of disease and illness are important when considering the ethics of any aspect of medical care. Intersex provides a useful illustration why this is so. If someone has an illness this legitimises clinical intervention in order to try to treat it. If intersex (or perhaps some aspect of it, such as the unusual genitalia) is not a disease, then it becomes more difficult to justify intervention, especially if it involves those who are unable to understand or agree to it. This has important ethical implications for clinical practice in intersex.

There are various theories concerning the philosophy of medicine and I will give a succinct account of only three of them here: biostatistical theory, a normativist approach and some aspects of phenomenological concepts, in order to try to evaluate if neonatal surgery for intersex is ethical. I discuss only the major points of each theory.

Health, disease and illness

There is a large literature on the meaning and correct use of the terms *disease*, *health* and *illness*. I will discuss them very briefly (when relevant) as I discuss the different philosophical approaches to medicine in this chapter.

The biostatistical approach

Perhaps the most obvious way to think about what might constitute a disease is the biostatistical (BST) approach.¹ The major proponent of this approach is Christopher Boorse. For Boorse, the goal of the BST is to analyse the distinction between the normal and the pathological, which he

¹ Sometimes called the naturalist approach because it describes illness in terms from the natural rather than the social world. See H Carel, *Illness* (Durham: Acumen, 2008) 11.

considers the ‘basic theoretical concept of Western medicine’.² He attempts to define health ‘solely in terms of empirical facts, without any sort of evaluative judgment’.³ This is how he defines disease:

A *disease* is a type of internal state which is either an impairment of normal functional ability, i. e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.⁴

In this approach, disease must be defined with reference to a class of subjects:

The *reference class* is a natural class of organisms of uniform functional design; specifically an age group of a sex of a species.⁵

It is also necessary to define what is meant by a normal function:

A *normal function* of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.⁶

The final part of Boorse’s formulation is the definition of health, which he simply defined in 1997 as ‘the absence of disease’.⁷ Following further refinements of his theory, by 2014, he stated:

Health in a member of the reference class is *normal functional ability*: the readiness of each internal part to perform all its normal functions on typical occasions with at least typical efficiency.⁸

² C Boorse, ‘A Rebuttal on Health’ in JM Humber & RF Almeder (eds), *What is Disease?* (Totowa, New Jersey: Humana press, 1997) 7.

³ E Kingma, ‘What is it to be healthy’ (April 2007) 67 *Analysis* 128-133, 128.

⁴ Boorse, above, n 2, 7.

⁵ Boorse, above, n 2, 7.

⁶ Boorse, above, n 2, 7.

⁷ Boorse, above, n 2, 8.

On the face of it, it might sound an easy task to identify disease using this definition and, in many cases, it is relatively simple. Consider again Scenario 2 (page 70) from the previous chapter, a baby with unusual genitalia and deficiencies of some adrenal hormones. In this case, the blood levels of adrenal hormones can be measured and considered statistically in relation to the levels of those in a population of female neonates. The low level of functional hormones in CAH may shorten life considerably if replacements are not administered. This is not normal functioning and is disease. This is non-controversial.

The difficulties arise when assessing the atypical genitalia. First, the unusual appearance does not imply a functional problem. The two matters are largely unrelated.⁹ So if functional deficit is a requirement, the atypical genitalia cannot be described as diseased by this definition. Secondly, even if a variation in appearance is accepted as sufficient to constitute disease in the absence of a functional deficit, problems remain. There has been comparatively little work on the normal anatomy of the infant clitoris and the first such study was published in the 1980s,^{10, 11} some 30 years after the introduction of clitoral surgery for intersex infants. The studies that exist demonstrate a wide range of clitoral (and penile) size in the neonatal population. Unlike the situation for adrenal hormones, there is no objective distinction between normal and abnormal.

⁸ C Boorse, 'A second rebuttal on health' (2014) 39 *Journal of Medicine and philosophy* 683-724, 684.

⁹ it is possible that there are functional problems with genitalia in intersex individuals, just as it is possible that genitalia of normal appearance may have functional problems.

¹⁰ W Riley & A Rosenbloom, 'Clitoral size in infancy' (1980) 96 (5) *Journal of Pediatrics* 918-919.

¹¹ K Karkazis, *Fixing Sex: intersex, medical authority and lived experience* (Durham: Duke University Press, 2008) 151.

At least some of the physicians and surgeons who assessed the genital anatomy of the children concerned did this simply by sight.¹² No measurements were involved. The standard that they used was not an objective scientific one, but an aesthetic one, which was strongly influenced by cultural notions regarding what is normal or abnormal.¹³ The need for surgery was based on this aesthetic standard but seems to have been regarded as if it were based on a scientifically determined criterion and this presumably continues to be so, given that surgery is still regarded as a valid therapeutic option. Therefore, using the biostatistical definition of disease, the atypical genitalia *do not* fall into the 'disease' category but were and are treated as if they did. Variation is not a disease, but in the case of intersex it was, and is, regarded as such.

However, it is also necessary to consider whether or not Boorse's biostatistical theory is an appropriate tool for this assessment. Theories of health have limits and there have been criticisms. The problem of common disease is one of these. Swartz, for example, points out that human aging carries with it many conditions that are very prevalent in the population, such as benign prostatic hypertrophy in men. Because this definition of disease relies on statistical assessment, a physiological or anatomical state that is very common in a reference class may be 'normal' for that class, but may still carry adverse consequences.¹⁴ Another difficulty for the BST is how to choose the reference class.¹⁵ Kingma points out that it is quite possible to manipulate what counts as normal functioning by changing the reference class; for example, it would be possible to devise one composed entirely of those with Down

¹² Karkazis, above, n 11, 151.

¹³ Karkazis, above, n 11, 151.

¹⁴ PH Swartz, 'Defining dysfunction: natural selection, design and drawing a line', (2007) 74 (3) *Philosophy of Science* 364-385, 375.

¹⁵ Kingma, above, n 3.

syndrome,¹⁶ where the associated problems, such as congenital heart disease would be so frequent as to be normal.

To try to circumvent these difficulties, some theorists postulate that health and disease cannot be defined by the biological facts alone but must be seen in the context of the social environment and the harm experienced by those with the condition. These accounts are therefore *social models of disease and health* rather than descriptions of the physiological and anatomical facts. I will now consider briefly one of the accounts that take this approach. I will also examine what this implies for the child in Scenario 2 (page 70): can she be regarded as healthy?

A normativist (or holistic) theory of health and disease

Normativist accounts consider the individual in relation to the society in which she lives rather than as a set of physiological facts; disease is generally seen as something undesirable that handicaps her in her social environment and prevents her living what might be termed 'the good life' in that environment.¹⁷

Whilst this sort of approach seems to avoid some of the problems raised by the biostatistical theory (such as the problem of common disease), there are problems with normativist theories because there are many variables to consider and define.¹⁸ How harmful does something have to be before it counts as harmful for the purposes of a normativist account? Normativists vary in what sort of things might be harmful and, if harmful, which of them might be considered a disease; illiteracy and homelessness, for example, are harmful but are not diseases.¹⁹ Entities that are considered harmful in some societies may be seen differently

¹⁶ Kingma, above, n 3.

¹⁷ Carel, above, n 1, 11-12.

¹⁸ H Carel & R Cooper, 'Introduction' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 1-22, 6.

¹⁹ Carel & Cooper, above, n 18, 7.

elsewhere so what constitutes disease can vary with different circumstances.²⁰ Is disease to be considered in terms of how the problem interferes with the life of the individual? Or is it in terms of how the individual is prevented from contributing to society?²¹ If one, for example, postulates that disease prevents one living 'the good life', then there is considerable difficulty in deciding what sorts of things are needed for 'the good life'; this is one of the major problems of philosophy.²² There are further problems with assessing disease using this type of approach. One obvious problem is deciding who might make the judgment; is it the medical profession or others?

For this reason there is not just a single normativist theory but I will consider only one formulation here. Nordenfeldt, one of the major proponents of normativism, takes as his primary object the definition of *health*, rather than disease and then defines how illness differs from it. He considers that health is a state of body and mind in which one's ordinary human goals may be reached, given that the external circumstances, such as the political situation, permit this.²³ For him the goals are those that are *normal* for the social environment in which the individual exists.²⁴ This is, for example, Nordenfeldt's formulation of health:

²⁰ Carel, above, n 1, 12. Carel gives as an example endemic Spirochetosis, a skin infection that has a characteristic appearance considered attractive by some South American Indians, but which is usually seen as a 'disease' in the UK.

²¹ C Boorse, 'On the distinction between disease and illness' (Autumn 1975) 5 (1) *Philosophy and Public Affairs* 49-68, 51.

²² Carel & Cooper, above, n 18, 6-7.

²³ L Nordenfeldt, *Animal and Human Health and Welfare* (CABI: Wallingford, Oxfordshire, 2006) 12-13.

²⁴ Nordenfeldt, above, n 23, 149.

A is completely healthy if, and only if, A is in a bodily and mental state such that A has the ability, given standard or otherwise reasonable circumstances, to realize all his or her vital goals.²⁵

He calls this the holistic theory of health (HTH). According to Nordenfelt vital goals are those whose fulfilment leads to 'long term minimal happiness'²⁶ Nordenfeldt is not thinking of goals that people consciously set themselves but more of those possessed by all human individuals, including babies and those with dementia. It is perfectly possible for an individual to have a disease state, as measured by the biostatistical theory, but to be fully able to fulfil vital goals.²⁷ It is also possible to possess degrees of health; in Nordenfelt's model, someone can fulfil some goals, but not achieve others.²⁸

The child in the scenario 2 (page 70) may fall into the 'not healthy' category by Nordenfelt's formulation because of hormone deficiencies. It is probable that she would have a shortened life if this aspect is untreated and therefore she would be unable to fulfil many of her vital goals. However, there would be no reason to assume that the unusual genitalia per se would prevent her from fulfilling these. If the more life threatening aspects of her conditions are treated, it is possible that she may fulfil many of her vital goals and much more. Therefore whilst some aspects of her condition place her in Nordenfelt's 'unhealthy' category, others do not. This formulation might suggest that surgical treatment to change the appearance of genitalia is not really necessary for health reasons. The

²⁵ L Nordenfelt, 'Naturalistic and holistic theories of health and disease' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 23-36, 24.

²⁶ Nordenfelt, 'Naturalistic and holistic theories of health and disease', above, n 25, 25.

²⁷ Nordenfelt, 'Naturalistic and holistic theories of health and disease', above, n 25, 25.

²⁸ Nordenfelt, 'Naturalistic and holistic theories of health and disease', above, n 25, 28.

individual may *choose* appearance altering surgery for herself when able to do so, but not to become more healthy under Nordenfelt's definition.

Whereas the HTH appears a more sophisticated and nuanced account of what renders people healthy or ill, both the biostatistical theory of disease and the HTH attempt to disconnect the definition of health from the perception of the individual. Particularly in the case of intersex, this can be problematic. The experience of intersex can vary significantly among individuals, and the clinical response ought to consider this experience. It may be completely devastating and life-changing for the individual who discovers that her body is constructed differently to how she had previously thought. In order to consider this aspect, another approach to disease, health and illness is required.

Phenomenological approach

First a case scenario -

Scenario 4

A 15-year-old girl has recently been under investigation, as she has not yet started periods. She has no body hair, but is showing some breast development and her body has a female form. She has female genitalia and an entirely female appearance. There has been no previous suspicion that she has an intersex state. She did have two aunts who had no children (though they never sought medical help for this), but otherwise there is no significant personal or family history. Initial investigations reveal that she has a 46, XY karyotype, testes and an absent uterus, with a small vagina. She has the X-linked recessive complete androgen insensitivity syndrome (CAIS). Here the testes can produce testosterone but the organs and tissues of the body are unable to respond, so the individual appears outwardly as a 'normal' female. Genitalia are not unusual in form. This is one of the more frequently encountered intersex states. She will be unable to reproduce by technologies currently available. Not only does she not have ovaries or a uterus, but testes in CAIS lose all germ cells in the first year of life or so. (1) This scenario involves an individual who will continue to live as a female into adulthood.(2)

Refs.

1. MJ Newbould, 'Germ cell tumours of the ovaries and dysgenetic gonads' in N Wilkinson (ed), *Pathology of the Ovary, Fallopian tube and Peritoneum* (London: Springer, 2014) 289-326
2. These individuals are perceived as and therefore treated as female from the moment of birth and it used to be believed the incidence of those wishing to transition to the male gender is not increased in comparison with the rest of the female population, though recently this has been questioned. F Brunner, M Flegner, K Krupp, K Rall, S Brucker & H Richter-Appelt, 'Gender role, gender identity and sexual orientation in CAIS ('XY-Women') compared with subfertile and infertile 46, XX women' (2016) 53 (1) *Journal of Sex Research* 109-124.

Biostatistical analysis of the gonadal hormone levels in the girl with testes in Scenario 4 will indicate levels outside the normal range and this will further indicate that she has 'abnormal' gonads and, therefore, is infertile.

However there is another side to these simple numerical results. The discovery of a condition such as CAIS is likely to be truly devastating or at least distressing. It could be argued that the condition of the sufferer cannot be understood properly without an understanding of how she experiences her condition. For the girl in scenario 4 (page 105), her view of herself may be shattered and her hopes for the future might have to undergo revision. In order to access insight into this aspect of intersex, a different way of approaching disease and illness is needed.

From the 1980s onward, there has been a great emphasis on the so-called phenomenological approach to health and illness. There is a very large literature dealing with phenomenology and medicine and I can provide only a very brief account here. Phenomenology is a philosophical tradition 'that focuses on phenomena (what we perceive) rather than on things (what really is)'.²⁹ Neither biomedical nor normative theories allow for substantial input from the person at the centre of the experience and both can be seen as 'objective (and objectifying)'.³⁰ The phenomenological approach to illness and disease augments the biomedical or normativist approach by giving a voice to the person at the centre of the whole experience and so 'privileges the first-person experience thus challenging the world's objective, third-person account of disease'³¹ and 'sees illness as a way of living, experiencing the world and interacting with other people'³².

According to Merleau-Ponty human beings are embodied and:

²⁹ H Carel, 'Phenomenology and its application in medicine' (2011) 32 (1) *Theoretical Medicine and Bioethics* 33-46.

³⁰ Carel, *Illness*, above, n 1, 8.

³¹ Carel, *Illness*, above, n 1, 8.

³² Carel, *Illness*, above, n 1, 8.

the body is not an automaton operated by the person but the embodied person herself. We are our bodies; consciousness is not separate from the body.³³

It follows that bodily changes actually change perception and subjectivity.³⁴ Also when we learn that our body is not as we previously thought it was, this can change the way in which we perceive the world.

³⁵ This latter point is highly relevant to considering the experience of people with intersex as illustrated in Scenario 4 (page 105).

Proponents of the phenomenological approach sometimes talk about illness rather than disease, and there is also a large literature dealing with this difference. Briefly, as expressed by Svenaeus:

A disease is a disturbance of the biological functions of the body (or something that causes such a disturbance), which can only be detected and understood from the third person perspective of the doctor investigating the body with the aid of her hands or medical technologies³⁶

He goes on to say:

The patient can also [...] adopt such a third-person perspective towards her own body and speculate about diseases responsible

³³ Carel, *Illness*, above, n 1, 13.

³⁴ Carel, *Illness*, above, n 1, 8. Havi Carel is using the work of Merleau-Ponty (1908-1961), for whom 'the body is our general means of having a world'. See M Merleau-Ponty, *Phenomenology of Perception* (DA Landes (trs), Abingdon: Routledge, 2012) 147. Therefore our body is how we interact and react with the world.

³⁵ K Zeiler & L Guntram, 'Sexed embodiment in atypical pubertal development' in K Zeiler & LF Käll (eds), *Feminist Phenomenology and Medicine* (Albany: State University of New York Press, 2014) (Kindle Edition) 141-160, 141.

³⁶ F Svenaeus, 'What is phenomenology of medicine?' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 97-111, 105

for her suffering. But the suffering itself is an illness experience of the person ...³⁷

Under this perspective, the actual *illness* experience is important rather than the biomedical facts. Toombs says that:

as embodied persons, we experience illness primarily as a disruption of lived body rather than as a dysfunction of our biological body.³⁸

Therefore an illness is partly defined by the inability to achieve certain goals. Since there is an additional emphasis on the individual in the phenomenological approach the goals are not determined objectively, as vital goals are for example, but are uniquely shaped by individuals.

The illness experience does not have to be seen as an unmitigated *bad* thing. Illness may be seen as a 'life-transforming process, in which there is plenty of bad but also, surprisingly, some good'.³⁹ Havi Carel writes about illness from her point of view. As such this is obviously highly personal, but it is of particular interest as she is a philosopher who uses ideas from Heidegger, Freud and Merleau-Ponty amongst others to describe health, illness and death. Because of this background she is able to bring clarity and insight to her analysis of her condition. After writing a book on death⁴⁰ she was diagnosed with an incurable and terminal illness. She describes the experience of finding she was 'disabled.' One of her points is that experience of illness may have positive effects for the individual concerned. There is no doubt that this was a devastating discovery for her, no matter what provisions were made to accommodate her loss of ability – '(f)rom thinking of myself as a young,

³⁷ Svenaeus, above, n 36, 105.

³⁸ S Toombs, 'Illness and the paradigm of lived body' (1988) 9 *Theoretical Medicine* 201-226, 201.

³⁹ Carel, *Illness*, above, n 1, 12.

⁴⁰ H Carel, *Life and Death in Freud and Heidegger* (Amsterdam: Rodopi, 2006).

healthy, promising life and body I had to start thinking of myself as fragile damaged, unable'⁴¹. She takes Heidegger's account of human existence as 'being able to be', normally taken to mean that humans have potential and ability to pursue self-chosen goals, and modifies it so that it includes 'inability to be' as an alternative way of being.⁴² She suggests that we should think about 'being unable to be as a form of existence that is worthwhile, challenging and, most importantly, unavoidable'.⁴³ To her, this acknowledgment led to a realisation that there is a spectrum of ways to be, some of which must take into account inability or disability. To some extent, this applies to everyone and can relate to a wide range of matters not connected with illness; not many of us will expect to be able to write a book on philosophy, for example.

Though an account as personal and specific as this cannot be generalised, the point is that the full story of an illness experience does not emerge from consideration of the biomedical facts alone. How might the phenomenological point of view be of relevance to intersex? The description of the disease process is much fuller if consideration is given to the experiences of the intersex person and a phenomenological approach permits this. I will now consider scenario 4 (page 105).

Discovering the absence of a uterus

Scenario 4 described the bare facts of the situation in which a teenage girl finds that she has no uterus, testes rather than ovaries and a small vagina. Zeiler and Guntram have described the experiences of women in this position in detail. They interviewed a group of Swedish women who discovered that they had no uterus and no vagina or no uterus and a

⁴¹ Carel, *Illness*, above, n 1, 66.

⁴² Carel, *Illness*, above, n 1, 67.

⁴³ Carel, *Illness*, above, n 1, 68.

small vagina. ⁴⁴ The following is a quote from one of the women in their survey:

The doctor said 'You might not have one.' But I just thought he was joking really, so I just laughed. I really thought 'No, but that's not possible, that's kind of like saying that you don't have a heart.' ⁴⁵

For most, the moment of discovery was a time of great shock. One woman describes the doctor's silence during the examination as a cause of enormous anxiety ⁴⁶, just as it was for the parents at the delivery in scenario 1 in chapter 3 (page 61) when the midwife was silent. The problem is that on making this shocking discovery women may find that their view of their body changes. Often we forget about the parts of our body as we go about our lives; they can be considered to 'dis-appear'. Sometimes however, we become suddenly aware of them; if, for example, we injure ourselves, then the affected body part 'dys-appears'; ⁴⁷ we became aware of it as something painful. ⁴⁸ The young women involved described exactly the same experience on learning that they possessed no uterus or vagina; they suddenly became aware of something that they had previously taken for granted. The absent structure is a source of pain and loss, even though it was *never* there. ⁴⁹ They also felt the loss of an envisaged future involving pregnancy and

⁴⁴ Zeiler & Guntram, above, n 35.

⁴⁵ Zeiler & Guntram, above, n 35, 141. This is a quote from a girl called Joanna on discovering that she might not have a uterus,

⁴⁶ Zeiler & Guntram, above, n 35, 144.

⁴⁷ 'Dys' is used here rather than 'dis'. 'Dys' in medical terminology is a prefix meaning painful or difficult. Therefore '*dys-appeared*' is a term used by Zeiler and other phenomenologists meaning 'to become painfully aware of'. See for example K Zeiler, 'A phenomenological analysis of bodily self-awareness in the experience of pain and pleasure: on dys-appearance and eu-appearance' (2010) 13 (4) *Medicine, Healthcare and Philosophy* 333-342.

⁴⁸ Zeiler & Guntram, above, n 35, 144.

⁴⁹ Zeiler & Guntram, above, n 35, 144.

childbirth and of other experiences that they had thought would be part of their future as women. They even felt the loss of the possibility of menstruation.⁵⁰ The 'bodily absence is painfully present'.⁵¹

Merleau-Ponty describes the process in which something external to the body can be incorporated into the body and function as one of its parts, such as a blind person using a stick to find her way.⁵² Zeiler and Guntram point out that everyone learns gendered patterns of behaviour and that this is incorporated into one's every action, just as the stick is for the blind person. The point is that, when functioning, no attention needs to be paid to what is incorporated. Therefore the young women expressed these patterns prior to their discovery, but they were merely there and not subjected to conscious attention. Excorporation takes place when the incorporated item suddenly becomes drawn to one's attention. For example, if the blind individual breaks her stick; she is now aware of it as something that is no longer serving to guide her. For the woman in scenario 4 (page 105) learning that she has no uterus can have a similar effect. The gendered world in which she previously lived is now shattered.⁵³ This is clearly a major and life-changing discovery for the women who experience it.

A phenomenological approach may provide an added dimension to the understanding of the intersex condition in scenario 4 (page 105). Using this approach, it is clear that this individual experiences shock and pain that might be qualified as a sort of illness. However, the important point is that it is not the sort that can be easily cured by a straightforward medical or surgical approach in the way that, say, an inflamed appendix might be. Rather, it is something that requires a very different sort of therapy. At the end of this chapter I suggest a possible practical use for a phenomenological approach that might help.

⁵⁰ Zeiler & Guntram, above, n 35, 146.

⁵¹ Zeiler & Guntram, above, n 35, 146.

⁵² Merleau-Ponty, above, n 34, 144.

⁵³ Zeiler & Guntram, above, n 35, 147-148.

Phenomenology, surgery and the child with atypical genitalia

First, two scenarios:

Scenario 5

(Taken from from EK Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm, in (K Zeiler & LF Käll (eds) *Feminist Phenomenology and Medicine* (Albany: State University of New York Press, 2014) 161- 176)

J had no idea that there was anything out of the ordinary until aged 12 years, when informed by his mother that he was a hermaphrodite at birth but did not provide any additional details. At birth, he had been assigned to a female gender and had lived as such up to that point. He recalled hearing the news about his birth with great excitement and exhilaration, since he had always somehow felt a strange ineffable distance from his body; a sense that somehow things were wrong. However, at this point he was not able to articulate the nature of his feelings. In his early teens, he felt so indifferent towards his body that he agreed to undergo vaginoplasty and to accept feminizing hormone therapy. A few years later, he learned more about his past medical history. In the second year of life, he had undergone surgery to alter the shape and size of his phallus (which was deemed too small to permit life as a male) and later he had removal of his undescended testes. When he made this discovery he found he could no longer disregard his body. He found that the somatic changes with hormone therapy also clarified his feelings of deep discontent. Eventually when in his twenties, he was able to articulate his feelings and experiences and saw a physician about taking testosterone. He did and suddenly he found that the distance between his body as it was and how he felt it should be was diminished. He transitioned to live as a male.

Scenario 6

This concerns a child with CAH who had clitoroplasty in the first two years of life. She was brought up as a girl and had no major problems with that. No one in the family ever talked about what had happened to her surgically as an infant, though when she reached her early teens her mother told her that she was 'born with a hormone deficiency'. The topic was never discussed in the wider family. She learned to dread hospital visits, where she was subjected to examination and questioning from multiple members of the medical team. Sometimes they examined her scars. As she got through her teens, she sometimes explored the site of her early surgery, touched the scars and realized that she has no feeling in that area. In her twenties, she discovered that sexual experiences were not entirely satisfactory for her. She was able to find out more about what happened to her by looking in her hospital notes and she met others who also had undergone clitoroplasty as young children (having asked the psychology department at the hospital for support group details) and she found her experiences were not so uncommon amongst others in the group.

These scenarios illustrate what might happen following genital or gonadal surgery. Feder points out that, despite the reform of the medical approach to infants that occurred in the middle of the first decade of the twenty-first century, discussed in Chapter 6 ('Intersex, medicine and pathologisation'⁵⁴) and chapter 7 ('When parents choose gender'⁵⁵)

⁵⁴ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180. (In this thesis, see chapter 6, 171).

there is no significant reduction in normalising surgery.⁵⁶ She notes that today's surgeons often consider the harms of the past to have been caused by undeveloped and inadequate surgical techniques, rather than consider that the actual surgical approach is unhelpful.⁵⁷ Creighton's group also point out that, in England, there has been little change in surgical practice over the past ten years or so.⁵⁸

The reasons for surgery may have changed –

Whereas in the past, surgery was undertaken by physicians who understood themselves to be responding to a 'social emergency' today these surgeries are performed in response to 'what parents want'.⁵⁹

What J's parents (scenario 5, page 112) and the parents of the girl in scenario 6 (Page 113) had consented to for their infant children Feder sees, at some level, as satisfying the parents' own needs.⁶⁰ Perhaps this is harsh; I have discussed this difficult and complex decision earlier (in Chapter 3, page 78). There are a number of reasons why some might perceive that surgery is in the child's best interests. However, I

⁵⁵ M Newbould, 'When parents choose gender: intersex, children and the law' Accepted for publication in *Medical Law Review* (2016). (In this thesis, see chapter 7, 203).

⁵⁶ EK Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm' in K Zeiler & LF Käll (eds) *Feminist Phenomenology and Medicine* (Albany: State University of New York Press, 2014) (Kindle Edition) 161- 176, 161.

⁵⁷ Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm', above, n 56, 168.

⁵⁸ For example, L Michala, L-M Liao, D Wood, GS Conway & SM Creighton, 'Practice changes in childhood surgery for ambiguous genitalia' (2014) 10 *Journal of Pediatric Urology* 934-940.

⁵⁹ Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm', above, n 56, 161.

⁶⁰ Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm', above, n 56, 175.

mention this decision again here in order to analyse it more deeply in a phenomenological context.

Feder suggests that in making the child's body fit with their view of it, the parents do not see the child himself or herself. Rather they see their child in a way that conforms to how they think he or she ought to be. Malmqvist and Zeiler suggest that the concepts of incorporation and 'excorporation' (discussed earlier on page 111) assist in understanding the issues involved.⁶¹ Using the existing literature on the reactions of parents to the birth of an intersex child, they have analysed how they feel the situation relates to a phenomenological analysis. They suggest that ideas regarding the two-sex model are incorporated in the fabric of everyday social interaction, just as the blind person's stick is. Basically it is taken as a common-sense fact so obvious as to be beyond argument that there are two sex/genders and everyone must be either one or the other.⁶² Therefore these ideas are there, but not usually brought into conscious thought. At the birth of a child with ambiguous genitalia, the bodily facts regarding sex differentiation are suddenly brought to attention and 'excorporated'. Therefore parents are confronted by the question of what makes someone a given sex, often for the first time. Some parents feel great relief when the child is assigned to a gender, sometimes finding that they are now able to relate to the child more easily, because now the child fits the two sex model that was always there in the back ground. Surgery can serve to show that this binary model, which underpins so much social interaction, is vindicated.⁶³ The child is once again conforming to this model. The idea that there are really two sexes can

⁶¹ E Malmqvist & K Zeiler, 'Cultural norms, the phenomenology of Incorporation and the experiences of having a child born with ambiguous sex' (2010) 36 *Social Theory and Practice* 133-156.

⁶² E Feder, ' "In their best interests": Parents' experience of atypical genitalia' in E Parens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*, (Baltimore: Johns Hopkins University Press, 2006)189-210, 191.

⁶³ Malmqvist & Zeiler, above, n 61.

once again become incorporated for the parents, and for the child, for a while.

For J (Scenario 5, page 112), all was incorporated and hidden until he discovered his medical history. At this point he was able to articulate his feelings of gender dysphoria. When he understood his history, what he had lost (testes and genitalia, which, though atypical, had male features) was brought to his attention, 'excorporated' in the language used in the preceding paragraph. This seems to have enabled him to understand what his feeling of unease with his body actually was. For the woman in Scenario 6 (page 113), medical attention served to draw her attention to what she had lost; she gradually became aware that she had no clitoral sensation. She became fully aware of her body when she read her notes and discussed her situation with others who had undergone the same procedure. Over time her genitalia 'dys-appeared'⁶⁴. She became gradually aware of them as problematic.

There is an assumption that surgery creates *normal* genitalia, but there is a marked difference in perception regarding the results of the surgery from the point of view of the surgeon and the point of view of the patient.⁶⁵ Surgery is finished when the surgical incision heals, but the child has to live with the consequences (such as loss of clitoral sensitivity) for the rest of her life. There are written accounts of this such as that of Katrina Karkazis;⁶⁶ I discuss some of this literature in Chapter 6, the paper 'Intersex, medicine and pathologisation'.⁶⁷ Some consider that harm has resulted from clitoral surgery, sex reassignment in boys with micropenis, psychosocial damage because of the emphasis of the need for secrecy, the trauma of multiple medical examinations and medical

⁶⁴ 'Dys' is used here rather than 'dis'. See footnote 47 above for explanation.

⁶⁵ Karkazis, above, n 11, 204-205.

⁶⁶ Karkazis, above, n 11. For example, 219-233.

⁶⁷ Newbould, 'Intersex, medicine and pathologisation', above, n 54. (in this thesis, see Chapter 6, 185).

photography.⁶⁸ In the past a neo-vagina was sometimes constructed in a young child, leading to the need for painful (both physical and psychological) dilatation procedures.⁶⁹ It may help if there were more dialogue between people with intersex states, their families and health care professionals to facilitate mutual understanding.

How might a phenomenological approach in medicine help in the management of intersex?

Scenarios 4 (page 105), 5 and 6 (pages 112-113) have been subjected to a brief analysis in the above section and, in each case, I have tried to see the circumstances from the point of view of the intersex person to see if this is enlightening. Looking at their hormonal and anatomical circumstances from a biostatistical point of view (and, prior to replacement, from a normativist approach), it might be construed that all of these children have a disease (because of severely non-normal hormone profiles that might prove life threatening if left untreated). As I discuss above, the unusual genital anatomy with which the children were born is rather more difficult to characterise as a disease by a biostatistical or a normativist approach. The children in scenarios 5 and 6 received the standard surgical treatment on offer. Corrective surgery has been performed, just as if unequivocal disease were present. The aim was, presumably, resolution of problems and ‘healing’. However, as described in the scenarios, neither individual felt that they were healed but experienced the consequences of their treatment in a way that might be described as ‘illness’. Though not necessarily diseased or unhealthy by biostatistical or normativist approaches (if appropriate hormone replacement is given), intersex individuals may experience ‘illness’ using a phenomenological analysis. I realise that this may be so whether or not there is a history of childhood surgery, though those who had surgery

⁶⁸ Feder, ‘Reassigning ambiguity. Intersex, biomedicine and the question of harm’, above, n 56, 164.

⁶⁹ Feder, ‘Reassigning ambiguity. Intersex, biomedicine and the question of harm’, above, n 56, 164.

may experience the specific problems described in the scenarios. The approach I suggest to the illness experienced by those with intersex is not a simple medical or surgical one, but rather that individuals need to have opportunities to discuss, analyse and understand their experiences.

Phenomenological approaches do not have to be confined to theory, but may have use in practice. Havi Carel suggests that phenomenological analysis of experiences might provide a useful tool-kit for those with conditions of many sorts to 'reflect on and expand their understanding'⁷⁰ of what is happening to them. She envisages daylong workshops in which patients are guided through an analysis of their experiences, rather like the one that she carried out on herself. She describes her own isolation and confusion on receiving her diagnosis of a fatal lung disease. She described how the illness was initially an intrusion into an otherwise normal life that gradually became embedded in, and part of the fabric of, her existence.⁷¹ I suppose it is as if the blind person's stick is whole (before the diagnosis), then breaks at the point of diagnosis, but then the broken stick once more is able to function as a sensory tool.

The point of a phenomenological view of illness is that it is '*experienced* by patient and physician'⁷² (italics in original) and others also, such as family members. Though Carel is discussing very different sorts of experience to those described in the scenarios in this chapter, she notes that philosophical support for patients could be very flexible allowing them to develop their understanding of what had happened and their present situation.⁷³ One of the strengths of using this approach is that it permits interaction between those with intersex, their families and healthcare professionals, all of whom might be able to bring unique knowledge and

⁷⁰ H Carel, 'Phenomenology as a resource for patients' (2011) 37 (2) *Journal of Medicine and Philosophy* 96-113.

⁷¹ Carel, 'Phenomenology as a resource for patients', above, n 70.

⁷² Carel, 'Phenomenology as a resource for patients', above, n 70.

⁷³ Carel, 'Phenomenology as a resource for patients', above, n 70.

experiences to the discussion. They might gain deepened understanding of the feelings and difficulties experienced by those with intersex conditions.⁷⁴ The idea is that it enables a descriptive mode of engagement, which is in contrast to the biostatistical approach. It might prove to be a valuable learning experience for health care professionals to engage with patients in this way, whether the patients have intersex state or anything else.

Conclusions

Engagement with the epistemological issues relating to the definition of health and illness provides valuable insight as far as intersex is concerned. The account provided here is necessarily concise and succinct but it hopefully assists comprehension of some of the ethical issues relating to the clinical management of intersex.

We have seen that there are various approaches to health and illness, defined earlier in this chapter. All these approaches have advantages but all have limitations. I have briefly considered the phenomenological approach to health and illness and this may be a useful tool in providing a more rounded and nuanced understanding of some of the predicaments of people with intersex. In this way, the phenomenological approach provides a valuable adjunct to other approaches. I suggest that the voice and experience of the individuals concerned should always form a central part of any difficult clinical decision, perhaps by use of a support group or by the use of the type of event described above in which, via a facilitator, individuals are encouraged to talk about their experiences. From an ethical point of view, this means that the experience of those who have had surgery will inform the clinical management of intersex. In particular, it might provide the opportunity for the dis-satisfaction experienced by many who had surgery in early childhood to be seriously considered

⁷⁴ Carel, 'Phenomenology as a resource for patients', above, n 70.

when framing clinical guidelines. The voices of some of those with intersex conditions indicate that early genital surgery might be regarded as clinically inappropriate and ethically dubious. Though the central justification for surgery is held to be the experience of the individual, in at least some cases, that experience is perceived as harmful rather than healing.

I will now move on to consider the legal approach, in which I consider two areas of the law in particular; gender law and the law concerning genital surgery in minors.

CHAPTER 5:

LEGAL APPROACH

In this chapter I will initially look at some broader issues which are not fully developed in the published papers but are helpful in explaining the context in which the law engages: first, with intersex and gender and, secondly, with genital surgery, particularly when infants and children are involved. Both of these topics form important background information to my main topic of genital and gonadal surgery in intersex.

I will examine very briefly the radical change in gender law occurring in England in the 33 years between 1971¹ and 2004.² Then, I will look at the jurisprudence concerning infantile genital surgery, including cases that deal with intersex and non-medical circumcision carried out on young males. I further discuss aspects of this in my paper 'When parents choose gender' (forming Chapter 7 of this work). Most of the cases I cite are from the English-speaking world, though I have found and address some intersex and male circumcision case law from other jurisdictions. In this chapter I will not be using case scenarios to illustrate the issues, since case histories form an integral part of case law.

How does twenty-first century law approach gender?

The topic of sex and gender forms a central part of any discussion of intersex. The account given below reflects how the understanding of sex and gender in English law was initially very simplistic, but has become more complex over the last 40 years or so, though there may still be further complexity to be negotiated. For many years, there was no legal definition of gender and the important matter was biological sex. In

¹ *Corbett v Corbett* [1971] P 83

² Gender Recognition Act 2004.

*Corbett v Corbett*³ this was governed by genital anatomy *at birth*.⁴ This case involved April Ashley.⁵ In 1935 she was born male and named George Jamieson. By 1956 she had started to take oestrogens to gain a more female physique. In May 1960 she had surgery in Casablanca, consisting of removal of the penis, scrotum and testes followed by vaginoplasty. She subsequently lived as a female. She married Arthur Cameron Corbett in Gibraltar in September 1963, following a three-year relationship. He was fully aware of her history. They separated a month later and Arthur (the petitioner) sought a decree of nullity from April (the respondent) on the grounds that April was a man and that there was incapacity or a wilful refusal to consummate the marriage.⁶ April answered by denying being of male sex and denying any incapacity or wilful refusal to consummate the marriage but cross-prayed for a decree of nullity, also on the grounds of incapacity or wilful refusal to consummate the marriage, but on the part of the petitioner.⁷ She pleaded (in an amendment made during the trial) that the petitioner should be estopped⁸ from having the marriage voided on the grounds of her being of male sex.⁹

Counsel for April Ashley argued that, with the recognition of transsexualism, there was sufficient doubt about the relationship of physical characteristics to gender to warrant regarding April as a case of

³ *Corbett v Corbett* [1971] P 83

⁴ *Corbett v Corbett* [1971] P at 104

⁵ Who celebrated her 80th birthday recently. N Payton, 'Trans pioneer April Ashley turns 80' (29/04/2015) *Pink News*
<http://www.pinknews.co.uk/2015/04/29/trans-pioneer-april-ashley-turns-80/>

⁶ *Corbett v Corbett* [1971] P at 84-85

⁷ *Corbett v Corbett* [1971] P at 85

⁸ Meaning that he should be prevented from asserting that the marriage was void because of her male sex, since this assertion carried implications regarding April's sex and, presumably rights to marry as a woman.

⁹ *Corbett v Corbett* [1971] P at 85

intersex and as such she should be assigned to the female gender, arguing that a person's psychology was as important as physical characteristics.¹⁰ Ormrod J held that the issue to be decided was the primary validity of the marriage and that this depended on the 'true sex' of the defendant and the capacity to consummate the marriage, if there had been one.¹¹ Ormrod J stated that sex was to be decided on those aspects of an individual's *biological* make-up that can actually be seen and assessed; he ruled that chromosomes, gonads, and genitalia at birth were of primary importance.¹² Much of the expert evidence centred on whether April was a hermaphrodite or a true biological male,¹³ but, having decided that there was no evidence that she was anything other than a biological male, he declared that the marriage was void.¹⁴ Further, he held that April was physically incapable of consummation of a marriage:

[h]aving regard to the essentially hetero-sexual character of the relationship which is called marriage, the criteria must, in my judgment be biological, for even the most extreme degree of transsexualism in a male or the most severe hormone imbalance that can exist in a person with male chromosomes, male gonads and male genitalia cannot reproduce a person who is naturally capable of performing the essential role of a woman in marriage.

¹⁵

To Ormrod J, who was medically qualified,¹⁶ sex was very much a biological entity that was fixed at birth. Though a first instance decision,

¹⁰ *Corbett v Corbett* [1971] P at 85

¹¹ *Corbett v Corbett* [1971] P at 89.

¹² *Corbett v Corbett* [1971] P at 106.

¹³ *Corbett v Corbett* [1971] P at 100 – 104.

¹⁴ *Corbett v Corbett* [1971] P at 106

¹⁵ *Corbett v Corbett* [1971] P at 106

¹⁶ PL Chau & J Herring, 'Defining, assigning and designing sex' (2002) 16 (3) *International Journal of Law, Policy and the Family* 327-367.

Corbett was enormously influential around the world for 30 years or so. The criteria for determining sex and intersex were used in the English courts on several occasions. For example, *W v W (Physical Inter-sex)*¹⁷ was concerned with a marriage contracted between a man and a woman who was intersex. This is one of the rare times that intersex has been considered by the courts. She had been labelled a boy at the time of birth registration but had lived as a woman from the age of 17 years. She had surgery to feminize her genitalia when aged 40 years and married (for the second time), aged 46 years, in 1993.¹⁸ The couple divorced four years later. Following this, the husband sought a decree of nullity on the grounds that at the time of the marriage, he and his wife were not male and female respectively. Charles J used the biological test set out in *Corbett* to make his decision. In *W v W* the biological evidence was scanty because the wife had undergone extensive surgery. It seemed likely she had male gonads. She certainly had a 'male' 46XY karyotype and it seemed most probable that her genitalia, prior to surgery, were atypical.¹⁹ She seems to have developed a womanly appearance at puberty without taking exogenous hormones.²⁰ Charles J considered that her physical characters indicated that she was intersex at birth by the criteria set out by Ormrod J in *Corbett*²¹ and that it was most likely that she had a partial insensitivity to testosterone. Charles J considered that there was sufficient evidence to indicate that the wife was actually female at the time of marriage and that the birth registration should be regarded as an error.²² He further held that that there was no

¹⁷ *W v W (Physical Inter-sex)* [2001] Fam 111

¹⁸ *W v W (Physical Inter-sex)* [2001] Fam 111

¹⁹ *W v W (Physical Inter-sex)* [2001] Fam at 118

²⁰ *W v W (Physical Inter-sex)* [2001] Fam at 118

²¹ *W v W (Physical Inter-sex)* [2001] Fam at 146

²² *W v W (Physical Inter-sex)* [2001] Fam at 146

reason to believe that she had any incapacity to consummate the marriage and that the marriage could not be considered null. ²³

In *Bellinger v Bellinger*, ²⁴ the English Courts were concerned as to whether *Corbett* continued to be applicable in 2001. Though *Bellinger* initially came to court before *W v W (Physical Inter-sex)* the former was to have consequences relating to gender law so I am discussing it after *W v W*. The two cases are different because whereas it is most likely that the wife in *W v W* was intersex, there was no reason to consider that Mrs Bellinger was. She had been declared male at birth and her chromosome complement was 46, XY. From an early age she had wanted to live as a woman but had entered into marriage with a woman in her early twenties because of strong pressures from her family. The marriage had been unsuccessful and shortly after its breakdown she started to live as a woman. At the age of 35 years she had gender reassignment surgery and shortly following this she married Mr Bellinger, who was fully aware of her history. The court was asked to adjudicate on the validity of the marriage. Though much evidence was heard from medical experts to the effect that there had been marked social change since *Corbett*, Johnson J felt that he had to abide by precedent; the lack of knowledge about the relationship of brain structure to gender meant that there was no objective test and he felt that the only criteria that could predict gender were those defining sex mentioned in *Corbett*. ²⁵ At the Court of Appeal, ²⁶ the appeal was dismissed, though there was considerable sympathy for trans people who wanted to enter into legal marriage and Thorpe L J dissented from the decision, noting that there

²³ *W v W (Physical Inter-sex)* [2001] Fam at 147

²⁴ *Bellinger v Bellinger and another* [2000] All ER (D) 1639; *Bellinger v Bellinger (Attorney General intervening)* [2002] Fam 150, [2001] EWCA 1140; *Bellinger v Bellinger (Lord Chancellor intervening)* [2003] UKHL 21

²⁵ *Bellinger v Bellinger and another* [2000] All ER (D) 1639

²⁶ *Bellinger v Bellinger (Attorney General intervening)* [2002] Fam 150, [2001] EWCA 1140

was inconsistency in a country that provided a medical service enabling sex change to take place but then failed to take account of the legal consequences of this.²⁷ The majority expressed their opinion that it was for Parliament rather than the judiciary to decide the status of a trans person and that this was a matter for statute.

Before *Bellinger v Bellinger* could be heard in the House of Lords, on a further appeal, there had been two decisions made in the European Court of Human Rights. *Goodwin v United Kingdom*²⁸ did not specifically concern marriage but was highly relevant to all aspects of the legal status of transsexual people. Christine Goodwin was a trans woman, considered male at birth in 1937. She had dressed as a woman some of the time from childhood onwards. However, on reaching adulthood she was living as a man and married a woman. The couple had four children, but Christine Goodwin always felt that her 'brain sex' did not match that of her body and eventually the couple divorced. In 1990 she underwent gender reassignment surgery. Most of the matters she placed under consideration at the European Court were concerned with practicalities, such as the desirability of obtaining a National Insurance number with her new identity or her wish to receive a pension at age 60 rather than 65. She also had hopes of having lower (female) car insurance premiums²⁹ without having to reveal her medical history and former identity. Finally, she also questioned the matter of legal marriage. Considering all of these factors, she alleged that English law, in refusing to recognise her acquired gender violated her rights under the Human Rights Act 1998, involving Articles 8 (the right to respect for private and family life), 12 (the right to marry and found a family), 13 (the right to an effective remedy) and 14 (the prohibition of discrimination); the court

²⁷ *Bellinger v Bellinger (Attorney General intervening)* [2002] Fam, Thorpe, LJ at 193

²⁸ *Goodwin v United Kingdom* [2002] 35 EHRR 447(application no 28957/95)

²⁹ *Goodwin v United Kingdom* [2002] 35 EHRR 447 (application no 28957/95)

found that there *was indeed* a violation of Articles 8 and 12, but that there was no separate violation of Article 14.

I v United Kingdom (25680/94) concerned a 47 year old trans woman, who wished to enrol on a nursing course, but she was prevented from doing this as she refused to show her birth certificate.³⁰ As a result, she had been unemployed for some years. She also complained that her pension and retirement entitlement were those of a man and not a woman. Further, under the law in England, she could marry a woman, but not a man. She therefore sought a declaration that her rights under the Human Rights Act 1998, Article 8 and article 12 had been breached. The European Court of Human Rights found that her rights under these articles were indeed breached by the failure of the UK to make changes in the registration of births and marriages and in its National Insurance systems to accommodate trans individuals.³¹

At this stage, *Bellinger v Bellinger* was reconsidered by the (then) highest court in England.³² In the House of Lords³³ the unanimous decision was that the marriage of Mr and Mrs Bellinger was *not* valid, since it was not possible to give extended meaning to the expressions 'male' and 'female' in the Matrimonial Causes Act 1973 but Mrs Bellinger also sought a declaration that, in so far as section 11 (c) of the Matrimonial Causes Act 1973³⁴ made no provision for the recognition of gender reassignment, it was incompatible with Articles 8 and 12 of the Human Rights Act 1998. Though it was argued by the Lord Chancellor that the *Goodwin* judgment implied that the United Kingdom (UK) should

³⁰ *I v United Kingdom* [2002] 2 FLR 518, [2002] 2 FCR 613

³¹ *I v United Kingdom* [2002] 2 FLR 518, [2002] 2 FCR 613

³² *Bellinger v Bellinger* [2003] 2 AC 467 [2003] UKHL 21

³³ *Bellinger v Bellinger* [2003] 2 AC 467 [2003] UKHL 21

³⁴ Matrimonial Causes Act 1973, s11 (c) which stated at the time that the parties contracting the marriage must be respectively male and female or the marriage was void.

have time to attend to this incompatibility, this submission was not accepted and the House of Lords gave the declaration of incompatibility; the UK was in breach of Articles 8 and 12.³⁵ The European Court of Human Rights therefore refused to allow the UK any margin of appreciation and the Gender Recognition Bill was introduced to remedy the incompatibility and received Royal Assent on 1st July 2004.³⁶

In brief, the Gender Recognition Act, 2004, makes it clear that gender and anatomical or physiological sex need not be related. There is therefore no need for all those who are legally female to have female genital anatomy and no need for those who are legally male to have male anatomy. As already discussed throughout this work, for many years (and to this day) medical and surgical management of intersex children was (and is) concerned with making sure the child had (and has) genital anatomy appropriate to the gender of upbringing.

Under the Act, transgender individuals may apply to the Gender Recognition Panel³⁷ for a gender recognition certificate by which a trans woman is female and a trans man is male for the purposes of all other legislation. The Act dispensed with any need to have either surgical or medical treatment; therefore there is no requirement that an individual's anatomy or physiology conform to their adopted gender.³⁸ Applicants must be at least 18 years of age (so must provide their birth certificate) and must provide a statutory declaration that they intend to continue living

³⁵ *Bellinger v Bellinger* [2003] 2 AC at 468, [2003] UKHL 21

³⁶ AN Sharpe, 'A Critique of the Gender Recognition Act 2004' (2007) 4 *Bioethical Inquiry* 33-42.

³⁷ Applying for a Gender Recognition Certificate. <https://www.gov.uk/apply-gender-recognition-certificate>
Accessed 29/05/2016.

³⁸ However, it may be more difficult to prove that there are intentions to live permanently in the identified gender if reassignment surgery is not planned and applicants are *recommended* to state that they do intend this. Press for Change, 'The standard Track Gender Recognition Application Process' <http://www.pfc.org.uk/StandardTrackGRCS.html>
Accessed 29/05/2016.

in their identified gender, *permanently*.³⁹ A considerable volume of additional written evidence is required. For example, there are two types of medical evidence needed. There must be a statement from a suitably qualified and registered healthcare professional verifying that the individual has been diagnosed with gender dysphoria at some time, giving details of how the diagnosis was made and when.⁴⁰ A general practitioner's statement is also needed stating the past and current gender reassignment therapy.⁴¹ Applicants must show that they have lived in their preferred gender role for at least two years by providing three or four pieces of evidence such as a passport, rent book, wage slips, benefits book, household bills, some of which must have dates covering the two years prior to application.⁴² Since 2005, approximately 3500 individuals have used the Act to gain gender recognition.⁴³

Between 2004 and 2013 the individual wishing to change gender had to end a marriage or civil partnership before transition, though it was possible to contract a civil partnership immediately if the parties were the same gender following transition of one of them,⁴⁴ or a marriage if of different genders.⁴⁵ Over the years, one of the major changes has been the introduction of the English and Welsh Marriage (Same-Sex Couples

³⁹ Press for Change, above, n 38.

⁴⁰ Press for Change, above, n 38.

⁴¹ Press for Change, above, n 38.

⁴² Press for Change, above, n 38.

⁴³ P Dunne, 'Ten years of gender recognition in the United Kingdom: still a model for reform' (2015) (4) *Public Law* 530-539.

⁴⁴ Civil Partnership Act 2004, <http://www.legislation.gov.uk/ukpga/2004/33/contents> Accessed 29/05/2016.

⁴⁵ Press for Change, above, n 38.

Act) 2013,⁴⁶ which meant that married persons wishing to transition no longer have to end the marriage, providing that the non-transitioning spouse does not use the Spousal veto option of Schedule 5 of the Act.⁴⁷ This Schedule has attracted some criticism since it implies that the spouse can prohibit transition, though the couple would be able to dissolve their marriage if there were spousal objections; however, there is no such clause in the Marriage and Civil Partnership (Scotland) Act 2014.⁴⁸ For married individuals wishing to be recognised in their identified gender, the evidence provided must indicate that they have lived in the identified gender for 6 years.⁴⁹

There is some call for reform in other aspects of law with respect to gender. People may not wish to live within one of the binary categories as far as sex and gender are concerned, but the law in England does not permit this. In chapter 3, I wrote about the problem of those who identify as other than of male or female gender as adults. This general group may include intersex individuals or persons transitioning between genders who have not undergone full legal transition. The group may also include people who do not identify as male or female, but something between. There is, as yet, no legal provision for persons within this general group. However, the Member of Parliament and current chair of the women and equalities committee, Maria Miller, has recently stated (January 2016) that she is in favour of removing the need to state one's gender in matters such as driving licences, passports and job

⁴⁶ Marriage (Same-Sex Couples) Act 2013.
<http://www.legislation.gov.uk/ukpga/2013/30/contents/enacted/data.htm>
Accessed 29/05/2016.

⁴⁷ Dunne, above, n 43, discussing Marriage (Same-Sex Couples) Act 2013, Schedule 5, Pt 1, s3 (6A) (6B) (6C).
<http://www.legislation.gov.uk/ukpga/2013/30/schedule/5/enacted> Accessed 29/05/2016.

⁴⁸ Dunne, above, n 43, discussing Marriage and Civil Partnership (Scotland) Act 2014. <http://www.legislation.gov.uk/asp/2014/5/contents/enacted> Accessed 29/05/2016.

⁴⁹ Applying for a Gender Recognition Certificate, above, n 37.

applications, making these gender neutral.^{50, 51} The report on the enquiry that she instigated looking into many matters concerning transgender equality is now published.⁵² Therefore this situation may undergo change in the future, though as the law stands, gender in English law is either male or female.

The Gender Recognition Act attracts criticism because it stipulates an age of 18 years old before legal transition can start. Further, there is a requirement for a medical diagnosis of gender dysphoria in order to begin legal transition.⁵³ There is certainly a call from some to dispense with the need for medical input and substitute self-declaration (as Denmark and Malta do).⁵⁴ Argentina passed a law permitting self-identification of gender in 2012⁵⁵ and Colombia, South America, did so in 2015.⁵⁶

⁵⁰ This is not primarily a move to permit intersex people to identify as such but a change that would help all people who identify as a gender other than male or female. It would also be helpful to trans individuals in the process of transition who have not yet acquired legal recognition in their acquired gender. It is also information that is irrelevant for many purposes.

⁵¹ A Cowburn, 'Tory MP Maria Miller calls for gender-neutral driving licenses and passports (02/01/2016) *Independent* (<http://www.independent.co.uk/news/people/tory-mp-maria-miller-calls-to-remove-gender-from-uk-passports-and-driving-licences-a6793806.html>) Accessed 29/05/2016.

⁵² House of Commons Women and Equalities Committee, Transgender Equality, 14th Jan 2016 (<http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf>) Accessed 29/05/2016.

⁵³ Dunne, above, n 43.

⁵⁴ Dunne, above, n 43.

⁵⁵ Transgender Europe, 'Argentina Gender identity Law' (<http://tgeu.org/argentina-gender-identity-law/>) Accessed 29/05/2016.

⁵⁶ N Duffy, 'Colombia's new gender recognition law doesn't require surgery' (12/06/2015) *Pink News* (<http://webcache.googleusercontent.com/search?q=cache:mRkiBS4hhZoj:www.pinknews.co.uk/2015/06/12/colombias-new-gender-recognition-law-doesnt-require-surgery/+&cd=1&hl=en&ct=clnk&gl=uk&client=safari>) Accessed 29/05/2016.

Sweden and Norway are to do this in the next year⁵⁷ and Belgium has declared an intention to do so.⁵⁸ Ireland passed the Gender Recognition Act 2015 on 22nd July 2015, based on the Argentinian Law.⁵⁹ This permits persons of 18 years and above⁶⁰ to self-declare their gender. They must apply to the Minister for Social Protection by completing a simple two-page form. The Irish Act also permits young persons aged 16-18 years to apply for recognition in the gender in which they identify, though here there must be a court application, those with parental responsibility must consent (where possible) and information from two medical practitioners is required.⁶¹ In England, a petition to Parliament was set up to test support for allowing transgender people to self-define their legal gender. Had it attained 100,000 signatures, debate in Parliament might have taken place. However, the petition is now closed and the number of signatories fell short of this figure.⁶²

Whilst gender law has undergone major reforms over the past twelve years or so, there has been no change at all in the law concerning infantile genital surgery during this period and there has been little change in clinical practice.⁶³ Despite this, there is growing awareness of

⁵⁷ M O'Toole, M, '6 reasons why the UK's gender laws are failing transgender people' *Pink News* (15/10/2015) <http://www.pinknews.co.uk/2015/10/15/6-reasons-why-the-uks-gender-laws-are-failing-transgender-people/> Accessed 29/05/2016.

⁵⁸ O'Toole, above, n 57.

⁵⁹ Gender Recognition Act 2015. <http://www.irishstatutebook.ie/eli/2015/act/25/enacted/en/html> Accessed 29/05/2016.

⁶⁰ Gender Recognition Act 2015, above, n 59. Pt 2, s9 (2).

⁶¹ Gender Recognition Act 2015, above, n 59. Pt 2 s12.

⁶² Petition: Allow transgender people to self-define their legal gender. <https://petition.parliament.uk/petitions/104639> The petition is closed having obtained 35,351 signatures, so did not reach the target. Accessed 29/05/2016.

⁶³ L Michala, L-M Liao, D Wood, GS Conway & SM Creighton, 'Practice changes in childhood surgery for ambiguous genitalia' (2014) 10 *Journal of Pediatric Urology* 934-940.

the potential harm that may result from such procedures and there are a number of International Human Rights Instruments, discussed in the next section, that hold intersex people to be particularly vulnerable to unnecessary medical procedures. I am now going to discuss the lawfulness of genital surgery, particularly where it involves children.

Case law and statute relevant to genital cutting

As will be demonstrated later in this chapter and also in my paper, 'When parents choose gender'⁶⁴ (Chapter 7 of this thesis) there is no judgment from the English Courts expressly relating to the legality of intersex surgery on infants. There is however a growing awareness of the potential harms of surgery of this type. I will begin this section by discussing some International Human Rights Instruments that are of relevance to intersex and then I will discuss some of the case law and statutes that relate specifically to intersex from other jurisdictions. I will then discuss some of the jurisprudence associated with the related area of male circumcision and female genital mutilation.

Relevant International Human Rights Instruments

Over the years there have been several human rights instruments that might be considered to be of relevance to intersex surgery and some of them may also be relevant to male circumcision and female genital mutilation. The *Convention on the Rights of the Child*⁶⁵ was adopted by the General Assembly of the UN in 1989 (but is not incorporated into domestic law in England). This carried obligations not to discriminate on the grounds of sex and, in all actions concerning children, held that the best interests of the child should be paramount. The child's opinion should be taken into account in all matters concerning them and the

⁶⁴ M Newbould, 'When parents choose gender: intersex, children and the law' Accepted for publication in *Medical Law Review* (2016).

⁶⁵ United Nations Human Rights, 'Convention on the Rights of the Child' <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx> Accessed 29/05/2016.

child's right to privacy should be protected. Though not mentioned specifically in the *Convention*, all of these stipulations may be breached by many instances of intersex surgery, where the primary aim is to alter appearance rather than avert an immediate threat to life.⁶⁶ Possibly, other forms of genital cutting might also be regarded as in breach of them.

Article 24(3) of the *Convention on the Rights of the Child*⁶⁷ concerns the obligation of states to abolish practices harmful to the health of children.^{68, 69} The Convention itself does not include any list of what sort of procedures this might involve, but the implication is that it involves the practices listed in the United Nations document concerning *Harmful traditional Practices affecting the Health of Women and Children*.⁷⁰ The procedures mentioned include female genital cutting, facial scarification, early marriage and dowries. It has been pointed out that the practices listed are now practised almost exclusively in non-Western countries.⁷¹ In contrast to the attitude taken to female genital cutting, the committee has failed to make any comments specifically regarding male ritual circumcision.⁷²

Much more recently, there are signs that the movement to protect intersex individuals is growing and their situation is gaining recognition by

⁶⁶ JA Greenberg, 'International Legal Developments protecting the Autonomy Rights of Sexual Minorities' in SE Sytsma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006) 87-102, 92-94.

⁶⁷ United Nations Human Rights, above, n 65.

⁶⁸ J Tobin, 'The international obligation to abolish traditional practices harmful to children's health: what does it mean and require of states?' (2009) 9 (3) *Human Rights Law Review* 373-396.

⁷⁰ Tobin, above, n 68. The document under discussion is United Nations, 'Fact Sheet 23. harmful traditional practices affecting the health of women and children' <http://www.ohchr.org/Documents/Publications/FactSheet23en.pdf> Accessed 29/05/2016

⁷¹ Tobin, above, n 68.

⁷² Tobin, above, n 68.

major international bodies involved in healthcare, such as the United Nations (UN), World Health Organisation (WHO) and European Union (EU). As yet this has not had any effect on UK medical practice. In March 2014, intersex activists held the first UN event on the human rights of people with intersex.⁷³ There was a call to end ‘normalising’ genital surgery.⁷⁴ The WHO has recently published a paper on forced sterilisation (gonadectomy rather than genital surgery) and has recognised that intersex (and transgender) individuals form a group that are especially vulnerable to this.⁷⁵ The Special Rapporteur on Torture at the UN has called for special protection for lesbian, gay, bisexual, transgender and intersex (LGBTI) individuals in medical situations, including normalising surgery and procedures that result in sterilisation carried on intersex individuals without their consent.⁷⁶ The *Yogyakarta Principles*⁷⁷ address a broad range of matters concerning International Human Rights Law and its application to sexual orientation and gender identity. Principle 18 is relevant to intersex surgery:

Take all necessary legislative, administrative and other measures to ensure that no child’s body is irreversibly altered by medical

⁷³ W O’Brien, ‘Can international human rights law accommodate bodily diversity’ (2015) 15 (1) *Human Rights Law Review* 1-20.

⁷⁴ O’Brien, above, n 73.

⁷⁵ WHO ‘Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement’ (2014) http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf 7. Accessed 29/05/2016.

⁷⁶ JE Méndez, ‘Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or Punishment’ (1 February 2013) United Nations General assembly, Document A/HRC/22/53 page 23 paragraph 88 This looks specifically at human rights abuses in the health care setting. Accessed 04/06/2016. http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf Accessed 04/06/2016.

⁷⁷ United Nations, ‘The Yogyakarta Principles; the application of International Human Rights Law in relation to sexual orientation and gender identity’ <http://www.yogyakartaprinciples.org> Accessed 29/05/2016.

procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration.⁷⁸

Though, as yet, very few governments have taken action on this, the Chilean Ministry of Health has very recently (January 2016) instructed doctors to stop carrying out ‘normalising’ genital procedures on intersex children.⁷⁹ This *could* be the first of other prohibitions.

In 2014, the European Union Agency for Fundamental rights published *The Fundamental Rights Situation of Intersex People*.⁸⁰ This document states that:

EU Member States should avoid ‘sex-normalising’ medical treatments on intersex people without their free and informed consent. This would help prevent violations of the fundamental rights of intersex people, especially through practices with irreversible consequences.⁸¹

Specific Statutes in the EU countries

It is only in Malta that something approaching the above has been integrated into domestic law. On the 1st April 2015 Malta introduced a reform in law regarding intersex children, the Gender Identity, Gender

⁷⁸ United Nations, above, n 77, at 18 (b)

⁷⁹ Morgan, ‘Chilean Ministry of Health issues instructions stopping ‘normalising’ interventions on intersex children’ (11/01/2016) <https://oii.org.au/30250/chilean-ministry-stops-normalising/> Accessed 29/05/2016.

⁸⁰ FRA Focus, ‘The fundamental rights situation of intersex people’ <http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> Accessed 29/05/2016.

⁸¹ FRA Focus, above, n 80, 8

Expression and Sex Characteristics Act.⁸² This Act set out stringent requirements for surgical intervention in intersex children who are not old enough to consent. The child must be cared for by an interdisciplinary team, appointed by a Government Minister including those professionals that the minister feels are appropriate. The child can express an opinion (if sufficiently mature to do so), but any treatment must be considered by the team to be in the child's best interests and must be deferred if at all possible until the child can consent. Surgery may be carried out in exceptional circumstances when there is an agreement between the medical team and those with parental authority and must not be based only on social factors.⁸³ The assumption is therefore that surgery must not be carried out primarily to alter appearance but must fulfil a medical purpose, such as urinary diversion in a child with urethral obstruction.

Intersex case law throughout the world.

These cases are all from outside England. There is an emerging jurisprudence regarding intersex surgery, but it seems that wherever the specific issue regarding its lawfulness has been considered it has eventually been held to be lawful. The international human rights instruments referred to above suggest that change is needed and, as I try to suggest in my paper, 'When parents choose gender' (Chapter 7), it may be argued that early surgery is not always in the child's best interests and therefore possibly unlawful. However, it remains a part of standard medical care. For example, a recent study has shown there has

⁸² United States affiliate of the Organization Intersex International website, 'Huge Intersex Rights Victory in Europe: Malta bans Intersex Genital Mutilation' (2 April 2015), <http://oii-usa.org/2432/press-release-intersex-rights-victory-in-europe/> referring to the Gender identity, Gender Expression and sex Characteristics Act 2015 <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1> Accessed 29/05/2016.

⁸³United States affiliate of the Organization Intersex International website, above, n 82.

been very little practice change regarding infantile clitoral surgery over the past 12-13 years.⁸⁴

In Colombia, genital surgery was briefly *not* permitted following the first of the cases that I also discuss in 'When parents choose gender' (Chapter 7).⁸⁵ I discuss this here again just to make the point that the prohibition applied to any form of genital surgery that might be considered to affect gender identity following this first case was *temporary*. There was no permanent moratorium. This case involved a teenage boy (*the Decision of YY*) who had suffered penile ablation in a medical accident during a circumcision, just like David Reimer.^{86, 87} Following this, his parents consented to treatment, including a 'sex change', which went ahead in 1981. However, he was unhappy living as a female and during his teenage years, sued the hospital and doctors who had suggested he live as a female and carried out the surgery. The Constitutional Court of Colombia held that the doctors who cared for him following the accident had violated his right to his identity.⁸⁸ The Court cited Article 8 of the United Nations *Convention on the Rights of the Child*, emphasising the State's role in protecting the identity of children.⁸⁹ The court further suggested that there should be a moratorium on surgery until the child was able to give his or her own consent.⁹⁰ The point that I want to emphasise here is that when genital surgery on two further children (both

⁸⁴ Michala & others, above, n 63.

⁸⁵ Newbould, 'When parents choose gender: intersex, children and the law', above, n 64, chapter 7, 223.

⁸⁶ R White, 'Preferred private parts: importing intersex autonomy for *MC v Aaronson*' (2013) 37 *Fordham International Law Journal* 777-821, discussing *The Decision of YY* Corte Constitucional [CC] [Constitutional Court], octubre 23, 1995, Sentencia T-477/95, Gaceta de la Corte Constitucional [GCC] (Colom.)

⁸⁷ Information and discussion also to be found at Intersex Society of North America website. <http://isna.org/node/21>, (Accessed 29/06/2016).

⁸⁸ White, above, n 86.

⁸⁹ White, above, n 86.

⁹⁰ White, above, n 86.

with intersex conditions) came to be considered by the Constitutional court (*The Decision of XX and The Decision of NN*),⁹¹ the moratorium was overturned and the court held that surgery could take place with parental consent, providing this was sufficiently well informed.⁹² Therefore the ban on surgery was short lived. The process that replaced it, one of surgery following parental consent (which should include abundant information, provided over a prolonged period) was very influential in determining the model adopted by the Consensus statement.⁹³

Since this period in the 1990s, courts in Australia,⁹⁴ South Carolina in the US⁹⁵ and Cologne in Germany,⁹⁶ have considered surgery in intersex persons. In several cases the major issue has been gonadal or uterine surgery (or both), rather than genital surgery, and the individuals concerned have been well past infancy. *Völling* was a case that came before Germany's Cologne Regional Court in 2008 and concerned an adult woman with an intersex condition.⁹⁷ She was born with ambiguous

⁹¹ White, above, n 86. The cases are *The Decision of XX* Corte Constitucional [CC] [Constitutional Court], May 12, 1999, Sentencia SU- 337/99, Gaceta de la Corte Constitucional [GCC] (Colom.) and *The decision of NN* Corte Constitucional [CC] [Constitutional Court], Aug 2, 1999, Sentencia T-551/99, Gaceta de la Corte Constitucional [GCC] (Colom.)

⁹² White, above, n 86.

⁹³ IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

⁹⁴ Greenberg, above, n 66, 98-99, discussing *Re A Family Court of Australia* [1993] 16 FLR 715

⁹⁵ White, above, n 86.

⁹⁶ White, above, n 86.

⁹⁷ White, above, n 86. Discussing *Re Völling, Regional Court Cologne, Germany* (6 February 2008). To be found at <http://icj.wpengine.netdna-cdn.com/wp-content/uploads/2008/02/In-re-Volling-Regional-Court-Cologne-Germany-English.pdf> Accessed 02/06/2016.

genitalia and had been raised as a boy.⁹⁸ When she was eighteen she needed surgery for acute appendicitis. During the procedure the surgeon discovered that she had a uterus and ovaries, which he removed without informing her or gaining her consent.⁹⁹ Nor did he inform her following the procedure. She started to transition to live as a female over twenty years after the surgery and discovered her medical history. Thirty years following this operation, Völling successfully sued the surgeon for ‘culpably violat[ing] her health and self-determination’.¹⁰⁰

There are a number of intersex cases in Australian jurisdictions but all are primarily concerned with the sterilising effects of gonadectomy. In all cases involving children, *Marion’s case (1992)* (the commonly used name for *Secretary of the Department of Health and Community Services v JWB and SMB*¹⁰¹) must always be considered where a nontherapeutic surgical procedure is invasive, irreversible and where there is a possibility of making the wrong decision.¹⁰² This is a sterilisation case, not directly concerned with intersex but it is highly relevant to gonadectomy so therefore *probably* applicable to such procedures in intersex children. ‘Marion’ was 14 years old at the time and her parents wished her to have her uterus and ovaries removed, in order to effect sterilisation. She suffered from epilepsy, learning difficulties and deafness. The High Court of Australia decided that those with parental responsibility do not have the authority to consent to such a procedure but the authority of the courts was also needed.¹⁰³ Whilst some might argue that there are medical

⁹⁸ White, above, n 86.

⁹⁹ White, above, n 86.

¹⁰⁰ White, above, n 86.

¹⁰¹ *Secretary of the Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218.

¹⁰² T Bennett, *Cuts and Criminality: body alteration in legal discourse* (Burlington: Ashgate publishing Company, 2015) (Kindle Edition) Chapter 5, Loc 3834 of 6169.

¹⁰³ *Secretary of the Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218.

reasons for gonadectomy in those with intersex, several medical teams have taken the decision that *Marion's case* might be applicable and have therefore applied to have the matter considered by the courts before proceeding with parental consent only.

A was a teenager (aged 14 years in 1993) with congenital adrenal hyperplasia who though raised as a girl (he had 46,XX chromosomes, ovaries and a uterus) was living as a male.¹⁰⁴ This is a similar situation to that considered in Scenario 3 (page 90) in Chapter 3. He sought gender realignment surgery and was supported by his family and surgeon. Court approval was sought because the surgery would result in sterility. Despite considerable worries that A was insufficiently mature to understand the procedure, the court decided to grant A's request, particularly since a psychologist had assessed that there was a problem of possible suicide if he were made to wait until attainment of the age of competence.¹⁰⁵ Though it appears on the face of it that this case was one in which the rights of an intersex child to determine his own future was upheld, in fact it is made clear that the court made the decision only on the psychological advice and had seriously considered denying the petition, on the grounds that in a few years A could decide for himself without the intervention of any court.¹⁰⁶ Greenberg cites this case as evidence of how difficult it can be for courts to understand the medical and psychological issues involved in intersex and how this can easily lead to a misunderstanding and erroneous decision.¹⁰⁷

More recent Australian cases have included *Re Lesley (Special Medical Procedure)* [2008]¹⁰⁸ and *Re Sally (Special Medical Procedure)* [2010].¹⁰⁹

¹⁰⁴ Greenberg, above, n 66, 98-99.

¹⁰⁵ Greenberg, above, n 66, 98-99.

¹⁰⁶ Greenberg, above, n 66, 98-99.

¹⁰⁷ Greenberg, above, n 66, 98-99.

¹⁰⁸ *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226.

Both involved parents seeking authorisation for gonadectomy in children with undescended testes who were to be raised as female. In *Re Sally*, Murphy J also authorised cosmetic (presumably genital) treatment for her, but it was not clear that court authorisation would have been necessary had sterilisation not been part of the procedure.¹¹⁰ She was, however, 15 years old at the time, so presumably may have had involvement in the decision making process.¹¹¹

There is one case in the US courts that is under way as I write this and, in part, it is concerned with genital surgery. *MC v Aaronson* concerns MC (also known as Crawford) who was 8 years old in 2013.¹¹² He sought redress in the Courts of South Carolina (through his adoptive parents), complaining that surgery that he had undergone when aged sixteen months of age had violated his constitutional rights to self-determination.¹¹³ MC had been born with both male and female gonadal tissue. His biological parents had decided to give up their parental rights when he was an infant and his adoptive parents gained custody of him in December 2006. Before his adoption, his medical team had decided that he should be regarded as a girl and a surgeon, Dr Aronson, carried out feminising surgery on his external genitalia.¹¹⁴ At the time his social work team had parental authority and gave consent to the surgery. His adoptive parents considered he was not happy living as a girl and were planning to bring him up as a boy. In January 2015, his complaint was dismissed in the Court of Appeals for the Fourth circuit. The court decided that since there was no precedent, it would not have been clear to the surgeon that carrying out such surgery would have violated the

¹⁰⁹ *Re Sally (Special Medical Procedure)* [2010] FamCA 237.

¹¹⁰ Bennett, above, n 102, Loc 3859 of 6169

¹¹¹ *Re Sally (Special Medical Procedure)* [2010] FamCA 237

¹¹² White, above, n 86.

¹¹³ White, above, n 86.

¹¹⁴ White, above, n 86.

child's constitutional rights. ¹¹⁵ This is however not necessarily the final decision and the matter is also under consideration by the State courts at the time of writing. ¹¹⁶

Therefore what can be concluded from this brief survey is that, whilst international human rights instruments are indicating increasing concern about genital and other surgeries carried out on children before they can give consent, as yet there is no case-law reflecting that this surgery might be considered unlawful and medical practice does not seem to have undergone any significant change. I will now consider the related area of law concerning other forms of genital cutting.

Lawfulness of non-medical male circumcision in those too young to consent

Male circumcision might be considered to share common features with intersex surgery, as I discuss in Chapter 3. I also briefly consider the lawfulness of male circumcision and female genital mutilation in Chapter 3 and I discuss the case law concerning male circumcision in my paper 'When parents choose gender'¹¹⁷ (Chapter 7).

First, in this section, I will consider here the reasoning behind the presumed lawfulness of male circumcision carried out on those too young to consent. The view taken by the English courts so far is that the male circumcision is assumed to be lawful ¹¹⁸ though frequently carried out on infants and children too young to give consent. Though not currently prohibited in any jurisdiction, this assumption of lawfulness has been

¹¹⁵ *MC v Aronson*. Update 2015
<http://blogs.law.harvard.edu/billofhealth/2015/03/05/m-c-v-aaronson-update/>

¹¹⁶ *MC v Aronson*. Update 2015
<http://blogs.law.harvard.edu/billofhealth/2015/03/05/m-c-v-aaronson-update/>

¹¹⁷ Newbould, 'When parents choose gender: intersex, children and the law', above, n 64, (chapter 7, 220).

¹¹⁸ British Medical Association, 'The law and ethics of male circumcision: guidance for doctors' (June 2006), s4.1, p2 (previously published in (2004) 30 *Journal of Medical Ethics* 259-264).

questioned both in academic literature¹¹⁹ and in the Courts of at least one other jurisdiction (see page 149). The British Medical Association (BMA) states 'parents should be entitled to make choices about how best to promote their children's interests, and it is for society to decide what limits should be imposed on parental choices.'¹²⁰ Revised guidelines were issued in 2006,¹²¹ reiterating that both parents (if there are two and both hold parental responsibility) must give consent for non-medical male circumcision on their child.¹²² These guidelines represent the current advice to doctors, though issued ten years ago. Any case where there is parental disagreement should be referred to the courts.¹²³ It is acknowledged that the procedure carries medical and psychological risks and that definite medical benefit has not been convincingly proven.^{124,125} However, social and cultural circumstances play a part in the balance; if the boy is brought up in a culture where circumcision is the norm, he may suffer by exclusion. This is precisely the same argument as that used by Jomo Kenyatta (the first Prime Minister of Kenya, first president of Kenya

¹¹⁹ H Gilbert, 'Time to Consider the Lawfulness of Ritual Male Circumcision' (2007) 3 *European Human Rights Law Review* 279-294.

¹²⁰ British Medical Association, above, n 118, s4, p1.

¹²¹ British Medical Association, above, n 118, s4, p1.

¹²² British Medical Association, above, n 118, s4.2.2, p3.

¹²³ British Medical Association, above, n 118, s4.2.2, p3.

¹²⁴ British Medical Association, above, n 118, s4, p1.

¹²⁵ It has been suggested that that circumcision in the newborn period may carry medical benefits (such as a lower risk of diseases such as urinary tract infections, penile cancer and transmission of some sexually transmitted infections such as HIV) and that the benefits may outweigh the risks. For example, the American Academy of Pediatrics Task Force on Circumcision, 'Circumcision Policy Statement' (September 2012) 130 (3) *Pediatrics* 585-586. Nonetheless, this report points out that the benefits are not sufficiently large to warrant routine neonatal circumcision for health reasons alone. The British Medical Association takes the view that '[a]t present, the medical literature on the health, including sexual health, implications of circumcision is contradictory, and often subject to claims of bias in research.' See 'The law and ethics of male circumcision: guidance for doctors', above, n 118, s4.4, p4.

and also an anthropologist) concerning ritual female circumcision as practised in Kenya.¹²⁶

The three cases of male circumcision considered by the English courts, *Re J*^{127,128}, *S (Children)*¹²⁹ and *Re S (change of names: cultural factors)*¹³⁰, all involved parental disagreement. I discuss these also in the paper, 'When Parents choose gender',¹³¹ but I consider the specific question regarding the lawfulness of male circumcision in England in more detail here. In *Re J* one of the first questions considered by Wall J was whether ritual male circumcision carried out on an infant is lawful. One of the few statements considering this occurs in *Brown*; Lord Templeman says, in passing, that 'Ritual circumcision, tattooing, ear-piercing and violent sports including boxing are lawful activities'.¹³² These activities are all very different and in the context of *Brown* he was considering the limits of what an *adult* could consent to, so these comparisons are not relevant to an infant. Parents may decide to have their infant's ears pierced, but boxing and tattooing are in a different category and are practised by consenting adults; tattooing is illegal unless the person has actually consented and is aged over 18 years.¹³³ Clearly, however, Lord Templeman saw male circumcision as something that is lawful, with valid consent.

¹²⁶ R Cerny Smith, 'Female Circumcision: bringing women's perspectives into the international debate' (1992) 65 *Southern California Law Review* 2449-2504.

¹²⁷ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345

¹²⁸ *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307 regarding the decision in the Court of Appeal.

¹²⁹ *Re S (Children)* [2004] EWHC 1282 (Fam)

¹³⁰ *Re S (change of name: cultural factors)* [2001] 3 FCR 648

¹³¹ Newbould, 'When parents choose gender: intersex, children and the law', above, n 64, Chapter 7, 220.

¹³² Lord Templeman in *R v Brown* [1993] 2 All ER 75 at 78-9.

¹³³ Tattooing of Minors Act 1969.

Wall J then considered a Law Commission report, which endorsed the view that circumcision is lawful:

it is generally accepted that removal of the foreskin has little, if any, effect on a man's ability to enjoy sexual intercourse, and this act is not therefore, regarded as a mutilation. ¹³⁴

As Howard Gilbert points out, it does not follow that something is not a mutilation because it does not interfere with the ability to enjoy sexual intercourse. ¹³⁵ The Law Commission did not quote any legal authority; rather, it appeared that the procedure was simply assumed to be lawful. An unreported case from the criminal court concerning Mrs Felicia Adesanya¹³⁶ was cited. She was charged with assault to her sons aged 14 and 9 years, when, with the boys' consent, she inflicted minor razor cuts on their faces in line with a Yoruba custom. The family were Christians and following the cutting they dressed in ceremonial robes and all took part in an act of worship. King-Hamilton J argued that the fact that this was a Yoruba custom could *not* be held as a defence and that the procedure carried the potential for serious injury to the eye.¹³⁷ This was stated to be in contrast with circumcision which *would* be considered in the child's interests and therefore lawful, though it is difficult to see quite why there might be a difference as far as the child's best interests are concerned. It is also interesting to consider if there really is any evidence that facial scarification might be associated with serious injury, in contrast to circumcision, which certainly is potentially harmful.

¹³⁴ Law Commission Consultation Paper No. 139, *Criminal Law, Consent in the Criminal Law* (1995), Can be found at https://sexualitymatters.files.wordpress.com/2013/01/cp139_pt09.pdf Accessed 30/05/2016) 9.2

¹³⁵ Gilbert, above, n 119.

¹³⁶ AS Diamond & P Lloyd, 'The case of Mrs Adesanya' (Sep-Oct 1974) 4 *Royal Anthropological Institute of Great Britain and Ireland* 2 http://www.jstor.org/stable/3032371?seq=1#page_scan_tab_contents Accessed 30/05/2016.

¹³⁷ Law commission Consultation Paper No. 139, above, n 134, 9.14.

Wall J then considered other authorities such as the British Medical Association Guidance for Doctors in which the lawfulness of male circumcision was simply accepted and, as mentioned above, this continues to be the position held by the BMA.¹³⁸ He then considered the legal position of female circumcision, which he felt was:

undoubtedly a mutilation, which is designed to control female sexuality and which, when performed without anaesthetic, with crude cutting instruments and with few or no precautions against infection is life-threatening.¹³⁹

He acknowledged that there is a body of medical opinion that equates male circumcision with this. Overall the result of his consideration of these precedents and authorities was that he held that male circumcision was generally considered lawful. The specific circumstances of the three cases that have come under consideration in the English courts and the resulting decisions are considered in the paper 'When parents choose gender'.¹⁴⁰

The position in England is, therefore, that male circumcision carried out on a child is lawful if the child is to be brought up in an appropriate cultural setting and providing both parents give their consent. It may, under some circumstances be lawful, even if only one parent consents, providing that the other parent does not actively object to the procedure and providing the procedure is carried out in what is deemed the best interests of the child rather than the parent. Though, of course, the detailed issues surrounding the child's best interests are only scrutinised if there is a parental dispute. Howard Gilbert¹⁴¹ notes that the possibility that it might *never* be in the interests of a male child to undergo

¹³⁸ British Medical Association, above, n 118, 4.1, p2.

¹³⁹ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 357

¹⁴⁰ Newbould, 'When parents choose gender: intersex, children and the law', above, n 64. (In this thesis, see chapter 7, 220)

¹⁴¹ Gilbert, above, n 119.

ritual circumcision *even if* both parents consented to it has not been considered. In the case of infant circumcision it is extremely unlikely that any case where both holders of parental responsibility wish the procedure to take place would ever come to court, because if there is no disagreement then there is no one to bring the case, unless other relatives decided to intervene. Having reached the age of 18 years, the child himself could decide to challenge the lawfulness of the procedure and sue his parents and practitioners involved for battery. A similar case in the US¹⁴² involved William Stowell, aged 19 years, who filed a lawsuit for battery against the obstetrician who circumcised him as an infant, on the grounds that the procedure was unnecessary and was not done with appropriate consent; this was settled out of court so the lawfulness of the procedure or the validity of his claims were not reported. Therefore so far, there has been no opportunity to air these matters in the courts in England.

There is evidence that children may be afforded protection by the Human Rights Act 1998.¹⁴³ Gilbert suggests that *R. (on the application of Williamson) v Secretary of State for Education and Employment*¹⁴⁴ may have relevance here. A group of parents and teachers at a Christian Independent School stated that they held a fundamental belief that a Christian education meant that teachers had to be able to administer physical punishment to children who were guilty of indiscipline; they felt that the Education Act 1996, which extended the ban on corporal punishment to independent schools, was impeding their Right to religious freedom in accordance with Article 9 of the Human Rights Act 1998. Whilst it was accepted that this was part of their religious belief and that

¹⁴² ABC News, 'Man Sues For loss of Foreskin'
<http://abcnews.go.com/GMA/story?id=127183> Accessed 30/05/2016.

¹⁴³ A Opromolla, 'Children's rights under Articles 3 and 8 of the European Convention: recent case law' (2001) 26 [Supp (Human Rights)] *European Law Review* 42-57.

¹⁴⁴ *R (on the application of Williamson and others) v secretary of State for Education and Employment and others* [2005] 2 All ER 1.

the Education Act did interfere with that right, the House of Lords considered that this was justified because the Education Act was there to protect vulnerable children from harm. Might this be relevant to male ritual circumcision? *Williamson* involved parents pursuing their religious freedom to a point in which there was a strong possibility of physical harm to their offspring and the courts found this was unacceptable. There are parallels with male circumcision here. However, it seems unlikely that a similar claim involving circumcision would be successful given its presumed lawfulness and the assumption that it usually *is* in the best interests of the male infant to be circumcised if his parents wish him to be so, but such a claim would permit this issue to be fully aired in the courts.

Male circumcision in other jurisdictions and the English Criminal Court

The lawfulness of male circumcision has been considered in other jurisdictions, but the situation is rather like that in infantile genital surgery in intersex. Though there was a brief period in which male ritual circumcision was banned and considered unlawful (in Cologne, Germany), the ban was rapidly overturned so, as far as I am aware, it is not currently unlawful in any jurisdiction. I will discuss the events in Germany of a few years ago.

Infantile male circumcision in Cologne, 2011-2013.

A case reached the courts in Germany that resulted in criminalisation of non-medical male circumcision for a brief period of time. The case concerned a 4-year-old boy who was circumcised by a doctor in Cologne at the request of his parents, who adhered to the Islamic faith.¹⁴⁵ The child bled and needed treatment from a hospital in the city.¹⁴⁶ The

¹⁴⁵ K Dyer, 'Lessons from Germany: should UK legislation circumnavigate or circumvent the issue of male circumcision?' (2013) 25 *Denning Law Journal* 225-239.

¹⁴⁶ Dyer, above, n 145.

hospital doctors treating him became uneasy about the validity of consent for the procedure and informed the prosecution service.¹⁴⁷ Though it was conceded that there had been no negligence, an expert gave evidence to the effect that circumcision is not a procedure required to promote health care and the prosecution service charged the doctor conducting the circumcision with 'causing bodily harm to another using a dangerous instrument' and a lesser charge of 'causing bodily harm'.¹⁴⁸ The first instance court found the consent valid but decided that the criteria for the lesser charge *were* met.¹⁴⁹ However it was felt that overall the procedure was beneficial, for both general and, medical reasons (contravening the medical opinion) and the doctor performing the procedure was acquitted, as it was held that his actions would result in positive consequences for the child.¹⁵⁰

The Cologne prosecution service appealed.¹⁵¹ The appeal court made the decision that male circumcision for non-medical reasons fulfilled the conditions for battery in criminal law, even if both parents consented.¹⁵² It was considered that for such a procedure parental consent was insufficient as circumcision could be considered to infringe the religious rights of the individual.¹⁵³ It required consent from the child, so could not be carried out if the child was too young to consent to it.¹⁵⁴ The implication was that, in future, those performing ritual male circumcision in the absence of consent of the individual undergoing the procedure

¹⁴⁷ Dyer, above, n 145.

¹⁴⁸ Dyer, above, n 145.

¹⁴⁹ Dyer, above, n 145.

¹⁵⁰ Dyer, above, n 145.

¹⁵¹ Dyer, above, n 145.

¹⁵² Dyer, above, n 145.

¹⁵³ Dyer, above, n 145.

¹⁵⁴ Dyer, above, n 145.

would be carrying out an unlawful act. However, once again the doctor involved in this particular case was acquitted, as the court decided that, in the absence of any clear jurisprudence to follow, he could not have been aware that his actions were unlawful.¹⁵⁵

The German Medical Association found the appeal court decision that circumcision was unlawful an astonishing and worrying development.¹⁵⁶ They considered that this declaring circumcision unlawful could lead to an increase in ‘backstreet’ procedures and thereby an increased likelihood of harm to minors circumcised for non-medical reasons.¹⁵⁷ The German *Bundestag* announced in July 2012 that circumcision for religious reasons could still be lawful. The Bill was passed in December 2012¹⁵⁸ coming into force on 01 January 2013. The Bill made it clear that parental authority did permit non-therapeutic circumcision on that child, so long as the procedure is carried out to medical standards. In the first 6 months of life, the procedure can be performed by a non-medical practitioner nominated by the religious community, provided this person is appropriately trained to a medical standard of competency.¹⁵⁹

The criminal court in England

In recent years there have been occasional deaths associated with male ritual circumcision in England that have been reported to the Coroner’s office, though very few of these have resulted in subsequent criminal or civil proceedings.¹⁶⁰ Several infants have bled to death following the

¹⁵⁵ Dyer, above, n 145.

¹⁵⁶ Dyer, above, n 145.

¹⁵⁷ Dyer, above, n 145.

¹⁵⁸ Dyer, above, n 145.

¹⁵⁹ R Merkel & H Putzke, ‘After Cologne: male circumcision and the law. Parental right, religious liberty or criminal assault.’ (2013) 39 *Journal of Medical Ethics* 444-449.

¹⁶⁰ Dyer, above, n 145.

procedure. In at least one instance, there was a prosecution. The point of interest relevant to this thesis is that the lawfulness of the procedure was not questioned. Rather it was the degree of care given subsequent to it that was subjected to scrutiny. Goodluck Caubergs, a one-month-old infant, was circumcised at his home by Grace Adeleye in 2010 and bled to death within 24 hours of the procedure. She was found guilty of manslaughter by gross negligence, but the lawfulness of the procedure itself was not considered. ¹⁶¹

Female genital cutting.

Whereas intersex surgery on young children and male circumcision are both lawful, female genital mutilation (FGM) is unlawful in England. It is unlawful in many states, including eighteen African nations and many other industrialized nations. ¹⁶² I also discuss this in Chapter 3, chapter 5 and in the paper 'When parents choose gender'¹⁶³ (Chapter 7). In the present section, I discuss briefly some aspects of this law not covered in the other sections, including the attempted prosecution.

The Prohibition of Female Circumcision Act came into being in 1985. ¹⁶⁴ Under this Act it became an offence to:

excise, infibulate, or otherwise mutilate the whole or any part of the labia majora or labia minora or clitoris of another person

or to:

¹⁶¹ Dyer, above, n 145.

¹⁶² Center for Reproductive Rights, 'Female Genital Mutilation (FGM): Legal prohibitions worldwide. <http://www.reproductiverights.org/document/female-genital-mutilation-fgm-legal-prohibitions-worldwide> Accessed 30/05/2016.

¹⁶³ Newbould, 'When parents choose gender: intersex, children and the law', above, n 64, (chapter 7, 212).

¹⁶⁴ Though even without the Act the practice if performed on a minor, might have constituted a criminal assault under common law.

aid, abet or procure the performance by another person of any of these acts on that other person's own body'¹⁶⁵

The Female Genital Mutilation Act 2003 extended the penalties involved and also extended the range of offences to include assisting:

a person who is not a United Kingdom national or permanent United Kingdom resident to do a relevant act of female genital mutilation outside the United Kingdom.¹⁶⁶

It also includes a prohibition of United Kingdom nationals or permanent United Kingdom residents performing such procedures outside the United Kingdom.¹⁶⁷ This applies to women of *all* ages and consent is irrelevant – the procedure cannot be carried out even *with her consent*. There is a comparable Act in Scotland.¹⁶⁸ It is not an offence to carry out such a procedure on a woman 'if necessary for her physical or mental health' or if 'in any stage of labour or [if she] has just given birth, for purposes connected with the labour or birth'.¹⁶⁹ In such circumstances the operation must be carried out by a registered medical practitioner or a midwife (or someone on a relevant training programme).¹⁷⁰ Both the Scottish and English Act mention that in assessing a person's mental

¹⁶⁵ NH Morris, 'Female genital mutilation' (2008) 14 (5) *AvMA Medical & Legal Journal* 189-192.

¹⁶⁶ Female Genital Mutilation Act 2003 s3 (1)

¹⁶⁶ Female Genital Mutilation Act 2003 s3 (1)

¹⁶⁷ Female Genital Mutilation Act 2003, s4.

¹⁶⁸ Prohibition of Female Genital Mutilation (Scotland) Act 2005.

¹⁶⁹ Female Genital Mutilation Act 2003, s1 (2) (b); Prohibition of Female Genital Mutilation (Scotland) act 2005, s1 (4) (b).

¹⁷⁰ Female Genital Mutilation Act 2003, s1 (3); Prohibition of Female Genital Mutilation (Scotland) Act 2005, s1 (5).

health, no account is to be taken of any belief that FGM is ‘needed as a matter of custom or ritual.’¹⁷¹

Prosecutions for female genital mutilation have been reported in several African nations.¹⁷² In England, the first prosecution commenced in April 2014.¹⁷³ Dr Dhanuson Dharmasena pleaded not guilty to the accusation of having carried out an infibulation procedure on a woman in November 2012, after she had given birth. A second man, Hasan Mohamed, pleaded not guilty to encouraging the offence and to aiding and abetting it.¹⁷⁴ Counsel for Dr Dharmasena claimed that he was performing a repair procedure. The court agreed and found the defendant not guilty of any offence in February 2015.¹⁷⁵ The Crown Prosecution Service have had 11 cases referred to them in the past few years but have decided against prosecuting at least four of them, sometimes because the girl herself is unwilling to come to court to give evidence against her family.¹⁷⁶ It has been suggested that the Dr Dharmasena case is an unusual one to attempt to prosecute, since, given the clinical situation, he may have had few options but to attempt a repair¹⁷⁷ and, in any case, most cases of FGM take place in very different circumstances, involving traditional practitioners, rather than doctors. Only rarely does it involve

¹⁷¹ Female Genital Mutilation Act 2003 s1 (5); Prohibition of Female Genital Mutilation (Scotland) act 2005 s1 (6).

¹⁷² Center for Reproductive Rights, above, n 162.

¹⁷³ C Dyer, ‘First UK prosecution for female genital mutilation raises concerns among doctors’ (2014) *British Medical Journal BMJ* 2014;348:g2424 doi: <http://dx.doi.org/10.1136/bmj.g2424> Accessed 30/05/2016.

¹⁷⁴ Dyer, above, n 173.

¹⁷⁵ News Agency, NHS doctor cleared in less than 30 minutes in first FGM case (04/02/2015) *Telegraph* <http://www.telegraph.co.uk/news/uknews/law-and-order/11390629/NHS-doctor-cleared-of-performing-FGM-amid-claims-he-was-used-as-a-scapegoat.html> Accessed 30/05/2016.

¹⁷⁶ Dyer, above, n 173.

¹⁷⁷ Dyer, above, n 173.

freely consenting adult women.¹⁷⁸ The decision to prosecute this case has been under criticism and it has been suggested that it may not have adequately fulfilled the criteria for prosecution.¹⁷⁹

It does appear that the Act is not effective. For example in recent weeks, newspapers have contained reports of 632 new FGM cases presenting to seven hospitals in the West Midlands over a six-month period.¹⁸⁰ The Serious Crime Act 2015¹⁸¹ has been introduced to attempt to make the legislation more effective. Police must be informed of all cases of FGM identified in girls under 18 years. In addition there is requirement for health care professionals to submit patient identifiable data on all women of any age who present to them for whatever reason to the Department of Health (DOH). There is no requirement for the woman concerned to give her consent. It has been noted that there is uncertainty as to what the DOH will plan to do with the information and have not given adequate assurance that it will not be passed onto third parties.¹⁸²

¹⁷⁸ I realise there are problems with the notion of free consent with any form of appearance altering surgery. However, there is insufficient space to discuss this interesting point.

¹⁷⁹ J Roger, 'The first prosecution for FGM' *Criminal Law and Justice Weekly* 6th March 2015 <http://www.criminallawandjustice.co.uk/features/First-Prosecution-FGM> Accessed 30/05/2016.

¹⁸⁰ J Tyler, 'Over 600 new FGM cases in West Midlands in six months' (24/06/2015) *Birmingham Mail* <http://www.birminghammail.co.uk/news/midlands-news/over-600-new-fgm-cases-9518251> Accessed 30/05/2016.

¹⁸¹ The Serious Crime Act 2015. The following sections are relevant:
s70 Offence of female genital mutilation: extra-territorial acts,
s71 Anonymity for victims of female genital mutilation,
s72 Offence of failing to protect girl from risk of genital mutilation,
s73 Female genital mutilation protection orders,
s75 Guidance about female genital mutilation (from the Secretary of State, which may be issued from time to time regarding any matters concerning FGM).
s74 Duty to notify police of female genital mutilation, is the section of the Act that has attracted some criticism, (see Footnote 182).
<http://www.legislation.gov.uk/ukpga/2015/9/part/5/crossheading/female-genital-mutilation/enacted> Accessed 30/05/2016.

¹⁸² B Kelly & C Foster, 'Mandatory submission of patient information about FGM: a pointless, damaging, discriminatory mess' (2015) *Practical Ethics*

The relevance of this to intersex is that it serves to illustrate that it can be more difficult to prohibit procedures effectively, even if there is clear legislation. Though unlawful for over 30 years, there are still enormous problems in making the legislation effective.

The way forward for intersex?

Perhaps a helpful start to reform in medicine and in the wider society would be change in how intersex individuals are viewed in law. There are several ways in which the law could help. The first possibility is to utilise anti-discrimination law, either specific or, alternatively, to recognise that existing anti-discrimination law applies to intersex. I mention this only very briefly here, as detailed consideration would be outside the scope of this work. Anti-discrimination law might permit identification as the individual wished and would mean that those who wish can opt in.¹⁸³ It might not even be obligatory to identify as intersex, to claim that anti-discrimination law applied. Both disability and gender legislation might be considered applicable. Intersex could be considered in a similar way to a disability, giving a protected legal space but not necessarily relevant to how an individual chooses to identify.¹⁸⁴ This might be rejected on the grounds that many would consider that intersex is a difference only and does not necessarily carry any disadvantages, as might be implied by classification as a disability or illness. I have argued for the position that intersex is not an illness in chapter 4 and in my paper 'Intersex, medicine

<http://blog.practicaethics.ox.ac.uk/2015/10/mandatory-submission-of-patient-information-about-fgm-a-pointless-damaging-discriminatory-mess/> Accessed 30/05/2016.

¹⁸³ M Travis, 'Accommodating intersexuality in European Union Anti-Discrimination law' (March 2015) 21 (2) *European Law Journal* 180-199.

¹⁸⁴ Y Menon, 'The intersex community and the Americans with Disability Act' (2011) 43 (4) *Connecticut Law Review* 1221-1251.

and pathologisation'.¹⁸⁵ Law that oversees gender equality is seen as protecting those who identify as men or women, rather than those who fall outside this binary¹⁸⁶ but it has been suggested that it might be possible to interpret 'sex' more broadly than hitherto to include intersex individuals in sex discrimination law.¹⁸⁷ This would allow protection in circumstances broadly related to employment.¹⁸⁸

One route by which law might prove helpful is by providing specific protective rights in an analogous way to those that protect women.¹⁸⁹ However the International human rights Instruments supportive of the rights of intersex persons have not yet influenced medical practice to any great extent.¹⁹⁰

Legal intersex rights might include protection against the specific harms such as 'normalising' genital surgery or castration, so casting intersex people similarly to women, as a special class needing specific protections. If this were the case, then the legal category 'intersex' would be one characterised as 'victimized other'.¹⁹¹ O'Brien has pointed out that special protection reinforces those protected as 'other' and

¹⁸⁵ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180. See chapter 6.

¹⁸⁶ Travis, above, n 183.

¹⁸⁷ Travis, above, n 183.

¹⁸⁸ Travis, above, n 183.

¹⁸⁹ Specific legal rights for women are a relatively recent innovation, dating from 1947. Some scholars maintain that the characterisation of women in law is essentially that of an object needing protection in certain specific areas, rather than a fully human subject who bears rights. Whilst this model is useful in describing everyday realities for many, it inevitably carries an asymmetric representation, with women cast as injured and vulnerable and men cast as protectors or perpetrators. See D Otto, 'International human rights law: towards rethinking sex/gender dualism' in M Davies, & VE Munro (eds), *The Ashgate Companion to Feminist Legal Theory* (Burlington: Ashgate Publishing Company, 2013) Chapter 11.

¹⁹⁰ O'Brien, above, n 73.

¹⁹¹ O'Brien, above, n 73.

serves to emphasise that the universal subject of the law is male. Clearly this is a major problem, but the fact is that, though there may be difficulties with forming protective instruments, this does not mean that they should not be formed. 'The pursuit of the right to physical integrity for intersex individuals is urgent'.¹⁹² O'Brien sees that there would be advantages in both feminists and intersex advocates working together in order to challenge the simple and simplistic biological model on which much law is built.¹⁹³

It is possible that changes in the law in England might take place in the future. Maria Miller's recently published enquiry into transgender equality has suggested that the Government does need to consider how best to address the needs of intersex individuals.¹⁹⁴ Matters such as gender-neutral passports and other legal documentation were mentioned in the report as being of relevance to intersex people as well as to transgender individuals.¹⁹⁵

The next three chapters of this thesis comprise the three core papers that have been published or accepted for publication according to the requirements of the programme for the PhD in Bioethics and Medical Jurisprudence.

¹⁹² O'Brien, above, n 73.

¹⁹³ O'Brien, above, n 73.

¹⁹⁴ House of Commons Women and Equalities Committee, *Transgender Equality*, above, n 52, 5.

¹⁹⁵ House of Commons Women and Equalities Committee, *Transgender Equality*, above, n 52, 61.

CHAPTER 6

INTERSEX, MEDICINE AND PATHOLOGISATION¹

Introduction

In this chapter I examine a group of conditions that are included under the general heading *disorder of sex development*, but which used to be called intersex conditions and, prior to that, hermaphroditism. Most of these conditions include atypical genital anatomy, frequently described as *ambiguous*, because it is not entirely typical of either sex. Much of what I discuss relates to congenital adrenal hyperplasia (CAH), which is the most common form of intersex and which is therefore one of the conditions in this group that is most frequently discussed in medical, sociological, psychological and ethical literature. In 2006, the term *disorder of sex development* was introduced in the medical literature, its use suggesting that all such conditions were within the remit of medicine,² in place of the former and, possibly, more neutral term, intersex, which might also imply the possibility of existence outside the medical context.³ This has proved a matter of some controversy since not all of the people included in this category regard themselves as suffering from a medical disorder. In this chapter I will use the term intersex.

¹ M Newbould, 'Intersex, medicine and pathologisation' in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180.

² AK Spurgas, '(Un)Queering Identity: The biosocial production of Intersex/ DSD' in M Holmes (ed), *Critical Intersex* (Farnham: Ashgate Publishing Limited, 2009) 102.

³ LS Long, 'DSD vs Intersex' (2006) 91 *Archives of Diseases in Childhood*. Responses to Hughes et al 2006. <http://adc.bmj.com/content/91/7/554/reply> Accessed 30/05/2016.

Though for some writers such as Boorse ⁴ disease is a matter of using statistical methods to identify the subnormal and, in most circumstances, does not involve value judgment, intersex conditions are important in that they provide an illustration of how, in practice, medicine relies heavily on social norms in deciding what constitutes 'normal' or 'abnormal' function. All biological characteristics are subject to variation and this includes entities such as penile or vaginal length. Decisions regarding what is normal are treated as if they were biological facts but any cut-off point that separates the normal from the abnormal must be defined arbitrarily and frequently relies on social norms regarding appearance. This is also true in other aspects of medicine. To give some examples, there is the perceived need for leg lengthening procedures in the skeletal dysplasia, achondroplasia, in which the limbs are short ⁵ or a need to alter the position of ears that are unusually prominent, so that they lie closer to the head

Appearance-altering surgery was performed on the genitalia of intersex infants and young children from the 1950s onwards and continues to be performed, though with less frequency. This procedure is based on the assumption that there is a 'normal' appearance to be achieved through surgery. There is a further complication in intersex because genital appearance is usually considered to be straightforwardly tied to an individual's sex. I argue that this premise is false. In biological terms, it can be extremely difficult to identify the 'true sex' of an individual because the presence or absence of a Y chromosome is no longer the sole determiner of sex; multiple individual genes located on several different chromosomes are known to be involved. Whilst gender is also complex, it is simplified by the fact that most individuals know which gender they

⁴ C Boorse, 'On the distinction between disease and illness' (1975) 5 (1) *Philosophy and Public Affairs* 49-68. 58

⁵ ES Sanford, 'My shoe size stayed the same. Maintaining a positive identity with achondroplasia and limb-lengthening surgeries' in E Parens (ed), *Surgically Shaping Children. Technology, Ethics and the Pursuit of Normality* (Baltimore: The Johns Hopkins University Press, 2006) 29-42.

are and this applies to both intersex and non-intersex individuals. Gender is therefore evident from the child concerned as he or she grows and cannot be reliably predicted from anatomical characteristics in infancy. Performing early genital surgery on a child fails to take this into account. Surgical intervention also relies heavily on the assumption that the ability to perform heterosexual intercourse will be of major importance in the future life of the individual. This may or may not turn out to be true.

I argue that, far from achieving its intention of making those with intersex conditions more 'normal', medical attention and intervention has the effect of emphasising the supposed abnormality. In some cases, intersex individuals who have lived their lives under medical observation have written accounts relating how this attention made them feel different. For those who had early surgery, scars and other problems emphasised any perceptions of abnormality. There is also some evidence from medical anthropology studies that involved intersex individuals in other cultures. Here the observations required by the study seem to have had the effect of introducing the notion of pathology to an entity previously considered a rare but normal and accepted phenomenon.

I will start by examining some of the biology of CAH and other intersex conditions. This involves a more general discussion of sex and gender.

Sex and gender

In the mid-nineteenth century, doctors first discovered that some women had testes. At that time the reasons for this were not understood but it is now known that in such individuals the body is unable to respond to testosterone, the major hormone produced by the testes.⁶ In most

⁶ There are several reasons why this is so. In some cases there is a complete congenital and genetically determined absence of the cellular receptors needed to respond to androgenic (male type) hormones such as testosterone produced by the testis and other organs in the body. This leads to complete androgen insensitivity and to phenotypic females showing no male characteristics. In other cases there may be a genetic deficiency of some of the enzymes needed for the effects of testosterone in the cells of the organs forming secondary sex

individuals with testes, testosterone leads to the development of characteristics usually recognised as 'male', such as male type genitalia, facial hair, deep voice, and so on. These women had no male characteristics. One of the first women identified was a celebrated Parisian beauty and fashion model, LS.⁷ The discovery caused concern to the doctors who made it, because it disturbed their view of what made someone male or female. It was considered vital to be able to identify sex accurately so that there was no risk of same sex marriages taking place and persons of uncertain sex provided considerable disruption to the social order of the time.⁸ The women concerned were in no doubt that they were female and had sought medical assistance for infertility, rather than any uncertainty about their sex.⁹ This served as an illustration that it might not be so easy to identify an individual's sex; an organ such as the testis that usually is thought of as straight-forwardly male can be found in someone who has an unambiguously female appearance. For some writers this continues to be a problem; for Germaine Greer, for example, no one with testes can be female.¹⁰

The difficulties can be better appreciated via briefly considering what is generally known about sex and how this relates to intersex. In mammals there are four biological entities normally considered to identify sex: chromosomes, type of gonad (testes or ovaries), anatomy of the internal pelvic structures (the presence of a uterus, for example) and, most easily

characteristics. This leads to a partial androgen insensitivity because there will be some cells that can respond and others than are unable to. See for example K Karkazis, *Fixing sex. Intersex, medical authority and lived experience* (Durham: Duke University press, 2008) 24.

⁷ AD Dreger, *A History of Intersex: From the age of Gonads to the Age of Consent* in A Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group 1999) 5-22, 9.

⁸ Dreger, *A History of Intersex: From the Age of Gonads to the Age of Consent*, above, n 7, 9.

⁹ AD Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge Mass: Harvard University Press, 1998) 1-3.

¹⁰ G Greer, *The Whole Woman* (London: Anchor, 2000) 88.

determined, the anatomy of external genitalia. In intersex individuals, one or more of these four entities is of a different 'sex type' to the others. Congenital adrenal hyperplasia (CAH) is one of the commonest forms of intersex and also one in which unusual genital anatomy frequently occurs in females. The physiological situation is relatively simple; the chromosomes are of the usual female type (which means that there are 46 in total, two of which are X-chromosomes), the gonads are ovaries, a uterus and fallopian tubes are present but the external genitalia have a variable degree of masculinisation. One of the enzymes needed to manufacture steroid hormones in the adrenal cortex is congenitally absent, resulting in varying degrees of deficiency of steroid hormones. Those with this condition sometimes cannot retain salt in the body so are particularly vulnerable to acute problems manifesting as diarrhoea or vomiting and they need life-saving hormone replacement.¹¹ Because the normal hormonal pathway is blocked, side-products are produced in excess and these have a virilising effect, hence the change in genital anatomy and the enlargement of the clitoris. The hormone deficiency which forms one part of CAH is a genuinely life threatening disease. However, the unusual genital anatomy is not life threatening but, rather, something that can make the sex of an infant at birth difficult to determine. Girls with congenital adrenal hyperplasia do have a disease, but it is one that is easily treated by hormone replacement. I argue that in itself the unusual anatomy is not a disease. Rather, CAH is a form of intersex which has been medically addressed by an attempt to put the body 'right' by surgical intervention, often by clitoridectomy. Male infants can also have CAH. In this situation, the genitalia are also atypical in that these boys have a larger than average penis; interestingly this is not usually considered a major disadvantage and surgery is not usually considered.

¹¹ CE Brain, SM Creighton, I Mushtaq, PA Carmichael, A Barnicoat, JW Honour & VJC Achermann, 'Holistic management of DSD' (2010) 24 *Best Practice & Research Clinical Endocrinology & Metabolism* 335-354.

In more general terms, the view that there are two distinct and easily distinguished sexes is becoming scientifically problematic. The molecular biology governing human sex differentiation is not straightforwardly binary and this has led Vernon A. Rosario, an American child psychiatrist, to use the term 'quantum sex' to describe the way in which the multiple various determinants of physical sex differentiation interact and finally arrive at the sex of an individual human.¹² He borrows this term from quantum mechanics, where the simplistic model of nucleus and electrons is now replaced by a more complex one involving statistical probabilities that gives a more accurate picture. In genetics, rather than a simple Mendelian model of 'one gene - one trait', it is now known that there are many genes conferring small statistical odds for different traits under particular environmental and developmental circumstances and this also applies to sex determination. Ultimately no one type of structure and no one form of gene can be said to be 'naturally' male or female. In the nineteenth century, mammalian embryologists discovered that the early embryo has the potential to develop into either a male or female form so that it is only at around the week 8 of gestation that the human embryo shows sex differences.¹³ From the early twentieth century onwards it had been recognised that in several species, including ours, one of the chromosome pairs differed between male and female, leading to speculation that the material leading to sexual differentiation was located there. It was not until 1990 that a gene governing differentiation into testes was identified and localised to an area of the Y-chromosome – named *SRY* (sex-determining region of the Y chromosome),¹⁴ though it is still not understood exactly what this gene does to control testicular development.¹⁵ It became rapidly clear that this was not the whole story. In humans there are both *SRY*-negative

¹² VA Rosario, 'Intersex and the molecular deconstruction of sex' (2009) 5 (2) *A Journal of Lesbian and Gay Studies* 267-284.

¹³ Rosario, above, n 12, 271.

¹⁴ Rosario, above, n 12, 273.

¹⁵ Rosario, above, n 12, 274.

individuals with testes and *SRY*-positive individuals without them. In some of the latter cases, it appears that a second gene, *DAX-1* (on the X chromosome) if present in a double dose can override the effect of *SRY* so that an individual with XY chromosomes and a functioning *SRY* gene develops ovaries and not testes. It is now clear that the Y chromosome plays only a part in the determination of male sex; many other genes on other chromosomes are also involved, such as *SF-1* on chromosome 9, *WT-1* on chromosome 11, *SOX-9* on chromosome 17, and *MIS* on chromosome 19. All of these play some role in the development of testes and male sex. Interestingly studies of ovarian tissue development are in their infancy but it does not appear that their growth and differentiation is a passive process resulting from the absence of male hormones, as was believed until recently. Rosario therefore predicts that there will be a shift to:

a dozen or more genes each conferring a small percentage likelihood of male or female sex that is still further dependent on micro- and macro- environmental interactions.¹⁶

Thus there is no single and simple biological parameter that confers a certain sex on an individual.

It is also no longer the case that sex can be determined by the role that an individual plays in reproduction (if they reproduce); new reproductive techniques have potentially blurred the margins between male and female. Both female spermatogenesis and male oogenesis are theoretical possibilities, since mammalian embryonic stem cells can be induced to develop into both sperm and oocytes in controlled conditions.

¹⁷ Ectogenesis and male pregnancy are sometimes topics for ethical and

¹⁶ Rosario, above, n 12, 279.

¹⁷ J Kehler, K Hübner, S Garrett & HR Schöler, 'Generating oocytes and sperm from embryonic stem cells' (2005) 23 (3) *Seminars in Reproductive Medicine* 222-233.

legal discourse,¹⁸ though all the techniques mentioned are at present only remote theoretical possibilities. However, this evidence leads to the conclusion that biological sex is not the straightforward binary ontology suggested by the medical approach described below. It is the product of the interaction of many genes and environmental factors. A simple binary model of sex, on which much of intersex treatment is based, is therefore no longer scientifically accurate.

Gender is not necessarily a simpler issue, but by the age of two and a half to three years most children know if they are boys or girls.¹⁹ During the latter half of the twentieth century there was a search for a physical entity that 'caused' gender; for example the English courts spent over thirty years arguing over the status of transsexual individuals, before the Gender Recognition Act 2004, was passed by Parliament. The Act clarified that gender was not directly tied to any physical entity such as genital anatomy. Perhaps the best way to think of gender is that it is not generated by any individual anatomical or physiological characteristic but is generated by the whole organism and the interaction with the ambient society. As gendered beings we continually attempt to approximate to a set of normative ideals that 'live outside of us and were always there before we arrived'.²⁰ For Judith Butler, gender is always a doing, a performance, rather like a drag act.^{21, 22} There is no inner essence of our being that is gendered. The majority, though not all, human individuals self-identify as male or female. This characterisation of gender applies to those with congruent chromosomes, gonads and internal and external anatomy. It also applies to those individuals classed as intersex, who, in

¹⁸ For example, on Ectogenesis, A Alghrani, 'The legal and Ethical Ramifications of Ectogenesis' (2007) 2 (1) *Asian Journal of WTO & International Health Law and Policy* 189-212.

¹⁹ G Siann, *Gender, sex and sexuality*. (Hove: Psychology Press, 1994) 69.

²⁰ R Wilchins, *Queer Theory, Gender theory*, (Los Angeles: Alyson Books, 2004) 131.

²¹ J Butler, *Undoing Gender* (New York: Routledge, 2004) 209.

²² Butler, above, n 21, 213-214.

the vast majority of cases, have a clear gender identity as either a male or a female and only rarely do they self identify as anything other than this.²³ Therefore, in the majority of cases intersex people are men and women who happen to possess anatomical differences. In other words:

it is not necessarily the case that it is any more work or harder work for intersexed persons to do gender than it is for anyone else.²⁴

So whilst the biological characteristics identifying sex may be difficult to identify and interpret in some circumstances, identification of gender can be easier. Often by the time a child can speak, he or she will tell you their gender. For most this will be just as predictable from physical parameters, but in some cases it will be a surprise. For example, chromosomally female Individuals with CAH, identify as female in most cases but a subset (around 10%, markedly higher than in the general female population) have a male gender identity.²⁵

So, many people are aware of their gender from their first words and this is not necessarily connected to their sex, which can be, in some situations difficult or perhaps impossible to identify. Thus in terms of anatomy, it is not possible to say what makes someone male and what makes someone female. However, in most areas of life, sexual difference is seen as so obvious and natural a matter that it needs no argument or discussion:²⁶

(t)hat the world is composed of men and women, boys and girls, orders our world and regulates practices. [...] In fact sexual difference could be said to be the primary structure that itself

²³ Spurgas, above, n 2, 104.

²⁴ M Holmes, *Intersex. A Perilous Difference* (Selinsgrove: Susquehanna University Press, 2008) 14.

²⁵ SF Kemp, 'The role of genes and hormones in sexual differentiation' in SE Sytsma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006) 1-16, 12.

²⁶ Holmes, *Intersex. A Perilous Difference*, above, n 24, 18.

structures the social order in which we move and make sense of the world.²⁷

Indeed, the idea that all beings must have a fixed male or female gender is so entrenched that there is even a recent report of a dog that required surgery for ambiguous genitalia before anyone would adopt it.²⁸

I now turn to the nature and effects of the surgical techniques employed in treating intersex people.

A history of intersex surgery

The story of medical involvement in intersex in the twentieth century has been frequently reported and discussed in the literature.^{29, 30, 31, 32, 33, 34}

From the nineteenth century onwards many aspects of medical care for intersex and other conditions have been conducted with what could be termed a scientific approach, dependent on an understanding of the science underlying physiology and psychology, prevalent at the time. Treatment has been presented as being based on a *naturalistic* or

²⁷ EK Feder, '“In their best interests”: Parents' experience of atypical genitalia' in E Parens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (Baltimore: Johns Hopkins University Press, 2006) 189-210, 191.

²⁸ The Telegraph, 'Sex change dog seeks new home' (13/10/2010) <http://www.telegraph.co.uk/news/newstoppers/howaboutthat/8060144/Sex-change-dog-seeks-new-home.html> Accessed 30/05/2016.

²⁹ S Kessler, 'The medical construction of gender: case management of intersexual infants' (1990) 16 *Signs* 3-26.

³⁰ A Fausto-Sterling, 'The five sexes: why male and female are not enough' (1993) 33 *The Sciences* 20-24.

³¹ AD Dreger, *Hermaphrodites and the Medical Invention of Sex*, above, n 9.

³² SE Preves, 'For the sake of the children: destigmatizing intersexuality' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group Inc, 1999) 51-81.

³³ C Harper, *Intersex* (Oxford: Berg, 2007).

³⁴ Karkazis, above, n 6.

biomedical approach to medicine, grounded on what is considered to *normal*; anything which deviates from this so that function is subnormal is considered to be diseased.³⁵ However, in the area of intersex, medical treatment was based on a simplistic view of sex and gender, in marked contrast to the complexity of the issues discussed above. As I outlined in the previous section, gender was considered to be congruent with physical sex. This, in turn, was taken to govern the nature of the role the individual would occupy in society. Whereas the model used was thought to be a biological one, in fact it was strongly influenced by cultural views regarding sex, gender and social roles.

From the 1950s onwards a treatment protocol based on the identification of sex and gender was developed in Baltimore³⁶ and proved influential throughout the world for forty years or more. It was at this point that surgical fashioning of ambiguous genitalia started. Management was based on the pioneering ideas of paediatric psychoendocrinologist,³⁷ John Money, who led a multi-disciplinary team, composed of surgeons, endocrinologists and others. At the time, girls and boys were treated differently by their parents³⁸ and Money believed that this was the most influential factor in the acquisition of a gender identity.³⁹ He believed that children were rewarded for gender-appropriate behaviour by the responses of parents, peers and society.⁴⁰ In turn it was felt that responses were generated by parents and peers in accordance with the perceived gender of the child, based on his or her appearance.

³⁵ C Boorse, 'A Rebuttal on Health' in JM Humber & RF Almeder (eds), *What is Disease?* (Totowa, New Jersey: Humana press, 1997) 1-134, 7-8.

³⁶ J Money & AA Ehrhardt, *Man & Woman, Boy & Girl* (Baltimore: Johns Hopkins Press, 1972) 151-154.

³⁷ J Money, *A First Person History of Pediatric Psychoendocrinology* (New York: Kluwer Academic, 2002).

³⁸ Money & Ehrhardt, above, n 36, 117-145.

³⁹ Money & Ehrhardt, above, n 36, 145.

⁴⁰ Siann, above, n 19, 65.

Therefore appropriate genital anatomy was considered vital in order for a child to develop a secure gender identity, which had to conform to the anatomical sex. Genital surgery was carried out on neonates and was considered a surgical emergency.⁴¹ Next, treatment with appropriate hormones took place to facilitate further gender-appropriate social interaction. Medical developments such as the discovery that synthetic cortisone was an effective treatment for the hormonal deficit of CAH⁴² at this time meant that this was all technically feasible for the first time in medical history.

Medical and surgical intervention in the 1950s to 1990s was based on a strong assumption: people had to be able to have heterosexual relationships. The sex of rearing was often based pragmatically on penis/clitoris size. A baby without a penis was reared as a female, whatever the gonad type or chromosome complement. In the case of a small penis, the structure might be deemed 'too small' (meaning that it was not thought likely to function as a 'copulatory organ'). If this was the case, then the child was castrated and reared as a girl.⁴³ The general rule was that the ability to have heterosexual intercourse was of prime importance for boys but fertility was less important. For girls, on the other hand, the ability to orgasm was not given much importance but they had to be able to take part in heterosexual intercourse, so a vagina was constructed where necessary. For females, fertility was deemed very important so that girls with CAH were always raised as girls, despite some of them having very masculinised genitalia and the fact that a proportion of them do develop a male gender identity.⁴⁴ Often the enlarged clitoris was removed surgically. It was never considered that a girl might have a use for a phallus capable of penetration. The possibility

⁴¹ Money & Ehrhardt, above n 36,152.

⁴² Money, above, n 37, 1.

⁴³ Karkazis, above, n 6, 56-57.

⁴⁴ Kemp, above, n 25,12.

of a future gender change or a desire to take part in non-heterosexual sex in years to come was never considered.

Intersex in the twenty first century

Some aspects of medical practice in this area have undergone a marked improvement from the situation in the 1950s. Genital surgery is no longer considered a neonatal emergency and is not performed on young infants without careful thought and planning; but such surgery is not proscribed. This is not an area where there is legislation, or case law or formal guidelines from an authority such as NICE (National Institute of Clinical Excellence). Guidelines from those experienced in managing the medical problems involved were published in 2006 in the form of a consensus statement.⁴⁵ Examination of this important paper reveals that in some respects there has been no change in medical attitudes. The consensus statement continues to assume that the ability to have heterosexual intercourse and to have appropriate genital anatomy to achieve this is very important, as indeed it might be for many individuals – but not, perhaps, for all. Clitoridectomy⁴⁶ in CAH also remains a valid option, although only for those children deemed to show severe enlargement and with preservation of the clitoral nerve supply wherever possible.⁴⁷ It had been suggested in the past that early clitoral surgery alleviated parental distress and improved attachment between parent and child, but the consensus statement concedes that good evidence for this is lacking.⁴⁸ As discussed later, such surgery can be seen as mutilating in those with a female gender identity but perhaps more importantly, it is based on the

⁴⁵ In IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

⁴⁶ This should read 'clitoral surgery'. The preferred option would now be clitoroplasty rather than clitoridectomy – that is a refashioning to change appearance rather than an amputation

⁴⁷ Hughes & others, above, n 45.

⁴⁸ Hughes & others, above, n 45.

assumption that gender identity can be accurately predicted in young infants which is not always the case. Girls with CAH and other conditions may have vaginal surgery after puberty where necessary.

There is now no suggestion that boys with micropenis⁴⁹ should be reared as girls; it is well established that these boys are as likely as any males to possess a secure male gender identity.⁵⁰ However, specifically discussing the associated problem of hypospadias in which the urethral opening is abnormally placed (sometimes lying beneath the phallus) the 2006 statement warns that the:

magnitude of phalloplasty in adulthood should be taken into account during the initial counselling period if successful gender assignment is dependent on this procedure. At times this may affect the balance of gender assignment.⁵¹

Therefore, even as practised today, surgical treatment may not take into account the complex question of what makes someone a certain sex.

⁴⁹ The size of a micropenis is usually considered to be less than 2.5SD below the mean; one recent study (S Khan, B Somani, W Lam & R Donat, R., 'Establishing a reference range for penile length in Caucasian British men: a prospective study of 609 men' (2011) 109 (5) *British Journal of Urology International* 740-744) gave a threshold figure of less than 10.1cm stretched flaccid length, defined as 'the distance from the pubic bone to the tip of the glans penis under gentle painless extension' but in some cases the structure may be much smaller. Many individuals with micropenis may have no other features of intersex but infants and children in this group in practice may be managed by the 'DSD team', because of their experience in the area of unusual genital anatomy. In at least some (but not all) of the individuals involved heterosexual intercourse is possible. For an example see AP Van Seters & AK Slob, 'Mutually gratifying heterosexual relationship with micropenis of husband' (1988) 14 (2) *Journal of Sex & Marital Therapy* 98-107. Two of the males described in this paper are genotypically female with congenital adrenal hyperplasia, but had been assigned a male identity at birth. They did not receive surgery as infants, perhaps because this was not available. Both were secure in their male identity and each chose to have hysterectomy, oophorectomy (surgical removal of ovaries) and mastectomy (surgical removal of the breasts) as adults.

⁵⁰ WG Reiner, 'Prenatal gender imprinting and medical decision-making' in SE Sytma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006) 153-164, 161

⁵¹ Hughes & others, above, n 45. Phalloplasty is the process of penile reconstruction.

Sex continues to be perceived as a simple binary and treatment of intersex is directed by this simplistic and inaccurate model.

Introduction of the term disorder of sex development

In 2005, fifty or so experts in the management of children with atypical sex development who produced the consensus statement on treatment met to discuss intersex. They also considered the appropriate terminology. They agreed to banish:

to antiquity the term, intersex and instead, introduce[d] an all-embracing Disorders of Sex Development (acronym, DSD) terminology.⁵²

The new guidelines for treatment and terminology were universally welcomed and adopted by European centres involved in the medical care of such children.⁵³ The medical experts involved had no problems with the word disorder. Hughes refers to one form of CAH associated with a mutation in a specific gene:

To imply that a mutation in the CYP21 gene resulting in 21-hydroxylase deficiency and leading to a life-threatening cause of ambiguous genitalia (congenital adrenal hyperplasia) is a variant or a difference, not a disorder, is akin to suggesting that atheromatous plaques in the coronary arteries resulting in a myocardial infarct is not a cardiovascular disorder.⁵⁴

Hughes implies that it is not possible to separate the different aspects of the problem he is describing. He argues that the unusual genital anatomy is as much a part of the medical state resulting from the enzyme deficiency as the salt loss. However, it might be argued that the consequences of the enzyme deficiency are associated with very different implications for the individual concerned and need to be considered

⁵² IA Hughes, 'The quiet revolution' (2010) 24 *Best Practice & Research Clinical Endocrinology & Metabolism* 159-162.

⁵³ Hughes, above, n 52.

⁵⁴ Hughes, above, n 52.

separately. The biochemical defect is, perhaps, straightforwardly a disorder and a genuine medical problem without treatment of which the people affected would be subject to serious morbidity and death. It is the status of the condition's other aspects, such as the atypical genital anatomy, that is disputed. Some people with intersex conditions, notably those represented by the Intersex Society of North America (ISNA),⁵⁵ broadly agreed with Hughes and had no problem with use of the term disorder for all aspects of intersex, including the unusual genitalia. This group disbanded in 2007 and later reformed as the Accord Alliance^{56, 57} with the intention of working with medical experts to implement reforms in a mutually acceptable framework. In contrast some patient groups have continued to argue that a difference in genital anatomy should not be regarded as a disorder.⁵⁸

Medicine as the arbiter of normality

The gulf between biology and the normative ideals of the social order has implications for the ethics of medical and surgical treatment of ambiguous genitalia. The aim of the treatment is to try to make the patient conform to a notion of normality based on a simple binary male-female model of sex; whereas the reality is much more complex. In sex there is no simple binary. However, potentially mutilating surgery continues to be carried out:

to remake the body in the social image of that gender. Such efforts at 'correction' not only violate the child but lend support to

⁵⁵ Intersex Society of North America 2007 website http://www.isna.org/farewell_message accessed 30/05/2016.

⁵⁶ M Holmes, 'Introduction. Straddling past, present and future' in M Holmes (ed), *Critical Intersex* (Farnham: Ashgate Publishing Limited, 2009) 1-14, 1.

⁵⁷ Accord Alliance web site, <http://www.accordalliance.org> Accessed 30/05/2016.

⁵⁸ AD Dreger & AM Herndon, 'Progress and politics in the intersex rights movement' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 199-224, 212.

the idea that gender has to be borne out in singular and normative ways at the level of anatomy.⁵⁹

In summary, some see a body with ambiguous genitalia as different, but others see something that is 'wrong', which needs to be 'put right' by medicine and which therefore lies within the broad scope defined by the term 'disease'. Consideration of how and when the different becomes pathological touches on an extensive debate in the philosophy of medicine that can only have the briefest mention here. For three decades or so there have been two major views concerning the concept of disease.⁶⁰ The first of these is the naturalistic concept, in which disease is seen in terms of biological dysfunction.⁶¹ Boorse is one of the major proponents of this approach. For him the 'normal is the natural'.⁶² In other words, the normal is the statistically typical form or function of a typical member of the species, as represented in a textbook of physiology or anatomy, and disease is a subnormal deviation from this. In Boorse's view, judgments regarding disease are value-neutral.⁶³ Because diseases are a 'deviation from species biological design',⁶⁴ their identification relies on science and, sometimes, statistical calculation, not 'evaluative decision'.⁶⁵

For many other philosophers of medicine, concepts of disease are not free of value judgment and their ideas fall into the second major, normative, approach to disease, illness, disability and medicine. For these writers, disease and disability are more than a biological malfunction. They may be seen as preventing an individual from achieving

⁵⁹ Butler, above, n 21, 63.

⁶⁰ H Carel, *Illness* (Durham: Acumen, 2008) 11.

⁶¹ Carel, *Illness*, above, n 60, 11.

⁶² Boorse, 'On the distinction between disease and illness', above n 4, 57.

⁶³ C Boorse, 'Health as a theoretical concept' (1977) 44 *Philosophy of Science* 542-573.

⁶⁴ Boorse, 'Health as a theoretical concept', above, n 63, 543.

⁶⁵ Boorse, 'Health as a theoretical concept', above, n 63, 543.

ordinary human goals in relation to the society given that the external circumstances, such as the political situation, permit this.^{66, 67} The normative approach also involves the way in which the person with the malfunction is perceived by society. For example, Amundson, discussing the disadvantages experienced by people who find themselves in the 'abnormal' category, considers that:

these difficulties derive not from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation.⁶⁸

This statement of Amundson's seems apt in the example of intersex. Standard medical practice continues to be informed by the idea that there are strict norms defined for genital anatomy and that deviation from these provides a reason for medical intervention.

There are of course many other matters in medical practice about which strict definitions of normality are made. Foucault (discussing the concept of mental disease) pointed out the importance of medicine in defining normality:

We are becoming a society which is essentially defined by the norm. [...] The norm becomes the criterion for evaluating individuals. As it truly becomes a society of the norm, medicine, par excellence the science of the normal and the pathological, assumes the status of a royal science.⁶⁹

Towards the end of the twentieth century there developed an idea that medicine was a tool wielded by a medical hegemony within society in

⁶⁶ L Nordenfelt, *Animal and Human Health and Welfare* (Wallingford, Oxfordshire: CABI, 2006) 12-13.

⁶⁷ Nordenfelt, above, n 66, 149.

⁶⁸ R Amundson, 'Against Normal Function' (2000) 31 (1) *Studies in History and Philosophy of Biological and Biomedical Sciences* 33-53.

⁶⁹ M Foucault, 'The Social extension of the norm' in S Lotringer (ed), *Foucault live: collected interviews 1961-1984* (L Hochroth, M Horwitz (trs), New York: Semiotext[E], 1976) 196-199, 197.

order to affect control over its subjects using normality as a means for control. From the 1970s this process has been subject to criticism and the 'medicalisation critique',⁷⁰ developing from these views has been an influential stance within social sciences. Ivan Illich, a Catholic priest, was one of the important writers in this field. For Illich, a profession is an elite that wields power over those who require its services. Professionals, like priests, supply unique services to those who consult them.⁷¹ Unlike merchants or craftsmen, who may tailor the goods they supply to your requirement, 'professionals tell you what you need...';⁷² 'professionals assert secret knowledge about human nature, knowledge which only they have the right to dispense'.⁷³ 'Medicine now determines what disease society shall not tolerate'.⁷⁴ Thus for Illich medicine undermined rather than improved health, both because of side effects of treatments and because it restricted lay autonomy by providing limited choices due to strict enforcement of norms about normality and health.⁷⁵

In the first volume of *The History of Sexuality*, Foucault discussed 'the importance assumed by the action of the norm'.⁷⁶ He pointed out how sex was an important commodity in the political economy from the eighteenth century onwards, because it was so important in the control of population numbers in addition to its importance in regulating individual behaviour. This led to societal controls on how sex could be used. It had become officially limited to the legalised relationship of marriage and all other

⁷⁰ D Lupton, 'Foucault and the medicalisation critique' in A Petersen & R Bunton (eds), *Foucault, Health and Medicine* (Oxford: Routledge, 1997) 94-110, 94.

⁷¹ I Illich, 'Disabling Professions' in I Illich, IK Zola, K Irving, J McKnight, J Caplan & H Shaiken (eds), *Disabling Professions* (London: Marion Boyars Publishers, 2005) 11-39, 17.

⁷² Illich, above, n 71, 17.

⁷³ Illich, above, n 71, 19.

⁷⁴ Illich, above, n 71, 21.

⁷⁵ Illich, above, n 71.

⁷⁶ M Foucault, '*The Will to Knowledge. The History of Sexuality*' (R Hurley (trs), London: Penguin Books, 1998) 144.

forms of sex were hidden or repressed. The need for constant control means that there has to be a constant preoccupation with the very subject. For example, schools: although everything was arranged so as to avoid discussing sex, in fact, matters such as the layout of the building (separate entrances for boys and girls) illustrated that this was a constant preoccupation. Foucault points out that there was a proliferation of discourses on relevant topics involving law (proscribing certain behaviours) and medicine, defining what might be regarded as perversion and what might be considered normal. As part of this recognition of the abnormal in the medical context, homosexuality came into being as a medical disorder in 1870.⁷⁷ The growth of this preoccupation with what was normal so far as sex was concerned also coincided with the development of medical interest in intersex and with the idea that it was a disease, which is to say a special sort of difference – one that was the object of study by physicians and that needed to be medically corrected.

Fear of difference

Many of those with unusual genital anatomy also find it difficult to escape the idea that there is such a thing as normal genitalia. Any difference or perceived difference to what is deemed the norm can be problematic for the individual concerned. It is interesting that many adult women with intersex disorders consent to have vaginoplasty and clitoridectomy in order to be made more 'normal', as indeed do many women who cannot be regarded as having a disorder by any objective standards.⁷⁸ The Department of Health website includes a section on cosmetic surgery to alter the appearance of female genitalia, giving information for those who

⁷⁷ Foucault, '*The Will to Knowledge. The History of Sexuality*', above, n 76, 43.

⁷⁸ MP Goodman, 'Female cosmetic genital surgery' (2009) 113 (1) *Obstetrics and Gynaecology* 154-159.

might be contemplating it.⁷⁹ In the case of intersex disorder those adults wishing to have surgical alteration of genitalia includes those with female partners in addition to those with male partners.⁸⁰ Thus a major goal for at least some adult women is to have an 'adequate' vagina. 'Inadequate' is the term used in the Consensus Statement⁸¹ to imply a structure requiring surgical reconstruction as judged by medical professionals, and used in the context of intersex in a functional sense, meaning adequate for the purposes of heterosexual intercourse but this term may also have a wider meaning implying not perceived as 'normal' or aesthetically pleasing as judged by the women concerned. The:

key issue facing the intersexed is actually a key issue facing humanity in general: fear of difference'.⁸²

It is of course true that this fear applies to many more situations than the relatively rare context described in this paper, hence the growing trend toward appearance-altering surgery. Indeed, there are television shows based around the idea of radical transformation of an individual through cosmetic surgery, for example in the UK, *10 Years Younger* on Channel 4:

[This] is a particularly obvious example of the homogenizing function of cosmetic surgery: every body appearing on the show must be measured for its deviation from a norm set by heterosexual desirability and youth read through a binary gender system.⁸³

⁷⁹ Department of Health Website <http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/CosmeticSurgery>, accessed 24/10/2010. This link is now no longer active.

⁸⁰ SM Creighton, JA Greenberg, K Roen & DL Volcano, 'Intersex practice, theory and activism' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 249-260, 254.

⁸¹ Hughes & others, above, n 45.

⁸² DL Volcano in Creighton & others, above, n 80, 253.

⁸³ CJ Heyes, *Self-Transformations. Foucault, Ethics, and Normalized Bodies* (Oxford: Oxford University Press, 2007) 97.

However, the situation is more complex. As Heyes points out, the narrative used by the shows in question is 'less about becoming beautiful, and more about becoming oneself'.⁸⁴ Therefore rather than aspiring to external norms, the participants engage in a narrative in which:

the makeover enables the recipient to achieve long-standing personal goals presented as intrinsic to her own individual authenticity.⁸⁵

There is a further question concerning surgical intervention carried out with the purpose of making atypical genital anatomy more normal. Does surgery achieve normalisation? As will be seen from some of the accounts given below, this is not always so. Rather it is as if medical attention and treatment reinforce the sense of abnormality and inadequacy. This may also apply in uncontested disease. As an example, those with respiratory disease may be subjected to respiratory function tests, the findings of which are expressed in terms of percentage of expected values. A low percentage value has the effect of emphasising the deviation from normality, heightening a sense of failure.

⁸⁶

Medicalisation as the cause of pathology

So far we have determined that difference from what is considered the normal is perceived as disease according to at least some models of health and disease because it is not what is usual as determined by our culture or, perhaps, for writers such as Boorse, can be shown to statistically deviate from the normal range. There are two further approaches that I will now discuss, in order to demonstrate that rather than affecting a cure in intersex, the medical approach actually

⁸⁴ Heyes, above, n 83, 96.

⁸⁵ Heyes, above, n 83, 97.

⁸⁶ Carel, *Illness*, above, n 60, 37-38.

unnecessarily pathologises intersex. First, I will discuss some anthropological evidence. Second, I will look at accounts from individuals subjected to medical treatment in the past forty years to investigate its effects.

In the 1970s and 1980s there was considerable Western anthropological research into intersex in several cultures where a specific condition is frequent. In partial androgen insensitivity, the children with XY chromosomes and other male-associated genes and testes, may fail to develop virilised genitalia at birth because of a failure to respond to the testicular hormones in utero and so can be born with female genitalia. However, at puberty, the increased androgen production inherent in this state does have some effect so that these individuals do virilise (that is, experience deepening of the voice, facial hair growth and other characteristics normally considered 'male'), sometimes to the extent that they appear to change sex. In the ambient culture this meant that they changed gender in some cases. This was recognised for many years in Papua New Guinea and the Dominican Republic where there were words and phrases in the language to describe such individuals.⁸⁷ Several Western investigators became interested in this phenomenon. For example, the work of Imperato-McGinley, an endocrinologist, examined the phenomenon in the Dominican Republic.⁸⁸ She was interested in the importance of nature (androgen exposure) rather than nurture (up-bringing) in determination of eventual gender identity and role. It has been pointed out that this work was done solely using terms and ideas from Western medical discourse but, perhaps more significantly, there is some evidence that this work has had the effect of changing and pathologising the phenomenon it was examining:

⁸⁷ L Eckhert, ' "Diagnosticism": Three cases of medical anthropological research into intersexuality' in M Holmes (ed), *Critical Intersex* (Farnham: Ashgate Publishing Limited, 2009) 41-72, 65.

⁸⁸ J Imperato-McGinley, RE Peterson, T Gautier & E Sturia, 'Androgens and the evolution of male-gender identity among male pseudohermaphrodites with 5 alpha-reductase deficiency' (1979) 300 (22) *New England Journal of Medicine* 1233-1237.

Through their investigations, Western Researchers created a social category of 'sexual deviation' that had not previously existed in the community.⁸⁹

There is evidence that it may also be true that medical intervention and even attention is the cause of pathology in western cases of intersex. To examine this I will look at some of the empirical data concerned with the experience of individuals with intersex conditions in general and most particularly women with congenital adrenal hyperplasia, who are the largest group of intersex individuals included in this literature and who are also particularly likely to have had appearance-changing genital surgery during infancy or childhood. This requires a method of examining the lived experience of the condition that is in contrast to those discussed earlier, for neither Boorse's biostatistical, theory nor the normative theories of health include substantial input from the ill person.⁹⁰ So in order to access the patient's experience we need a different, phenomenological, approach in addition to the objective accounts. We have already seen that in sensitive and socially loaded cases, such as those involving intersex, the objective accounts carry with them implicit cultural values, and so are not as objective as practitioners may think. Physicians with their scientific approach to medical care could be said to manage disease, whereas the patient experiences the consequences of the pathology and disease in terms of pain and inability to achieve goals; this could be described as experiencing the illness.⁹¹ By giving a voice to the ill person (or the person experiencing medical attention) this 'privileges the first-person experience thus challenging the medical world's objective, third-person account of disease'⁹² and 'sees illness as

⁸⁹ Eckhert, above, n 87, 65.

⁹⁰ Carel, *Illness*, above, n 60, 8.

⁹¹ SK Toombes, *The Meaning of Illness: A phenomenological account of the different perspectives of physician and patient* (Dordrecht: Kluwer Academic Publishers, 1993) 39.

⁹² Carel, *Illness*, above, n 60, 8.

a way of living, experiencing the world and interacting with other people’.

⁹³ This is a phenomenological approach in which the actual illness experience is important, rather than the biomedical facts of the disease process. One important matter to consider here is that:

the body is not an automaton operated by the person but the embodied person herself. We are our bodies; consciousness is not separate from the body. ⁹⁴

It therefore follows that bodily changes, including surgical intervention, actually change perception, subjectivity and the identity of the person. ⁹⁵

In order to access some of the first person experience of those with intersex conditions, I draw on empirical work carried out from the 1990s onwards (for example, that of Preeves, ⁹⁶ Harper, ⁹⁷ and most particularly, Karkazis). ⁹⁸ This research appears to show remarkable consistency in the conclusions reached. Accounts from those who have not experienced medicalisation of any sort are very rare in the modern era. ⁹⁹ It is as if the specific medical framework surrounding intersex people is essential for their identification. ¹⁰⁰ There is some literature describing the life experience of intersex individuals in a former era; for example, the autobiography of Herculine Barbin is well known. This was published in

⁹³ Carel, *Illness*, above, n 60, 8.

⁹⁴ Carel, *Illness*, above, n 60, 13.

⁹⁵ Carel, *Illness*, above, n 60, 13.

⁹⁶ Preves, above, n 32.

⁹⁷ Harper, above, n 33.

⁹⁸ Karkazis, above, n 6.

⁹⁹ Eckhert, above, n 87, 41.

¹⁰⁰ Eckhert, above, n 87, 41.

1980 with an introduction by Michel Foucault,¹⁰¹ but this account is not entirely relevant to present day experience.

Whilst there are undoubtedly intersex persons who feel that medical and surgical treatment was right for them,¹⁰² not everyone shares this view. Medical attention is a constant part of life for those with intersex from the very first moments of the child's existence. The literature describes the confusion and bewilderment of parents (and indeed midwives and doctors) at the delivery of an intersex infant:- 'either they called it wrong, or that's a bit different for a girl'¹⁰³ (Karkazis quoting Sara Finney, whose child was eventually declared female). Then, there is attention from nurses, doctors and medical students: 'who are all these people?'¹⁰⁴ (a quote from Gloria Jackson,¹⁰⁵ who was told by the attending hoards of doctors, nurses and medical students that '[w]e've never seen a baby with CAH'). As pointed out by Karkazis this has the effect of emphasising that a medical condition is present, rather than a difference in anatomy, albeit an unusual one. It also has the effect of making the child's atypical genitalia the defining feature in the life of that child and that family.¹⁰⁶ Parents commonly feel confusion and shame¹⁰⁷ and may decide not to tell wider family and friends. Whether the newborn is a boy or girl normally plays a fundamental part in their introduction to family, friends and to the social world in general. The process commences immediately following birth with the production of pink or blue cot cards in the postnatal ward. Some parents feel that they lack a vocabulary to talk to

¹⁰¹ M Foucault, *Herculine Barbin. Being the recently Discovered memoirs of a Nineteenth-century Hermaphrodite. Introduced by Michel Foucault.* (R McDougall (trs), New York: Vintage Books, 1980). Originally published in French as *Herculine Barbin dite Alexina B.* (France: Editions Gallimard: 1978).

¹⁰² Holmes, *Intersex. A Perilous Difference*, above, n 24, 16.

¹⁰³ Karkazis, above, n 6, 184.

¹⁰⁴ Karkazis, above, n 6, 185.

¹⁰⁵ A parent of newborn child with CAH

¹⁰⁶ Karkazis, above, n 6, 185.

¹⁰⁷ Karkazis, above, n 6, 186-188.

others; they lack a 'phenomenological toolkit'¹⁰⁸ to describe their experience. Some, though not all, parents also found it impossible to discuss the diagnosis with their growing intersex child, even if regular medication, such as hormone replacement therapy was needed,¹⁰⁹ partly because they found it difficult to discuss the matter and partly because they wished to protect the child.

What about intersex from the point of view of the patient? As noted above, many individuals were not informed of their diagnosis and often spent a childhood under medical surveillance and, in some cases, taking medication without knowing why.¹¹⁰ In some cases, girls had clitoridectomy and vaginoplasty in their early teens without being told that the surgery was going to happen.¹¹¹ For some children this reinforced their sense of otherness and difference.^{112, 113} The medical attention lavished on these children also resulted in similar feelings,¹¹⁴ particularly when subjected to repeated genital examinations from doctors and medical students. Some of the children were made to feel that their body was not right or shameful and that it was outside their control.^{115, 116} The sense that they were somehow abnormal and freakish was reinforced, whether or not there had been surgery to 'normalize' genital anatomy.¹¹⁷ In the context of intersex it seems that performing surgery emphasizes

¹⁰⁸ H Carel, 'Phenomenology as a resource for patients' (2011) 37 (2) *Journal of Medicine and Philosophy* 96-113.

¹⁰⁹ Karkazis, above, n 6, 188-196.

¹¹⁰ Karkazis, above, n 6, 220.

¹¹¹ Karkazis, above, n 6, 221.

¹¹² Preves, above, n 32, 56.

¹¹³ Karkazis, above, n 6, 220.

¹¹⁴ Karkazis, above, n 6, 222.

¹¹⁵ Preves, above, n 32, 55-56.

¹¹⁶ Karkazis, above, n 6, 223.

¹¹⁷ Karkazis, above, n 6, 224.

deviation from the normal in at least some individuals' experience.¹¹⁸ Also, it is not necessarily true that surgery results in a return to normal; for example, it may result in scarring. Iain Morland (discussing hypospadias repair, a form of childhood genital surgery carried out for a congenital variation of penile anatomy, in which the urinary passage opens on the underside of the penis rather than at the tip) describes how:

In the school locker-room (that fabled location on which some surgeons base judgments about the fate of intersexed people who don't receive surgery) I was teased not because of intersex characteristics [...] but specifically because of scars caused by surgery.¹¹⁹

Adolescence could be a particularly stressful time:

I was really isolated, extremely lonely, and couldn't talk to anyone about how I was different, my diagnosis or my body, or the surgeries. I was suicidal for most of my teenage years and a lot of my twenties.¹²⁰

Often it is not until their twenties or later that intersex individuals are able to discuss their diagnosis and other issues with family and others.¹²¹

Involuntary clitoridectomy can be a great source of regret and anger for the women who underwent it and they may direct their resentment towards their parents and also towards the medical team who treated them.¹²² The complaints usually centre on loss of sexual function and,

¹¹⁸ JA Greenberg, 'International Legal Developments protecting the autonomy rights of sexual minorities' in SE Sytsma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006) 87-102, 89.

¹¹⁹ I Morland, 'What can queer theory do for intersex?' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 191-356, 301.

¹²⁰ Karkazis, above, n 6, 224. Quotation by Elissa Ford who has partial androgen insensitivity syndrome.

¹²¹ Karkazis, above, n 6, 226.

¹²² Karkazis, above, n 6, 227-228.

particularly, clitoral sensation, following surgery; ¹²³ for these girls, the fact that their genitalia had been made to look more womanly was insufficient. Comparison with female genital mutilation for non-medical reasons is obvious here; a person is guilty of an offence if he excises, infibulates or otherwise mutilates the whole or part of a girl's labia majora, labia minor or clitoris (Female Genital Mutilation Act 2003). This is a comparison that has been made previously on numerous occasions, for example, by Alice Dreger. ¹²⁴

It is notable how different the perceptions of the individuals concerned are when compared to those of the treating physicians. The medical professionals think in terms of a *good cosmetic outcome* as satisfactory, but often the patients feel 'a lasting sense of discomfort and shame about their bodies' even when by all objective accounts the surgery is successful. ¹²⁵ The overwhelming impression is that the patient experience, the first-person view of intersex, is vastly different from that of the biomedical perspective and that it plays almost no role in medical decision making. It seems that at least some of the problematic experiences for these individuals arise from the process of medicalisation, which leads to feelings of alienation from and loss of control of their own bodies. What phenomenological accounts of intersex seem to suggest is that, if anything, genital surgery and, perhaps, medicalisation in general, is the cause of disease, rather than its remedy at least for some intersex individuals.

¹²³ Karkazis, above, n 6, 231.

¹²⁴ AD Dreger, ' "Ambiguous sex"- or ambivalent medicine' in AL Caplan, JJ McCartney & DA Sisti (eds), *Health, disease and illness* (Washington DC: Georgetown University Press, 2004)137-152, 149.

¹²⁵ Karkazis, above, n 6, 228-229.

Conclusions

There has been much work making a similar argument to that presented here. Suzanne Kessler was one of the first to analyse the understanding of gender amongst doctors working with intersex children in 1990, revealing the sexist and heterosexist assumptions implicit in the treatment offered.¹²⁶ In 1993, Anne Fausto-Sterling brought the matter of intersex to a wider audience with a much-cited publication 'The Five Sexes'.¹²⁷ The point here was to challenge the assumption that sex was a simple binary and the Intersex Society of North America was formed around this time. In 1999, Alice Domurat Dreger introduced the voice of those with intersex conditions into the literature.¹²⁸ Some of the accounts describe adverse experiences following surgery¹²⁹ and some describe a satisfactory life as a woman with a large clitoris¹³⁰ or as a man with a micropenis.¹³¹ Scholars increasingly challenged the notion of intersex as disease.¹³² Around this time many clinicians, certainly in the US and UK, wished to reform the treatment offered and this culminated in the consensus statement, discussed above.¹³³ However, there is no doubt that the debate surrounding medicine and intersex has escalated rather than died away. The sociologist Morgan Holmes described her own experience of 'normalising' genital surgery, reiterating that intersex is

¹²⁶ Kessler, above, n 29.

¹²⁷ Fausto-Sterling, above, n 30.

¹²⁸ AD Dreger, *Intersex in the Age of Ethics*, (Hagerstown, Maryland: University Publishing Group, 1999).

¹²⁹ A Moreno, 'In Amerika They call Us Hermaphrodites' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group, 1999) 137-140.

¹³⁰ AD Dreger & C Chase, 'A Mother's Care' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group, 1999) 83-89.

¹³¹ H Hawbecker, 'Who did this to you' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group, 1999) 111-113.

¹³² Dreger, ' "Ambiguous sex"- or ambivalent medicine', above, n 124.

¹³³ Hughes & others, above, n 45.

troubling, but that does not mean that those with intersex conditions are 'troubled'.¹³⁴ Over the past few years there have been several multi-author volumes that include contributions from legal scholars, bioethicists, and writers in gender studies, and which deal with a wide range of topics pertinent to intersex.^{135, 136, 137}

The argument about the need for early genital surgery in intersex infants (most commonly girls with congenital adrenal hyperplasia) continues, despite the work mentioned above. For example, a recent paper from Australia reports a high percentage of 'acceptable cosmetic results' for surgery of this type.¹³⁸ As we have seen, from the patients' perspective this is not necessarily the most significant outcome, though this study did include a patient questionnaire looking at general quality-of-life, assessed as not statistically different from that of peers. This seems to avoid the central problem of intersex. Men and women born with atypical genital anatomy are different. They do not conform to the societal norm. In the case of intersex the abnormality of genitalia results in questioning the strict cultural rules dictating what constitutes male and female, rules that carry with them a set of notions of behaviours and moral judgments. Because the binary division into male and female is so central to our culture, the threat intersex poses is perceived as much greater than it is, particularly since one's gender is not necessarily connected to one's sex. In theory, at least in England, the Gender Recognition Act 2004 makes it clear that, in legal terms, sex and gender are separate. We have seen

¹³⁴ Holmes, *Intersex. A Perilous Difference*, above, n 24, 13.

¹³⁵ M Holmes (ed), *Critical Intersex* (Farnham: Ashgate Publishing Limited, 2009).

¹³⁶ SE Sytsma (ed), *Ethics and Intersex* (Dordrecht: Springer, 2006).

¹³⁷ I Morland (ed), 'Intersex and After' (2009) 15 (2) *A Journal of Lesbian and Gay Studies* 191-356.

¹³⁸ JM Crawford, G Warne, S Grover, BR Southwell & JM Hutson, 'Results from a paediatric surgical centre justify early intervention in disorders of sex development' (2009) 44 *Journal of Pediatric Surgery* 413-416.

that it is becoming clear that identifying someone's sex can now be extremely difficult; biologically, there is no simple binary anymore. However, even today, infants and children may be subjected to surgery to which they are too young to consent in order that they conform anatomically to what is considered appropriate. From birth onwards they are subjected to the medical gaze. The available evidence seems to suggest that interaction with medicine fails to bring about a medical resolution but rather is itself pathologising. One possible solution is for those responsible for the care of intersex infants to try to form an idea of a possible future.¹³⁹ Whilst it is difficult to do, it is necessary that the child is seen as a person with a future outside infancy. Roen entreats people to think of possibilities other than those dictated by considerations of what is normal. She uses the term 'queer embodiment'¹⁴⁰ to discuss the possibility that what is normal is not all that can be natural and right. She believes that families should be assisted by all who work with them in supporting their children; without such support:

atypically sexed children very soon come to understand that their difference is the problem, rather than having any chance to find out about others who are like them and take up opportunities to celebrate difference.¹⁴¹

¹³⁹ K Roen, 'Clinical intervention and embodied subjectivity: atypically sexed children and their parents' in M Holmes (ed), *Critical Intersex* (Farnham: Ashgate Publishing Limited, 2009) 15-40, 34.

¹⁴⁰ Roen, above, n 139, 35.

¹⁴¹ Roen, above, n 139, 35.

CHAPTER 7:

WHEN PARENTS CHOOSE GENDER: INTERSEX, CHILDREN AND THE LAW ¹

Summary: In England and Wales it is usually lawful for those with parental responsibility to consent to treatment on children who have not acquired legal capacity, providing that they are acting in the child's best interests. Whilst in most instances this process is unproblematic and the decisions made are non-controversial, there are troubling examples where this is more problematic. The difficulties for a family with a child who has an intersex condition will be considered to illustrate that there may be cases of medical and surgical treatment where, even though both parents and doctors agree on a course of action in good faith, the treatment administered may not necessarily be in the best interests of the child. Sometimes procedures carried out on an infant apparently in their best interests may later be a cause of regret to the child as an adult. The law in England and Wales will be examined to investigate other examples of controversial treatments of young children involving legal interventions to consider whether there are any parallels and what the implications of these might be to the intersex child.

A model suggested by a Colombian legal case from 1995 is discussed. The courts ruled that infantile sex assignment surgery is lawful only following very stringent consent procedures. The possibility is considered that guidelines defining the consent procedure may afford some protection for the intersex child.

¹ M Newbould, 'When parents choose gender: intersex, children and the law'. Accepted for publication in *Medical Law Review* 2016.

Keywords: Best Interests, Children, Genital Surgery, Intersex.

Introduction

'(T)he minor's own interests may not in all circumstances be best served if the matter is left to the parents and the doctors' ²

This paper considers the treatment of conditions known as *Disorders of Sex Development (DSD)* ³ amongst medical practitioners, but often as *intersex* by scholars and patient activists, that occur more often than many may realise. This is an area that challenges the assumption that a well-motivated parental decision will always result in an outcome that fulfils their child's best interests because medical problems do not necessarily have a single, easy solution. For this topic, there are two different strands of literature. First, there is the medical literature, where the presiding model is that *DSD affects patients who need medical and surgical treatment.* ⁴ Whilst there is no doubt that some aspects of this treatment are truly life saving, other aspects, such as genital surgery, are controversial, though a body of medical practitioners still holds that individuals *need* surgery in their early years.⁵ In contrast, in the field of sociology, bioethics and law, the term DSD itself is controversial because it implies that the state is an illness, hence the term *Intersex* is favoured.

² *Re F (Mental Patient: sterilisation)* [1990] 2 AC 1 at 20.

³ In this article the term 'intersex' will be used rather than 'DSD'. Some patient activist groups prefer the term 'intersex', since they consider the use of the word 'disorder' inappropriately pathological and sometimes suggest that it may be more appropriate to use a more neutral term such as 'Divergence of Sex Development' See E Reis 'Divergence or disorder?: The politics of naming intersex' (2007) 50 *Perspectives in Biology and Medicine* 535-543.

⁴ F Yankovic, A Cherian, L Steven, A Mathur & P Cuckow, 'Current practice in feminizing surgery for congenital adrenal hyperplasia; a specialist survey' (2013) 9 (6) *Journal of Pediatric Urology* 1103-1107. In this paper (considering a survey of the practice of paediatric urologists looking after female children with congenital adrenal hyperplasia (CAH)) there was a consensus opinion that CAH is a medical problem needing early surgical intervention.

⁵ Yankovic & others, n 4.

Suzanne Kessler was an early writer in this area⁶ and Milton Diamond was one of the first to suggest a moratorium on surgical treatment for intersex in young children.⁷ Several writers such as Dreger,⁸ Preves,⁹ and Karkazis¹⁰ carried out empirical studies of adults who had received surgical treatment for intersex conditions in infancy and childhood, in which many of those affected contended that the treatment they received privileged societal norms above the well being of the individual.¹¹ This conflict can be summed up as follows:

[M]aking a decision based on one ethical principle—say, concern for future welfare—might conflict with another. [...] [A]ltering a child's genitals before she is old enough to consent violates the principle of autonomy—the tenet that people should have a say as to how their own bodies are going to look, feel, and behave.¹²

Despite this argument and controversy, children with intersex conditions continue to be managed using a medical model. My purpose in writing this paper is try to consider the situation as it is in medical practice in the UK today, and to try to find a practical way to tackle the central problem. In other words, how does one act in the best interests of an individual

⁶ SJ Kessler, 'The medical construction of gender: case management of intersexed infants' (1990) *Signs* 3-26.

⁷ K Kipnis & M Diamond, 'Pediatric ethics and the surgical assignment of sex' (1998) 9(4) *Journal of Clinical Ethics* 398-410.

⁸ AD Dreger (ed), *Intersex in the Age of Ethics* (University Publishing Group Inc : Hagerstown, Maryland, 1999).

⁹ SE Preves, 'For the sake of the children: destigmatizing intersexuality' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group Inc, 1999) 51-81.

¹⁰ K Karkhazis, *Fixing Sex: intersex, medical authority and lived experience* (Duke University Press: Durham, 2008).

¹¹ AD Dreger & AM Herndon, 'Progress and politics in the intersex rights movement: feminist theory in action' (2009) 15 *A Journal of Lesbian and Gay Studies* 199-224, 199.

¹² E Reis, 'Culture and Cutting' (2012) 42 (6) *Hastings Center Reports* 3.

who cannot consent for themselves or express any sort of opinion in a matter that is not concerned with preserving life but with the general well-being of that individual, as perceived by others?

The first question asked when told that there is a new baby arrived in one's family or social circles is almost always - 'girl or boy?' Consider this hypothetical scenario.

A young married couple are expecting their first child, an event anticipated with much joy. On the basis of the findings of a second trimester scan, the baby is probably a boy. They have no reason to believe that he will be anything other than normal. However, at delivery it becomes clear that not all is well; the midwife cannot tell them if the baby truly is a boy. The child's genitalia are not quite those of a boy, but nor are they those of a normal girl.

The baby has a *disorder of sex development*, or, as others might say, he/she has an intersex condition. In mammals, the four major biological entities that govern sex development (chromosomes, gonad type, internal and external genital anatomy) are normally all of the same sex type, but in an intersex individual some are of the form associated with one sex but one or more are of the type associated with the other sex. This baby has a female-type chromosome complement, a uterus and (most probably) ovaries; the baby could therefore be regarded as a girl with a very large clitoris, not the anticipated boy. Like many children with intersex conditions this child has genital anatomy that deviates from what is usual and is commonly described as 'ambiguous'. To the family concerned this may be devastating; they no longer have the male child for whom they have made extensive plans.

The condition described above is an illustration of one form of intersex.¹³
The child has a problem with one of the stages involved in producing

¹³ The overall prevalence of intersex conditions is difficult to calculate because it depends precisely which conditions are included. One estimate (using a meta-

hormones in the adrenal gland, which produces defective hormones resulting in unusual genital anatomy in females. This specific condition is called congenital adrenal hyperplasia (CAH).¹⁴ The hormone deficiency itself can prove rapidly fatal but this is easily remedied by giving physiological doses of the missing hormone. However, the abnormal genital anatomy forms the main consideration of this paper.

One of the first decisions made in practice by the parents and medical team in the UK is the child's sex of upbringing.¹⁵ This is a crucial practical decision. There is little known about how biological factors and other matters such as parental attitude and culture contribute in general to the development of gender identity.¹⁶ However, in many intersex disorders, such as CAH, there is a considerable body of evidence regarding likely gender identity.¹⁷ For the child in the scenario (page 194), it is likely that

analysis of the number of children who received surgical treatment of ambiguous genitalia in the decades prior to publication) is approximately 1 in 2000 live births. The number of children who have some sort of anomaly of sex development – including those with numerical abnormalities of the X and Y chromosomes may be nearer 2 in 100 live births – See M Blackless, A Charuvastra, A Derryck, A Fausto-Sterling, K Lauranne & E Lee, 'How sexually dimorphic are we? Review and synthesis' (2000) 12 *American Journal of Human Biology* 151-166. In an average maternity unit of 4000 to 6000 live births, this means that several children are delivered each year who have ambiguous genitalia.

¹⁴ There are many other forms of intersex, all of which have a much lower prevalence than CAH.

¹⁵ IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Disease in Childhood* 554-562.

¹⁶ PT Cohen-Kettenis, 'Psychosocial and psychosexual aspects of disorders of sex development' (2010) 24 *Best Practice and Research: Clinical Endocrinology and Metabolism* 325-334, 326.

¹⁷ CP Houk, IA Hughes, SF Ahmed & PA Lee, 'Summary of consensus statement on intersex disorders and their management' (2006) 118 *Pediatrics* 753-757. 'Outcome data indicate that 90% of patients with 46,XX CAH and all patients with 46,XY CAIS who are assigned female sex in infancy identify as females'. Though for the latest data on 46,XY CAIS see Scenario 4, Chapter 4, page 105 and the associated footnote.

she will have a female gender identity.¹⁸ Yet her genitalia do not look like those of most other little girls; she has a large clitoris and one option is surgery to ‘normalise’¹⁹ her appearance. Prior to the mid-twentieth century, there was little medical treatment of any sort for those with CAH. Most children did not survive because hormone replacement therapy was not available. Once survival had become more likely it became possible for children with intersex conditions to have genital surgery in early infancy. Clitoridectomy²⁰ for girls with a clitoris deemed too large was a particularly common procedure before the 1980s. Subsequent to this, the less radical clitoroplasty²¹ became the more usual procedure. The latter is more likely to lead to preservation of nerve supply and therefore, more likely to lead to preservation of sexual function, at least in theory.²²

If, following discussion, the parents in the hypothetical scenario on page 194 take the offered medical advice and this child is to be brought up a girl, they might feel that it is in their child’s best interests to have surgical intervention in order for the child to look more ‘normal’. It may be that they perceive that life will be very difficult for someone who does not conform to societal norms; they may consider that there are therefore sound reasons why the child must receive appropriate surgical treatment.²³ However, if the surgery is not needed to safeguard the

¹⁸ DE Sandberg, M Gardner & PT Cohen-Kettenis, ‘Psychological aspects of the treatment of patients with disorders of sex development’ (2012) 30 (5) *Seminars in Reproductive Medicine* 443-452.

¹⁹ Or so some would say.

²⁰ Surgical removal of the clitoris

²¹ Surgical procedure to remove some of the excess tissue and reshape the clitoris so it looks more ‘normal’, but which is less extreme than clitoridectomy.

²² CL Minto, L-M Liao, CRJ Woodhouse, PG Ransley & SM Creighton, ‘The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study’ (2003) 361 *The Lancet* 1252-1257.

²³ For a discussion of the problems of intersex for families who live in environments where gender is extremely important see SE Sytsma, ‘Intersexuality, cultural influences and cultural relativism’ in SE Sytsma (ed), *Ethics and Intersex* (Springer :Dordrecht, 2006) 259-270. Perceiving that life is

child's physical health, questions might arise concerning lawfulness, specifically whether it is lawful for the parents of this little girl to consent to her clitoroplasty.

Health care decision making in the case of children

Most procedures performed as part of medical care are unlawful in the absence of valid consent. When the procedure entails physical contact with the patient, that contact may amount to the tort of battery and the crime of assault if there is no consent. In some circumstances a mature minor below the age of 16 can be deemed sufficiently mature as to be capable of giving valid consent to medical procedures,²⁴ but it is impossible that young infants will possess the necessary level of understanding and capacity to consent to serious surgical procedures. There is no set lower limit to the age at which a child can consent, the emphasis is placed more on the capabilities for understanding possessed by the individual child,²⁵ but it is considered to be unusual for those under fourteen to possess the necessary capacity for consent to surgery,²⁶ though there is evidence that very young children (three or four years of age) with chronic health problems often possess some understanding of their illness.²⁷

easier for males, in some societies the family may request that their child is brought up as a boy.

²⁴ *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402

²⁵ P Alderson, 'Competent children? Minors' consent to health care treatment and research' (2007) 65 *Social science and medicine* 2272-2283.

²⁶ A Perera, 'Can I decide please? The state of children's consent in the UK' (2008) 15 (4) *European Journal of Health Law* 411-420. This paper discusses various aspects regarding consent in children. The lower age limit at which a child may consent involved a case concerning kidnapping rather than medical treatment – *R v D* [1984] AC 778

²⁷ Alderson, above, n 25.

In England and Wales, it is usual to expect an individual or individuals with parental responsibility to act as the child's representative, a matter endorsed by the Children Act, 1989 and the judgment of the European Court of Human Rights in *Glass*.²⁸ There are, though, several general constraints applicable to medical treatment on a child. The doctors responsible must assess if those giving consent do possess the necessary capacity, they must give the parent(s) appropriately full information to allow them to make the decision and they must not put those with parental responsibility under undue pressure to accept the course of action suggested.

The general principle used is that ordinarily those with parental responsibility are in the best position to make an appropriate decision for their child.²⁹ It is assumed that the decision will have the child's best interests in mind rather than the welfare of those caring for the child or the extended family or wider society. In reality, it may be difficult to separate the interests of the child and the parents, for they are intimately connected, at least through infancy and early childhood. In the example of the scenario presented here of a newborn infant with CAH living with her family, it is difficult to decide what actually is in the *child's* best interests; the context of the whole family may also be important.³⁰

If the parents wish her to have surgery, their next task is to find a doctor who will carry out the procedure. No treatment can take place unless a

²⁸ *Glass and another v United Kingdom* (2004) 39 EHRR 15 (application no 61827/00) See Children Act 1989, pt1 s3.

²⁹ S Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish: Abingdon, 2007) 51.

³⁰ As in *Re T (a Minor) (Wardship: Medical treatment)* [1997] WLR 242. T was born with a life threatening medical condition for which medical opinion held that a liver transplantation was necessary. The mother, a health professional who lived and worked outside the UK, considered that, in the family's circumstances, it was not in the child's best interests overall to undergo the procedure. In the Court of Appeal, it was held that the close attachment between mother and child in this particular family and the enormous practical problems that might ensue, should he undergo liver transplant, meant that decisions for the child's future were best left in the hands of his parents.

doctor is prepared to undertake it.³¹ Medical practitioners must act within general legal constraints concerned with harming and killing others.³² Whilst they do not have unlimited immunity from liability for battery or assault, if there is appropriate consent and if what they are doing constitutes reasonable surgery or proper medical treatment, then what would be a crime if committed by a lay person will be viewed as lawful.³³ The crucial question, therefore, is how to determine what constitutes proper and reasonable medical treatment in a case like this. One way to determine this involves use of guidelines issued by professional bodies such as the Royal Colleges, the General Medical Council (GMC) or a group of medical professionals concerned with the specific field under consideration.³⁴ The GMC has the statutory purpose of protecting, promoting and maintaining ‘the health and safety of the public by ensuring proper standards in the practice of medicine’.³⁵ One aspect of this role is the issuing of guidance for doctors concerning good medical practice³⁶ and such literature may provide powerful evidence as to what constitutes reasonable and responsible medical practice.³⁷ Usually if

³¹ As in *Regina (Burke) v General Medical Council (official Solicitor and others intervening)* [2005] EWCA Civ 1003.

³² S Elliston, above, n 29, 52.

³³ Lord Mustill points out in *Airedale NHS Trust v Bland* [1993] AC 789 at 891 that an act that constitutes ‘proper medical treatment’ when performed on a consenting patient ‘would be a very serious crime if done by someone else’, which implies that ‘bodily invasions in the course of proper medical treatment stand completely outside the criminal law’.

³⁴ For example, in the specific field of intersex management there are a number of guidelines issued by professionals with experience in the field – Hughes & others, above, n 15. Or more recently, FS Ahmed, JC Achermann, W Arit, A H Balen, G Conway, Z L Edwards, S Elford, I A Hughes, L Izatt, N Krone, H L Miles, S O’Toole, L Perry, C Saunders, M Simmonds, A M Wallace, A Watt & D Willis. ‘UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development’ (2011) 75 *Clinical Endocrinology* 12-26.

³⁵ <http://www.gmc-uk.org/about/role.asp> (Accessed 21/02/2016).

³⁶ http://www.gmc-uk.org/guidance/ethical_guidance.asp (Accessed 21/02/2016).

³⁷ As illustrated by the case of *W v Egdell and others* [1990] 1 All ER 835. Here the ‘Blue Book’ produced by the General Medical Council, Advice on Standards

there is consent and the family concerned find a qualified medical practitioner willing to undertake a given procedure, it is considered an indication that the treatment will not be primarily intended as harmful. Therefore if the parents of the child in our case find a surgeon willing to undertake clitoroplasty on their child, and if they are willing to consent to the procedure on the grounds that they all consider it is in her best interests, then no further approval is usually required and in many cases no one outside the family or the healthcare staff will ever know of what is proposed. However, there is no guarantee that the readiness of those with parental responsibility to consent to a procedure that a medical team is willing to perform is sufficient to ensure that a procedure is more likely to prove beneficial rather than harmful to the child, a point made by Elliston.³⁸

In most cases the courts are involved *only* when there is a disagreement regarding which course of action is in the child's best interests. The difference of opinion may involve the medical team caring for the child and one or both of those with parental responsibility or there may be a dispute between those who hold parental responsibility. Sometimes one parent may be opposed to a course of action thought beneficial by the other parent and the medical team, as in the highly publicised case of a seven year old boy whose estranged parents were in disagreement as to whether he should receive conventional treatment following surgery for a brain tumour. His mother wished him to receive experimental complementary therapies but his father agreed with the oncologists caring for him that his best chance of recovery lay with conventional treatment. In the ensuing court case, Bodey J had no hesitation in deciding that the child's interests were best served by the course of action proposed by the NHS Trust and agreed to by his father.³⁹ If

of Professional Conduct and medical Ethics, was used as evidence concerning the nature and extent of confidentiality within the patient/doctor relationship.

³⁸ Elliston, above, n 29, 53.

³⁹ *An NHS Trust v SR* [2012] EWHC 3842 (Fam).

doctors and parents agree, there is unlikely to be any evaluation of the interests of the child unless another person (such as a family member or member of the wider medical team) challenges the decision. The early sterilisation case, *Re D*, (discussed in more detail below) is an example of a procedure that was circumvented as someone in the wider medical team challenged its appropriateness.⁴⁰

It can however be very difficult to decide what is beneficial. Procedures that lie broadly within the remit of healthcare may confer different sorts of benefits. Many surgical or medical procedures are held more or less universally to confer medical benefit, such as prescribing of adrenal hormone therapy to the child in the hypothetical scenario, where, without this simple non-surgical treatment, death in infancy is probable.⁴¹ Other procedures, such as sterilisation of a minor, may be carried out not strictly for therapeutic reasons, but to benefit *general* welfare. This is one of the very few circumstances in England and Wales when the matter of what lies in the best interests of the child requires consideration by the courts and is thus formally investigated.⁴² Unless fulfilling an obviously therapeutic goal such as treatment of cancer, sterilisation always requires judicial approval.⁴³ There are procedures such as ritual male circumcision that are considered by some to be beneficial for social rather than medical reasons, but (so far in England and Wales) may be deemed in a child's best interests in some circumstances.⁴⁴ Otoplasty (correction of ear position for what is commonly known as 'bat ears'), is cosmetic in nature, though often considered to be in the child's best interests in order

⁴⁰ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326.

⁴¹ As discussed by IA Hughes, 'The quiet revolution' (2010) 24 *Best Practice and Research: Clinical Endocrinology and Metabolism* 159-162.

⁴² In *Re B (A Minor) (Wardship: Sterilisation)* [1988] AC 199.

⁴³ In *Re B (A Minor) (Wardship: Sterilisation)* [1988] AC at 199.

⁴⁴ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 367-370

to prevent teasing and bullying.⁴⁵ The distinction between the therapeutic and the cosmetic is therefore blurred to some extent.

Whilst it is frequently possible to argue that a cosmetic procedure is necessary to protect the psychological well-being of an individual, opinions regarding therapeutic benefits may be subject to change over time. Forms of genital cutting, involving male and female children, were performed for a wide range of medical and psychological problems including epilepsy, paralysis, alcoholism, gout, scoliosis (curvature of the spine), clubfoot, asthma, malnutrition, eczema and mental retardation from the mid 19th century to the first decade of the 20th century. When viewed with current scientific understanding, it is difficult to identify therapeutic benefits.⁴⁶ It is not always possible for those consenting to medical treatment on either themselves or their child (or the doctors administering it), to know how the matter will be perceived in the future, as will be shown in the brief history of clitoral surgery that follows.

Infantile surgery for intersex

The 'standard treatment protocol' for intersex was developed in the 1950s and was based on the pioneering ideas of John Money.⁴⁷ He observed that boys and girls were treated very differently in society and considered this an important factor in acquisition of the child's gender identity.⁴⁸ He thought that children were rewarded when they showed gender

⁴⁵ L Kitipornchai and S-N Then, 'Cosmetic Surgery on Children' (2011) 40 (7) *Australian Family Physician* 513-516.

⁴⁶ M Thomson, *Endowed; regulating the male sexed body* (Routledge: New York, 2008) 29-30.

⁴⁷ J Money, *A First Person History of Pediatric Psychoendocrinology* (Kluwer Academic/Plenum Publishers: New York, 2002).

⁴⁸ J Money & AA Ehrhardt, *Man and Woman, Boy and Girl* (The Johns Hopkins University Press: Baltimore, 1972) 145.

appropriate behaviour to peers and parents, but that the behaviour of those who interacted with the child was influenced by the child's appearance. Thus appearance dictated social interaction and this, in turn, influenced the child's gender-specific behaviour. Money considered that in cases of intersex, surgical refashioning of genitalia was a medical emergency to be performed in the early neonatal period before the family had a chance to adjust to the situation and in some cases, without fully informing them of the implications of their child's condition or of the proposed surgery. Secrecy was thought to be therapeutically helpful in order to minimise ambiguous cues from family members. Money's theory was that if the infant's family were aware of any doubt regarding her sex, their reactions to her would be ambiguous, resulting in problems with gender identity.⁴⁹

The development of medical management of intersex in the 21st century

The therapeutic model of treatment for intersex using the John Money model went more or less unchallenged until the 1990s,⁵⁰ when some of the patients, now adults, started to reassess what had happened to them in infancy.⁵¹ It had become possible to see problems with this medical model, with Kessler and others highlighting some of the difficulties encountered by the families, such as the paucity of full and completely frank information delivered to them by health care professionals.⁵² The development of the Internet facilitated the formation of support groups

⁴⁹ AD Dreger, 'A History of Intersex: from the age of gonads to the age of consent' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group Inc, 1999) 5-22, 11-12.

⁵⁰ JA Greenberg, 'International Legal Developments protecting the Autonomy Rights of Sexual Minorities' in SE Sytsma (ed) *Ethics and Intersex* (Springer :Dordrecht, 2006) 87-102, 88.

⁵¹ Karkhazis, above, n 10, 8.

⁵² Kessler, above, n 6.

such as the Intersex Society of North America (ISNA), founded by Cheryl Chase in 1993.⁵³ At birth she was thought to be a boy, but by 18 months she was re-diagnosed as a girl with a large clitoris, which was removed.⁵⁴ She only discovered this when she saw her medical notes as an adult⁵⁵ when she had consulted a gynaecologist because of her inability to experience orgasm.⁵⁶ Chase experienced years of emotional problems, but eventually became a voice for intersex individuals.⁵⁷ In October 2005, she was asked to meet with a group of international medical experts to help formulate medical treatment guidelines.⁵⁸

The new protocol that resulted advised continuation of the elements of good practice introduced by John Money, such as involvement of a team of medical, nursing and psychological professionals.⁵⁹ It was, and remains, inevitable that these children will be managed in tertiary paediatric centres where the necessary specialist skills are available. As it has always been, the first task is to assign a gender to the new born infant,⁶⁰ based on:

the diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, the potential for fertility, views of the family, and sometimes the circumstances relating to cultural practices.⁶¹

⁵³ According to Intersex Society website <http://www.isna.org> (Accessed 21/02/2016).

⁵⁴ Karkhazis, above, n 10, 1-2.

⁵⁵ Karkhazis, above, n 10, 251.

⁵⁶ Karkhazis, above, n 10, 251.

⁵⁷ Karkhazis, above, n 10, 251.

⁵⁸ The guidelines were eventually published as Hughes & others, above, n 15 and Houk & others, above, n 17.

⁵⁹ Hughes & others, above, n 15, 555.

⁶⁰ Hughes & others, above, n 15, 556.

⁶¹ Hughes & others, above, n 15, 556.

Female infants with CAH are assigned female gender in UK medical practice, because it is highly *probable* (though not inevitable⁶²) that the adult gender identity will be female and it is also likely that these women will be fertile.⁶³ Early genital surgery, particularly clitoroplasty for female infants with CAH, retains a place in modern treatment protocols,⁶⁴ although the surgeon should preserve the clitoral nerve supply wherever possible.⁶⁵ Clearly consideration as to what constitutes best interests is complex here and the consensus statement⁶⁶ acknowledges that it requires assessment of matters wider than purely medical benefits.

Why was (and is) early genital surgery considered in the child's best interests?

As mentioned above, in the early days an important reason for infantile genital surgery was that it was thought to facilitate development of gender identity. However, the relationship between anatomical sex and gender is complex and not as straightforward as was believed at that time.

Biological sex is not the simple binary entity that it was once thought to be, and the view that there are two distinct and easily distinguished sexes is actually scientifically problematic. The molecular mechanisms governing human sex differentiation are not all located on the so-called sex (X and Y) chromosomes, but rather, twelve or more chromosomes play a part in its determination.⁶⁷ Indeed, during differentiation of the

⁶² In Congenital Adrenal Hyperplasia, 1 in 10 to 1 in 20 girls (world wide) will chose to transition to male at some time. See Sandberg & others, above, n18, 443-452.

⁶³ In some societies, even today, for many women infertility can cause social difficulties, leading to economic and social exclusion. For some families therefore preservation of fertility as a female is important. See Houk & others, above, n 17, 754.

⁶⁴ Yankovic & others, above, n 4.

⁶⁵ Hughes & others, above, n 15, 557.

⁶⁶ Hughes & others, above, n 15, 557.

⁶⁷ VA Rosario, 'Intersex and the molecular deconstruction of sex' (2009) 15 *A Journal of Lesbian and Gay Studies* 267-284, 269.

gonads, approximately half the genome is involved; thus *many* genes in the mammalian genome act together, resulting in a male or female individual.⁶⁸ In the end, no one type of structure and no one form of gene can be said to be ‘naturally’ male or female. An uncomplicated binary model of sex, on which much of intersex surgery is based, is therefore no longer scientifically accurate or appropriate because gender is a complex issue with several components.⁶⁹

Gender identity is usually taken to mean an individual’s idea of himself or herself as male, female or indeterminate and an individual’s gender role is more concerned with the behaviour and attitude perceived as indicative of masculine or feminine in that individual’s society. By the age of two and a half to three years most children are beginning to be aware whether they are boys or girls and are starting to form patterns of behaviour appropriate to that gender.⁷⁰ During the latter half of the twentieth century there was a search for an anatomical structure that ‘caused’ gender as the English Courts strove to consider the status of transgender persons.⁷¹ There is still much to be learned about how gender identity develops however,⁷² and attempts at defining physical differences in the brains of trans women and men continue,⁷³ though anatomy became less important legally when Parliament introduced the Gender Recognition Act 2004. The Act takes the pragmatic view that gender is not generated by any individual anatomical or physiological characteristic but is expressed

⁶⁸ SC Munger & B Capel, ‘Sex and the circuitry: progress toward a systems-level understanding of vertebrate sex determination’ (2012) 4 *WIREs Systems Biology and Medicine* 401–412.

⁶⁹ Cohen-Kettenis, above, n 16, 326.

⁷⁰ G Siann, *Gender, Sex and Sexuality* (Psychology Press: Hove, 1994) 69.

⁷¹ S Whittle & L Turner ‘Sex Changes? Paradigm shifts in ‘Sex’ and ‘Gender’ following the Gender Recognition Act?’ (2007) 12 *Sociological Research Online* <http://www.socresonline.org.uk/12/1/whittle.html> (Accessed 27/02/2016).

⁷² Cohen-Kettenis, above, n 16, 326.

⁷³ I Savic & S Arver ‘Sex dimorphism of the brain in male-to-female transsexuals’ (2011) 21 *Cerebral Cortex* 2525-2533.

by how the individual actually lives, which coincides with the ideas of thinkers such as Judith Butler, for whom gender is a doing, a performance, rather like a drag act⁷⁴ where there is no inner essence of our being that is gendered. As far as the Act is concerned, genital anatomy or any other physical characteristic is not a pre-requisite for living in a specified gender.⁷⁵

Though the 2004 Act has no direct application to intersex infants, the general principle that it endorses, that gender is not tied to genital anatomy, is highly relevant. The incidence of assignment of gender to an intersex child at birth that seems inconsistent with the child's gender as she or he grows is unknown,⁷⁶ but this does sometimes occur.⁷⁷ However, although some individuals (whether intersex or not) feel that their biological sex and self-identified gender are incongruent, the majority of people self-identify as male or female rather than both or neither.⁷⁸ In the majority of cases intersex individuals are men and women who are no worse at 'doing gender' than anyone else.

⁷⁴ J Butler, *Undoing Gender* (Routledge: New York, 2004) 213-214.

⁷⁵ As indicated in the Gender recognition Act 2004, the applicant wishing to be legally recognized in the gender other than that assigned at birth must:

- under s2(1A), have gender dysphoria,
- under s2(1B) have lived in the acquired gender throughout the period of two years ending with the date on which the application is made
- under s2(1C) intend to do so until death.

Under s3 granting a Gender Recognition Certificate (enabling legal recognition in the acquired gender) depends on the opinion of either a registered medical practitioner practicing in the area of gender dysphoria and a second medical practitioner (who does not have to be an expert in this field), s3(1A) or a chartered psychologist practicing in that field and a medical practitioner, who does not have to work in that specific field, s3(1B).

The reports must give details regarding the diagnosis of gender dysphoria rather than any specific physical characteristics of the individual (s3(2)). Gender dysphoria implies that the individual feels that their psychological and emotional identity is at variance with their sex assigned at birth.

⁷⁶ Cohen-Kettenis, above, n 16, 330.

⁷⁷ Cohen-Kettenis, above, n 16, 330.

⁷⁸ AK Spurgas, '(Un)Queering Identity: the biosocial production of Intersex/DSD' in M Holmes (ed), *Critical Intersex* (Ashgate Publishing Limited: Farnham, 2009) 97-122, 104.

The fact that modern management of intersex starts with assignment of a gender of upbringing has been discussed above and it has been suggested that, in the child in the hypothetical scenario on page 194, it is likely that this will be as a girl. The available medical data indicates that if raised as female, almost all of those with CAH will retain a gender identity as girls/women throughout life, though a small proportion (five to ten per cent in Western countries) encounter gender dysphoria and transition to a male social gender role permanently as adults.⁷⁹ This can be the case whether or not the child has surgery to change the appearance of the genitalia and the available evidence seems to suggest that early genital surgery does not necessarily make acquisition of gender identity easier.

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Genital surgery, like other forms of appearance altering surgery in childhood is carried out because of the general need to be perceived as 'normal'. For infants and very young children, this is based on the perception of those with parental responsibility. Ellen Feder has suggested that it is considered to be a matter of 'common sense' that an individual's genital anatomy ought to conform to what is regarded as 'normal', and this is a notion that is therefore resistant to critical examination.⁸¹ The fear of being different is a major problem, not just for this narrow context but also for 'humanity in general'.⁸² Feder suggests that such rules of normality work at an unconscious level. They are not norms that are 'considered and weighed, thoughtfully enacted by individuals but conventions that could more precisely be understood to

⁷⁹ Sandberg & others, above, n 18.

⁸⁰ Minto & others, above, n 22, 1252.

⁸¹ EK Feder, ' "In Their Best Interests". Parents' experience of atypical genitalia ' in E Parens (ed), *Surgically Shaping children. Technology, Ethics and the Pursuit of Normality* (The Johns Hopkins University Press: Baltimore, 2006) 189-210, 191.

⁸² SM Creighton, SM Greenberg, K Roen & DL Volcano, (2009) 15 'Intersex practice, theory and activism' *A Journal of Lesbian and Gay Studies* 249-260, 253.

work through individuals'.⁸³ A further problem arises because, not only do such norms work in this complex fashion within the general society, but they also permeate ideas of 'normality' in medical practice. Therefore cultural ideas of what is 'normal' become enshrined as a biological/factual notion of what might be considered 'normal'. For this reason, many doctors consider surgery therapeutic for children with intersex and it is therefore carried out to fulfil what are perceived to be the best medical (or social) interests. It is usually believed that the child will have an easier life if he or she looks 'normal' and certainly as far as genital anatomy is concerned, this is viewed as a medical need.⁸⁴

However, because infantile genital surgery is permanent and therefore represents a significant and irreversible intervention akin to sterilisation, the question of whether it is actually in the child's best interests, and therefore lawful, remains. Whilst it may have helped some⁸⁵ there is evidence that others perceive that they have been harmed.⁸⁶ An examination of the literature describing the first person experience of those intersex individuals who have had surgery⁸⁷ provides evidence that an individual's best interests (from the point of view of that individual) are not always fulfilled by surgery. Common themes run through these accounts, for instance many believed that the encounters with medical personnel served only to emphasize difference. Some children, like Cheryl Chase, were not informed of their diagnosis even when old

⁸³ EK Feder, above, n 81, 192.

⁸⁴ I Vidal, DB Gorduza, E Haraux, C-L Gay, Chatelain P, M Nicolino, P-Y Mure & P Mouriquand, 'Surgical options in disorders of sex development with ambiguous genitalia' (2010) 24 *Best Practice and Research: Clinical Endocrinology and Metabolism* 311-324 and Yankovic and others, above, n 4.

⁸⁵ M Holmes, *Intersex: A Perilous Difference* (Selinsgrove PA: Susquehanna University Press, 2008) 16.

⁸⁶ There are many first person accounts from the 1990s onwards, for example, H Walcutt, 'Time for a change' in AD Dreger (ed), *Intersex in the Age of Ethics* (Hagerstown, Maryland: University Publishing Group Inc, 1999) 197-200.

⁸⁷ Karkhazis, above, n 10, Preves, n 9.

enough to understand and spent childhood under medical surveillance,⁸⁸ which reinforced their sense of otherness and difference,⁸⁹ particularly when subjected to many genital examinations from doctors and medical students.⁹⁰ It seemed to them that the body was wrong or shameful and outside their control.⁹¹ The sense that they were somehow abnormal and freakish was reinforced, whether or not there had been surgery to 'normalise' the genital anatomy.⁹² For those who received surgery, this frequently emphasised the deviation from the 'normal' rather than *normalised*⁹³ because that region of the body became the focus of attention. Clitorodectomy, the standard surgical procedure prior to the mid 1980s, was a great source of regret and anger for many of the women who underwent it.⁹⁴ Their complaints usually centred on loss of sexual function and clitoral sensation following surgery;⁹⁵ so for these women it was insufficient that their genitalia had been made to look more 'womanly'. Even in the more recent studies, there is evidence that, although the cosmetic effects were perceived by the women as successful, the sexual functioning of those who underwent clitoral surgery (now more usually clitoroplasty) in infancy was impaired,⁹⁶ but it may be that this is also true for those who had no surgery.⁹⁷ Thus, it remains a

⁸⁸ Karkhazis, above, n 10, 220.

⁸⁹ Karkhazis, above, n 10, 220

⁹⁰ Karkhazis, above, n 10, 222.

⁹¹ Karkhazis, above, n 10, 223.

⁹² Karkhazis, above, n 10, 224.

⁹³ Greenberg, above, n 50, 89.

⁹⁴ Karkhazis, above, n 10, 227-8.

⁹⁵ Karkhazis, above, n 10, 231.

⁹⁶ NS Crouch, LM Liao, CR Woodhouse, GS Conway & SM Creighton, 'Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia' (2008) 179 *Journal of Urology* 634-638, Minto & others, above, n 22, 1252.

matter of controversy as to whether genital surgery helps or if it actively harms those children who receive it. It is possible that for some women it is perceived as helpful in their adult lives,⁹⁸ but not in all cases. Thus the medical situation in our hypothetical scenario (page 194) is problematic and the parents (or those with parental responsibility) need to know and carefully consider all of this before giving consent to surgery. But are there any existing legal constraints that might afford more protection to the child?

Existing constraints on surgery carried on minors

Some of the general constraints on surgery on those who cannot give their own consent were discussed earlier. In the specific context of genital surgery, English law imposes limitations relating to ritual genital cutting (both male⁹⁹ and female¹⁰⁰), some of which might be of relevance to the case under consideration here. These forms of surgery are not precisely equivalent to each other or to infantile genital surgery for intersex, since the age of the children involved is frequently different. Male circumcision usually involves infants or children less than 10 years of age, but female genital mutilation usually involves girls in childhood or the teenage years, and only occasionally during infancy.¹⁰¹ There are however common

⁹⁷ N Callens, YG van der Swan, SL Drop, M Cools, CM Beerendonk, KP Wolffenbuttel & AB Dessens, 'Do surgical interventions influence psychosexual and cosmetic outcomes in women with disorders of sex development' (2012) *Endocrinology* 2012: 276742.

⁹⁸ Holmes, above, n 85, 16.

⁹⁹ See *Re J (child's religious upbringing and circumcision)*, [1999] 2 FCR 345; *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307; *S (Children)* [2004] EWHC 1282 (Fam) and *Re S (change of name: cultural factors)* [2001] 3 FCR 648.

¹⁰⁰ Female Genital Mutilation Act 2003. This was preceded by the Prohibition of Female Circumcision Act 1985.

¹⁰¹ CM Braddy & JA Files, 'Female Genital Mutilation: cultural awareness and clinical considerations' (2007) 52 *Journal of Midwifery and Women's Health* 158-163, 159.

features to all these types of surgery. With regard to infant male circumcision Thomson has noted that the procedure can be seen as 'sexing the infant male body',¹⁰² both because there is 'an understanding of the foreskin as feminised flesh'¹⁰³ and because of the way in which pain and risk have a 'role in defining the male body, masculinity and male privilege'.¹⁰⁴ There are many reasons why some cultures perform ritual female genital cutting, but one of these is because the procedure is seen as enhancing femininity and beauty by removing those tissues that have a more male appearance,¹⁰⁵ a reason that is not dissimilar to the rationale for performing clitoroplasty in girls with intersex conditions such as CAH. These procedures all involve the removal of 'healthy tissue from the body of a child who is unable to give consent'¹⁰⁶ and all forms are done because it is deemed necessary for the genital anatomy to conform to an externally determined norm.

In English law there are differences in how these three forms of surgery are characterised. Surgery carried out on the intersex child may in some (though not all) circumstances, be more extensive and have greater implications for future sexual and reproductive functioning than either form of genital cutting. However, many doctors consider this lawful medical treatment since intersex is viewed as a medical *disorder*. Female genital mutilation (FGM) is unlawful (unless carried out by a doctor or midwife for medical reasons) when performed on women of all

¹⁰² Thomson, above, n 46, 18.

¹⁰³ Thomson, above, n 46, 18.

¹⁰⁴ Thomson, above, n 46, 18-19.

¹⁰⁵ CJ Walley, 'Searching for 'voices': feminism, anthropology, and the global debate over female genital operations' (1997) 12 *Cultural Anthropology* 405-438, 415.

¹⁰⁶ M Fox and M Thomson 'Cutting it: surgical interventions and the sexing of children' (2005) 12 *Cardozo Journal of Law and Gender* 81-97, 81.

ages, even if the subject has freely given consent¹⁰⁷ and has been a specific criminal offence in England and Wales for almost 30 years, though at the time of writing, there have been no convictions.¹⁰⁸ The Crown Prosecution Service (CPS) has produced an action plan to circumvent barriers to prosecution¹⁰⁹ and the first prosecution has taken place.¹¹⁰ In contrast, *Cosmetic* procedures involving the genitalia of consenting adult women seem to be considered lawful.¹¹¹ It appears therefore that similar procedures are potentially lawful or unlawful depending on motivation, which is an unusual position for the law.

The names by which these processes are commonly known carry normative implications; as is clearly visible in relation to female genital *mutilation*. However, as Sheldon and Wilkinson point out, some of the arguments made against female genital mutilation, that it is a manifestation of oppressive behaviour toward women and that consent cannot be freely given for it, have also been applied to surgical

¹⁰⁷ Female Genital Mutilation Act 2003, preceded by the Prohibition of Female Circumcision Act 1985.

¹⁰⁸ I Torjesen, 'First UK prosecution for female genital mutilation moves a step closer' (2013) 346 *British Medical Journal* 1298.

¹⁰⁹ CPS, 'Female Genital Mutilation action plan launched' (23/11/2012) http://cps.gov.uk/news/latest_news/female_genital_mutilation_action_plan_launched (Accessed 27/02/2016).

¹¹⁰ S Laville, 'First FGM prosecution: how the case came to court' (04/02/2015) *The Guardian* <http://www.theguardian.com/society/2015/feb/04/first-female-genital-mutilation-prosecution-dhanuson-dharmasena-fgm> (Accessed 27/02/2016). The case, though, involved a doctor and relates to a repair of previous FGM for a woman who had just given birth, so the circumstances were unusual and Dr Dharmasena, the doctor involved in performing the repair, was found not guilty. See S Laville, 'Doctor found not guilty of FGM on patient at London Hospital' (04/02/2015) *The Guardian* <http://www.theguardian.com/society/2015/feb/04/doctor-not-guilty-fgm-dhanuson-dharmasena> (Accessed 06/03/2016).

¹¹¹ S Sheldon and S Wilkinson, 'Female genital mutilation and cosmetic surgery: regulating non-therapeutic body modification' (2002) 12 *Bioethics* 263-285, 269.

procedures commonly described as *cosmetic*.¹¹² The reason why women might consent to any of these interventions might be the perceived need to conform to certain physical ideals, which come about because women are supposed to look a certain way. If women can consent to cosmetic procedures, then it seems inconsistent that there is no possibility of consenting to FGM or conversely, if the latter is unlawful, then why are the former permitted?¹¹³ Kelly and Foster¹¹⁴ and Berer¹¹⁵ have made similar points. However, in practice, FGM is only rarely performed on freely consenting adult women¹¹⁶ and is generally carried out because of cultural and social ideas concerning the need for what is considered 'proper' sexual behaviour in women, in addition to the need to attain cosmetic ideals. FGM is considered to reduce female libido and to help women resist what are held to be illicit sexual acts¹¹⁷ within the relevant communities, and is therefore frequently regarded as an extreme form of discrimination against women.¹¹⁸

Whilst there are some parallels between FGM and genital intersex surgery, the former serves only a cultural function, often involves a child or young person beyond infancy and is *usually* not medicalised, but carried out by a traditional practitioner in less than clinically ideal circumstances.¹¹⁹ It therefore carries more physical risk and may be

¹¹² Sheldon & Wilkinson, above, n 111, 272.

¹¹³ Sheldon & Wilkinson, above, n 111, 273.

¹¹⁴ B Kelly and C Foster, 'Should female genital cosmetic surgery and genital piercing be regarded ethically and legally as female genital mutilation' (2012) 119 *British Journal of Obstetrics and Gynaecology* 389-392.

¹¹⁵ M Berer, 'Cosmetic Genitoplasty: it's female genital mutilation and should be prosecuted' (2007) 334 (7608) *British Medical Journal* 1335.

¹¹⁶ World Health Organization, 'Female genital Mutilation' (Feb 2014) <http://www.who.int/mediacentre/factsheets/fs241/en/> (Accessed 06/03/2016).

¹¹⁷ World Health Organization, above, n 116.

¹¹⁸ World Health Organization, above, n 116.

¹¹⁹ World Health Organization, above, n 116.

more traumatic than procedures performed under optimum medical and surgical conditions. If we lived in an ideal society where there were no problems associated with being 'different' in any way, the ideal way ahead might be to issue a complete ban on genital surgery for intersex children similar to that for female genital mutilation, but the situation is less clear. Life in our society may hold some difficulties for an intersex child, such as the little girl in the scenario with her distraught parents, and surgical intervention would be carried out in good faith to help all concerned. The culture in which a family lives undoubtedly does exert real force on their choices and actions. It is also a factor affecting the opinion of medical professionals and professionals working in this area of practice do not seem to be moving towards a ban on surgery.

Circumcision for non-medical reasons on a male child is currently regarded as lawful providing both parents, if there are two and both hold parental responsibility, give consent.¹²⁰ However there are jurisdictions under which it has been ruled unlawful. In 2012 a court in Cologne held that in the absence of medical necessity such a practice, with its inherent risks,¹²¹ should be viewed as harmful,¹²² though this was overturned a few months later.¹²³ It has been suggested that in England and Wales, the existing law does not protect the physical integrity of male children or

¹²⁰ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR at 345-346. The first instance decision was endorsed at the Court of Appeal, *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR at 307.

¹²¹ See, for example, Goodluck Caubergs, who bled to death aged one month following a home circumcision procedure carried out by Grace Adeleye, a midwife. She was found guilty of manslaughter in December 2012. N Evans, 'Circumcision Horror. Nurse guilty of manslaughter after baby bled to death after baby bled to death after 'botched £100 home operation using scissors' (15/12/2012) *Mirror* <http://www.mirror.co.uk/news/uk-news/circumcision-death-nurse-guilty-of-manslaughter-1490796> (Accessed 27/02/2016).

¹²² MT Johnson, 'Religious circumcision, invasive rites, neutrality and equality; bearing the burdens and consequences of belief' (2013) 39 *Journal of Medical Ethics* 450-455.

¹²³ M Chambers 'Circumcision ban overturned in Germany' (12/12/2012) *The Globe and Mail* <http://www.theglobeandmail.com/news/world/circumcision-ban-overturned-in-germany/article6288050/> (Accessed 27/02/2016).

their right not to receive inhumane treatment, and that these aspects have not been taken into account in the existing case-law (discussed in more detail in the section below).¹²⁴ The assumption usually made in English law is that circumcision will probably be in a male child's best interests if he lives in an environment where circumcision is the norm, but not if he lives in an environment where it is not. This is a position that continues to be argued for by some,¹²⁵ with others considering that this is not a sufficient good to counteract the child's right to bodily integrity.¹²⁶ So culture continues to be an important factor in the prevalence of male circumcision in England, though it has been suggested that the groups who practise circumcision hold responsibilities towards those in their society who feel they have been psychologically or physically harmed by it.¹²⁷ Overall, as far as male circumcision is concerned the present position is that cultural context is central in deciding where the child's best interests lie.

Is there any relevant case law?

The courts may become involved if there is disagreement about the appropriateness of a procedure, either because those with parental responsibility do not want it (and the medical team do) or because there is disagreement between those with parental responsibility or because a third party within (or even outside) the medical team caring for the child has worries the procedure is not in the child's best interests (and therefore not lawful) and pursues this via the courts. Finally, it is also possible that the medical team themselves may worry about the lawfulness of a procedure and seek a declaration to protect themselves

¹²⁴ H Gilbert 'Time to Consider the Lawfulness of Ritual Male Circumcision' (2007) *European Human Rights Law Review* (3) 279-294.

¹²⁵ J Mazor, 'The child's interests and the case for the permissibility of male infant circumcision' (2013) *Journal of Medical Ethics* 39 421-428

¹²⁶ RS Van Howe, 'Infant circumcision; the last stand for the dead dogma of parental (sovereign) rights' (2013) *Journal of Medical Ethics* 39 475-481

¹²⁷ Johnson, above, n 122

from litigation.¹²⁸ Though no intersex case has reached the English courts so far, there is case law concerned with situations that might be relevant.

The early sterilisation case, *Re D (a minor)*¹²⁹ illustrates the situation where a third party challenges the lawfulness of a procedure. D was aged eleven and suffered from Sotos' Syndrome, a condition characterised by accelerated growth, epilepsy, generalised clumsiness, emotional and behavioural difficulties with a level of intelligence at the lower end of the normal range. Supported by a consultant paediatrician and consultant gynaecologist, D's mother was keen that D be sterilised. The doctors involved had previously performed the same operation in similar circumstances.¹³⁰ D's sterilisation would probably have gone ahead, since all parties were agreed on this course of action, but D's educational psychologist heard about the plan and challenged the decision. Heilbron J held that the operation was irreversible and deprived D of her 'basic human right'¹³¹ to reproduce. It was impossible to be dogmatic about how D might progress; a future marriage was not out of the question and there was no reason to believe that she would not attain capacity to make up her own mind regarding contraception and sterilisation when she reached an appropriate age. It was held that:

a decision to perform an operation such as that proposed for non-therapeutic purposes on a minor was not solely within a doctors clinical judgment¹³²

Heilbron J thought that she could not 'conceive of a more important step than that proposed in this case'.¹³³ The procedure was not permitted.

¹²⁸ As in the adult sterilization case *F v West Berkshire Health Authority and another (Mental Health Act Commission intervening)* [1989] 2 All ER 545

¹²⁹ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326

¹³⁰ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326 at 333

¹³¹ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326 at 327

¹³² *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326 at 327

¹³³ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326 at 335

One of the important matters considered in making the judgment in *Re D* was that the girl in question would eventually be able to make her own decision. In many of the subsequent cases, it was common ground that the girl in question would never attain competence to make her own decision regarding her fertility.¹³⁴ One of the early cases involved a girl who was actually aged 17 years but with the mental age of a five or six year old.¹³⁵ The authorised sterilisation was felt to be entirely for her best interests, in order to avoid the pain and fear that it was felt would be associated with childbirth.¹³⁶ Since this time, it has been mandatory that the *sterilisation* of minors and others who lack competence should receive the sanction of the High Court in England and Wales; indeed failure to obtain this might result in criminal, civil or professional proceedings against the doctor concerned, as Lord Templeman made clear.¹³⁷

So is there any relevance here for the situation for intersex children? For there to be a parallel with *Re D*, it might be necessary for a third party challenge to be mounted to a decision made by the medical team and those with parental responsibility. Such challenges are in practice rare; for one thing it is unusual for a third party to know anything of what is proposed. However, modern management of complex paediatric problems involves a large clinical team, often composed of nurses, psychologists, psychiatrists, surgeons, gynaecologists, physicians, biochemists and geneticists. In the case of an intersex child, it might be possible that one or more individuals in the multidisciplinary team feel uneasy as to the appropriateness of surgical intervention and decide that the courts ought to decide the matter. As in *Re D* and in contrast to many of the sterilisation cases, intersex children will usually attain competence and be able to decide matters for themselves in due course. It might only

¹³⁴ For example, *In Re B (A Minor) (Wardship: Sterilisation)* [1988] A C 199

¹³⁵ *Re B (A Minor) (Wardship: Sterilisation)* [1988] A C 199

¹³⁶ *Re B (A Minor) (Wardship: Sterilisation)* [1988] A C 199

¹³⁷ *Re B (A Minor) (Wardship: Sterilisation)* [1988] A C 199 at 205-206.

take one campaigning medical professional to put a test case before the courts and if this came about, the logical conclusion might be that any decisions regarding appearance-altering surgery should wait until the child is able to make them for herself, or at least until her gender identity is clear. Although there is a body of medical opinion that holds that early surgical intervention is therapeutically appropriate and effective for intersex children,¹³⁸ it is worth considering that prior to *Re D* reaching court, several other sterilisations had been carried out on minors by the same team, who had not previously considered that it was anything other than appropriate and therapeutic.

On a small number of occasions the courts have considered male circumcision. Whilst some argue that there are therapeutic benefits,¹³⁹ male ritual circumcision is generally considered a non-therapeutic procedure¹⁴⁰ and not therefore serving the best medical interests but a matter that, in an appropriate cultural context, may serve other interests the child might possess (providing the child is male). Many male circumcisions are not performed by doctors in the health care setting, but carried out by traditional practitioners in the child's home, reiterating the fact that this is not primarily seen as a medical procedure.¹⁴¹ In contrast, as previously emphasised, surgery on the intersex child is still very much regarded as a *therapeutic* measure by medical practitioners, hence its

¹³⁸ F Yankovic & others, above n 4.

¹³⁹ Task Force on Circumcision, 'Circumcision Policy Statement' (2012) 130 *Pediatrics* 585-586.

¹⁴⁰ The BMA Consider that neither benefit nor harm has been proven unequivocally, providing that the procedure is competently carried out. See The Law and Ethics of male circumcision: Guidance for Doctors, June 2006, 1 <http://bma.org.uk/-/media/files/pdfs/practical%20advice%20at%20work/ethics/circumcision.pdf> (Accessed 06/03/2016).

¹⁴¹ See for example A Fogg, 'Male Circumcision: let there be no more tragedies like baby Goodluck' <http://www.guardian.co.uk/commentisfree/2012/dec/17/male-circumcision-baby-goodluck> (Accessed 06/03/2016).

inclusion in the consensus statement.¹⁴² However just as for any other form of '*normalising*' surgery, it is an attempt to ensure that the child is accepted in his or her community thereby making life easier, just as male circumcision might in a community where it is the norm. For this reason, it is possible that the courts may consider that male circumcision and intersex surgery share some common ground.

The three cases of male circumcision considered in detail by the courts involved difficult family circumstances and parental disagreement regarding cultural and religious practices.¹⁴³ In each case, one of the major questions was whether or not the procedure could go ahead with the consent of one parent only. In the first case of its kind, *Re J*,¹⁴⁴ J was born to a Turkish father, a 'non-practising Muslim', and English mother, a 'non-practising Christian', who met whilst the mother was on holiday in Turkey. They lived initially in Turkey and subsequently in England. When the marriage failed J lived with his mother but contact with his father was maintained. He only had contact with Islam when he met his father, but this was not of a markedly religious nature. J was aged 5 years¹⁴⁵ at the time of the first judgment, so was past infancy. Wall J considered that, in the circumstances under which J lived, it was likely that ritual circumcision would be an adverse event, surrounded by tension and stress, contrasting this with the same event in the context of a Muslim family where it would be an event of 'celebration and fulfilment'.¹⁴⁶ He therefore decided that the circumcision should not take place; under the Children

¹⁴² CP Houk & others, above, n 17.

¹⁴³ See *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345. See also *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307, *S (Children)* [2004] EWHC 1282 (Fam) and *Re S (change of name: cultural factors)* [2001] 3 FCR 648.

¹⁴⁴ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 for the first instance decision and *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307 for the Appeal Court decision.

¹⁴⁵ He was born in 1994. *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 348.

¹⁴⁶ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 365.

Act 1989 Section 2(7)¹⁴⁷ and taking into account the guidance given by the BMA, he considered that the consent of both parents was needed.¹⁴⁸ The father appealed against the decision, arguing that J was the child of a Muslim father and therefore was born a Muslim,¹⁴⁹ but the Court of Appeal upheld the first instance judgment.¹⁵⁰

*Re S (Children)*¹⁵¹ concerned the application by the mother of two children for them to become practising members of Islam; this would involve the younger male child, K, having to undergo ritual circumcision. Their father, from whom the mother was separated, was a Jain and actively opposed the application. The children lived with their mother and regularly and frequently spent time with their father. The child's paternal grandmother was very religious, and although K's father was not, he tried to adhere to the major tenets of his faith. Jainism strictly forbids circumcision, as it is seen as a violent and mutilating act. During the marriage, the children were brought up in the Jain community but following the breakdown of the marriage the mother lived with her family and children in a fully Islamic household and considered K's circumcision essential if she ever were to marry again as a Muslim. Baron J decided that the request was made by the mother in order to fulfil *her own* best interests rather than those of her child and that it was in the children's best interests to have contact with both Islam and Jainism and decide for themselves which faith, if any, they wished to follow when they were sufficiently mature.

¹⁴⁷ 'Where more than one person has parental responsibility for a child, each of them may act alone and without the other (or others) in meeting that responsibility; but nothing in this part shall be taken to affect the operation of any enactment which requires the consent of more than one person in a matter affecting the child'.

¹⁴⁸ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 367-370.

¹⁴⁹ *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307 at 312

¹⁵⁰ *Re J (child's religious upbringing and circumcision)* [2000] 1 FCR 307 at 307

¹⁵¹ *S (Children)* [2004] EWHC 1282 (Fam)

The third case, *Re S (change of names: cultural factors)*,¹⁵² concerned marital breakdown between a Muslim mother and Sikh father. Their son was to be brought up in the Muslim community and with a Muslim name¹⁵³ and though the father did not desire his son to be circumcised *he did not actually voice any objection to it*.¹⁵⁴ He accepted that his son was to live a fully Muslim life in the future and the fact that the father did not actively oppose circumcision and other aspects of the child's future life is probably a defining feature of this case, contrasting with the two other cases. Wilson J decided that in order to live fully as a Muslim, the boy could be circumcised when the time came.

The courts in these situations have considered the child's best interests in the wider social context, dependent on the family and cultural environment in which the child is to live. Though male infant circumcision is not normally considered to be necessarily in the child's best *medical* interests, it can be held to fulfil other interests that he has. The test for this is that he is to be brought up in a family in which the procedure is seen to be important and meaningful and neither parent actively opposes it. It is possible that a similar argument might be constructed should the courts ever consider infantile genital surgery on an intersex child. It could be argued that any benefits for the child would be nullified unless she is to live in an environment where they are clearly acknowledged as benefits.

A retrospective legal challenge may arise if a person who had undergone such surgery later sued for battery when he or she reaches the age of majority. Such a person, considering that surgery had harmed her, might sue both doctors and parents, arguing that what was done was not in her best interests. To my knowledge, in England and Wales there has never been a case involving intersex put before the courts on this premise however, in another jurisdiction a case of male circumcision has been

¹⁵² *Re S (change of name: cultural factors)* [2001] 3 FCR 648.

¹⁵³ *Re S (change of name: cultural factors)* [2001] 3 FCR 648 at 648.

¹⁵⁴ *Re S (change of name: cultural factors)* [2001] 3 FCR 648 at 660.

under consideration. An adult, William Stowell, of New York, objected to his circumcision as an infant and attempted to sue the doctor who performed the procedure. His case was settled out of court in 2003 when it was deemed that there had been inadequate consent for the procedure.¹⁵⁵

Improving the consent process

Infantile genital surgery is permanent and at least some of those who underwent it in the past have subsequently considered that they have been harmed by it. There is no single easy answer to fit all clinical scenarios or all children affected by intersex conditions, so it might be difficult to apply the circumstances pertaining to any given case more generally even if there were case law in this area. Whilst it might be possible to envisage a model of decision-making somewhat similar to that used for the sterilisation of a minor, or male circumcision, the situation in intersex is perhaps even more complex. Consequently, a preferable and more flexible way of trying to ensure that the risk of harm to intersex infants is minimised is to examine the consent process and try to make it as thorough and comprehensive as possible.

Such an approach was the outcome of several court cases involving intersex children in Bogota, Colombia, Central America, in 1995. The first case involved a young man who petitioned the Colombian Constitutional Court; he did not have an intersex condition but his circumstances were relevant. His penis had been destroyed accidentally in infancy and he was brought up as a female, a decision suggested by his medical team with the consent of his parents,¹⁵⁶ but in adulthood he considered that this

¹⁵⁵ abc News, 'Man sues for loss of foreskin'
<http://abcnews.go.com/GMA/story?id=127183&page=1> (Accessed 06/03/2016).

¹⁵⁶ Though some male children who lacked external genitalia have been brought up successfully as females, so experience suggests that failure was not inevitable here.

decision had proved detrimental to his wellbeing.¹⁵⁷ The court agreed and held that in the future those with parental responsibility could not consent to attempted manipulation of their child's gender identity.¹⁵⁸ Later in the same year, the Constitutional Court of Colombia was asked to consider the status of parental consent to genital surgery on two children aged two years and eight years, both of whom had been born with intersex conditions and for whom such surgery was proposed.¹⁵⁹ The medical team were concerned that the decision described above was relevant and applied to the court.

When considering the matter, the court held that surgery could be considered a violation of bodily integrity partly motivated by the parents' response to their child's difference to perceived '*normality*'. The court rejected an absolute prohibition of medical and surgical treatment and held that surgery could take place but the parental authority to permit this was to be qualified. Medical communities were told to develop a new level of informed consent that must be written, fully informed (including information about outcomes and alternatives), and must be given over an extended period of time.¹⁶⁰ Parents could only give consent for children aged five and under, not least because in those over five years of age¹⁶¹

¹⁵⁷ I gained this information from the Intersex Society of North America website. <http://isna.org/node/21> (Accessed 06/03/2016). The case is *The Decision of YY* Corte Constitucional [CC] [Constitutional Court], octubre 23, 1995, Sentencia T-477/95, Gaceta de la Corte Constitucional [GCC] (Colom.) (See also chapter 5, 137 onwards).

¹⁵⁸ Though as discussed later, this surgery does not actually determine sexual identity or gender. There is no one physical entity that does this.

¹⁵⁹ <http://www.isna.org/node/97>, (Accessed 06/03/2016). See ISNAs 'Amicus Brief on Intersex Genital Surgery'.

¹⁶⁰ Commentary at <http://isna.org/node/21>, (Accessed 06/03/2016). (The cases are *The Decision of XX* Corte Constitucional [CC] [Constitutional Court], May 12, 1999, Sentencia SU- 337/99, Gaceta de la Corte Constitucional [GCC] (Colom.) *The decision of NN* Corte Constitucional [CC] [Constitutional Court], Aug 2, 1999, Sentencia T-551/99, Gaceta de la Corte Constitucional [GCC] (Colom.)

¹⁶¹ Five years is younger than would be considered sufficiently mature to possess autonomy in England and Wales, though the General Medical Council suggests that the views of all children should be taken into account as far as

surgery was regarded as less urgent.¹⁶² This court case was influential in that it was one of the sources of information that led eventually to the consensus statement of medical professionals working in the area referred to earlier.¹⁶³

In the judgment from the Colombian Court, the main focus was on the process of consent taking. There is a need for families to have all possible information before deciding what is in their child's best interests. In relation to the hypothetical child discussed in this paper it would be important for the parents to know all the information about outcome and, if they wish, to meet with patient and parent support groups. In the UK, the GMC generally advises partnership between the patient, or parent(s), and doctor to try to obtain fully informed consent,¹⁶⁴ and in the case of intersex children it would be important for discussion to be in depth and to include other professionals, such as psychologists and specialist nurses. There are already guidelines published by groups of professionals involved in the management of intersex children, which should prove informative,¹⁶⁵ and Ahmed makes suggestions as to how discussions

possible when assessing their best interests- see '0-18 years: guidance for all doctors' 2007 http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp 8-9, (Accessed 06/03/2016). Furthermore there is some evidence that children under 7 years are much more aware of medical matters than is often acknowledged. See Alderson, above, n 25.

¹⁶² <http://isna.org/node/21> (Accessed 06/03/2016).

¹⁶³ Hughes & others, above, n 15.

¹⁶⁴ General Medical Council, 'Consent: patients and doctors making decisions together' (June 2008) http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp (Accessed 06/03/2016).

¹⁶⁵ FS Ahmed, JC Achermann, W Arit, A H Balen, G Conway, Z L Edwards, S Elford, I A Hughes, L Izatt, N Krone, H L Miles, S O'Toole, L Perry, C Saunders, M Simmonds, A M Wallace, A Watt & D Willis. 'UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development' (2011) 75 *Clinical Endocrinology* 12; Consortium on the Guidelines for the Management of Disorders of Sex Development in Childhood (2006) at <http://www.dsdguidelines.org/files/clinical.pdf> (Accessed 06/03/2016); Hughes & others, above, n 15.

regarding all aspects of management should proceed, rather than specifically surgery.¹⁶⁶ Time is needed in a quiet and peaceful setting with all information and access to written and online material. Professionals external to the team may be involved on different occasions according to need.¹⁶⁷ Although guidelines do not have the force of law, they do represent a model of good practice and can be used as evidence that an appropriate procedure is being followed and that treatment interventions are ‘proper’,¹⁶⁸ should this ever be under scrutiny by the courts. At the present time, there is no guidance from the GMC or the National Institute for Health and Care Excellence (NICE) dealing with the specific topic of intersex, though if these were available they would serve to strengthen the authority of the advice and it would not be difficult to adopt these existing protocols. The existence of GMC guidelines would lead to the possible sanction of professional misconduct if they were flagrantly flouted. However judicial guidance from the English courts might provide clarification of the precise requirements for the consent procedure, just as in the case of non-therapeutic male circumcision or sterilisation. In the absence of a legal test case however, it is difficult to know precisely how the matter might be viewed.

The current standard is for all cases of intersex children and adolescents to be managed by experienced multi-disciplinary teams of endocrinologists, paediatric urological surgeons, paediatric gynaecologists, psychologists, specialist nurses and also representatives of faith groups, in centres where there is experience of these conditions with the aim of providing ‘holistic’ management of each infant or child.¹⁶⁹ A relatively small number of tertiary paediatric centres in the UK do

¹⁶⁶ Ahmed & others, n 165, 14.

¹⁶⁷ Ahmed & others, n 165, 14.

¹⁶⁸ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 at 586.

¹⁶⁹ CE Brain, SM Creighton, I Mushtaq, PA Carmichael, A Barnicoat, JW Honour, V Larcher & JC Achermann, ‘Holistic management of DSD’ (2010) 24 *Best Practice & Research Clinical Endocrinology & Metabolism* 335-354.

provide services for intersex children meaning that it is not difficult to spread information regarding guidelines for optimum management to all involved. And, as there are a relatively small number of teams managing intersex children it would not be too difficult a task to devise and promote uniform consent procedures.

It may also help to use the skills of clinical ethics committees, where this service is available. There needs to be more research into how best to use clinical ethics groups,¹⁷⁰ but one of the uses of this resource might be to provide input into multi-disciplinary teams, assisting discussions regarding what might constitute best interests in difficult clinical circumstances. Though accessibility is slowly widening, this is not a resource that is currently universally available, formally recognised or funded in all Trusts in the UK.¹⁷¹

Conclusions

Surgery carried out on those who are not old enough to give their consent requires the consent of those with parental responsibility and any procedure performed must be in the child's best interests. In some situations this is extraordinarily difficult to assess but is, however, only considered formally in specific circumstances, such as when there is a disagreement between two people with parental responsibility or between the parent(s) and doctors. Therefore if both parents and medical team agree on a course of action, it is assumed that it will be in the child's best interests. It has been shown however, that this could mean that children with conditions that are a particularly difficult and troubling area of medical management, such as intersex, are given insufficient protection against potentially harmful surgery.

Even in the relatively recent past, some of the children who received surgery have later regretted the decision made by their parents. However,

¹⁷⁰ AM Slowther, L McClimans, C Price 'Development of Clinical Ethics Services in the UK: a national survey' (2012) 38 *Journal of Medical Ethics* 210-214, 213.

¹⁷¹ Slowther & others, above, n 170, 214.

not everyone has; some have felt grateful for it,¹⁷² and the parents concerned considered that they were taking on themselves the burden of making a difficult decision that might otherwise have fallen to their child.¹⁷³ Looking at the law in England and Wales, it seems that there is no protection against carrying out a procedure requested by the child's parents when they are in the initial phase of shock and bewilderment following the birth of their intersex child, as for example described in the scenario discussed above on page 194, where the parents who were expecting a healthy boy have suddenly become aware that they are faced by something else.

For an infant or child who cannot have capacity to make decisions regarding medical care, those with parental responsibility will be faced with a decision that may have major consequences for the child's future and, as in the scenario on page 194, many factors will influence the parents in coming to their decision. The legal constraints limiting surgical intervention on children and infants are very specific and have never been applied to an intersex child. Perhaps at the present time the best solution for a difficult decision such as the one discussed, is to focus on the consent process and to give the family time to think and as much support and information as they need regarding all aspects of what is planned. Specific GMC or NICE guidelines would strengthen this. However, perhaps the most helpful form of clarification would result from judicial consideration of these matters in the courts, should such a case ever be considered in this forum.

¹⁷² Holmes, above, n 85, 16.

¹⁷³ K Karkhazis, above, n 10, 203.

CHAPTER 8:

WHAT DO WE DO ABOUT WOMEN ATHLETES WITH TESTES?¹

Abstract

Elite sport and the measures imposed to prevent 'men' from 'cheating' by posing as women in women's events cast interesting light on notions of sex and gender. Some women have testes, organs that produce testosterone, because they are trans women or they have an intersex state. Testosterone is recognised as a performance-enhancing substance in at least some circumstances and, therefore, women with testes may possess an advantage when competing in some sports against women without testes, though this has never been subjected to rigorous scientific testing. The International Olympic Committee (IOC) and the International Association of Athletics Federation (IAAF) have decreed that such individuals can compete only if they undergo medical and surgical treatment, which is likely to mean gonadectomy. This might be considered to impose an unethical demand on the individual concerned and constitute an infringement of bodily autonomy for that individual. It also suggests a binary view of sex/gender that is simplistic and not scientifically accurate. I discuss this approach and consider alternative methods of approaching the problem of women with testes in athletics.

The problem: women with testes?

These kinds of women should not run with us....For me she is not a woman. She is a man. ²

¹ MJ Newbould, 'What do we do about women athletes with testes?' *Journal of Medical Ethics* Published online 6 November 2015 doi:10.1136/medethics-2015-102948

² Elisa Piccione, who finished 6th in the race that Caster Semenya won. Quoted in WL Adams, 'Could this women's world champion be a man?' (21/08/2009) *Time*. <http://content.time.com/time/world/article/0,8599,1917767,00.html> Accessed 31/05/2016.

In 2009 Caster Semenya, an 18-year-old South African won the women's world 800-metre world title by two and a half seconds. Almost immediately some of the other competitors called her victory into question, claiming that she was a man.³ Caster underwent medical investigations, the results of which were not publicly disclosed. She was not permitted to compete in any other events by the IAAF, the governing body for track and field athletics, until July 2010 by which time she had presumably been fully assessed and received whatever medical therapy was considered necessary.⁴

It is considered a point so obvious as to be beyond argument that humans are sexually dimorphic and that distinguishing between individuals of different sex is a simple matter. However, like Caster Semenya, many individuals are not easily categorized into one of the two sex groups. For example, in 2012, four athletes competing as women were found to have testosterone levels in the male range during routine drug testing.⁵ On further investigation, these women were found to have a 'male' set of chromosomes (46,XY) and functional testes. They have what is regarded medically as a Disorder of Sex Development (DSD), sometimes referred to as intersex.⁶ Specifically, these four individuals were found to have a distinct medical condition known as 5 α -reductase

³ S Camporesi & P Maugeri, 'Caster Semenya: sport, categories and the creative role of ethics' (2010) 36 *Journal of Medical Ethics* 378-379.

⁴ CF Sullivan, 'Gender verification and gender policies in elite sport: eligibility and "Fair Play"' (2011) 35 *Journal of Sport and Social Issues* 400-419.

⁵ P Fénichel, F Paris, P Philibert, SG Hiéronimus, L Gaspari, J-Y Kurzenne, P Chevalier, S Bermon, N Chevalier & C Sultan, 'Molecular diagnosis of 5 α -reductase deficiency in 4 elite young female athletes through hormonal screening for hyperandrogenism' (2013) 98 (6) *Journal of Clinical Endocrinology and Metabolism* E1055-E1059.

⁶ For a basic definition of this group of medical states see IA Hughes, C Houk, SF Ahmed & PA Lee, 'Consensus statement on management of intersex disorders' (2006) 91 *Archives of Diseases of Childhood* 554-563.

deficiency, in which some (though not all) areas of the body lack the enzyme needed to activate testosterone. Therefore, despite the presence of testes, they develop some male anatomical features and some female features. In this condition, known as partial androgen insensitivity syndrome,⁷ individuals are frequently born with female appearing external genitalia and may be brought up as females. They are therefore women with testes. In this paper, I will make the assumption that a person who self-identifies as a woman is a woman. Whilst I acknowledge that the question as to whether self-identification is a sufficient criterion for membership of the female sex or gender is a substantive one that is currently the subject of much debate in ethical, legal, political, sociological and other academic discourse, this complex topic is outside the scope of this short paper and will not be discussed further.⁸

The actual prevalence of intersex is uncertain, with estimates varying between 0.018% and 1.7% of the population.⁹ Therefore when routine 'gender' verification was attempted in international athletic competition, the IOC encountered difficulty. The major rationale of testing was to identify men masquerading as women as a means of cheating.¹⁰ Testing was routine from the 1960s to the 1990s.¹¹ Methods used included appearance of the genitalia,¹² chromosomal tests,¹³ and tests for a gene

⁷ Fénichel & others, above, n 5.

⁸ I am indebted to the editor for bringing this important matter to my attention and suggesting that it should be acknowledged in this paper.

⁹ L Sax, 'How common is intersex? A response to Anne Fausto-Sterling' (2002) 39 *The Journal of Sex research* 174-178.

¹⁰ JL Simpson, A Ljungqvist, MA Ferguson-Smith, A de la Chapelle, LJ Elsas, AA Ehrhardt, M Genel, EA Ferris & A Carlson, 'Gender verification in the Olympics' (2000) 284 *Journal of the American Medical Association* 1568-1569.

¹¹ Simpson & others, above, n 10.

¹² Camporesi & Maugeri, above, n 3.

¹³ Simpson & others, above, n 10.

closely associated with the development of the testis.¹⁴ All the methods used identified some individuals who were competing as women but whose test gave a 'male' result. At least some of these athletes may have been women with functional testicular tissue. As research has progressed, it seems that sex development is a highly complex matter, with many points at which there might be variation. There are multiple genes that play a role in the development of an individual's sex. Rosario suggests that there are at least 'a dozen or more genes, each conferring a small percentage likelihood of male or female sex that is still further dependent on micro- and macro- environmental interactions'.¹⁵ Thus there is no single or multiple set of biological parameters that confer a certain sex on an individual and it seems likely that many more people who do not fall easily into male or female will be identified, both within sport and in society in general.

It is not only intersex women who have testicular tissue. In England, under the Gender Recognition Act 2004 trans individuals do not have to undergo any medical or surgical treatment in order to achieve recognition in their self-identified gender. This means that individuals possessing the characteristics of one biological sex are able to identify themselves for all legal purposes as belonging to the opposite gender. Trans women will possess testes, unless they have had surgery.

Women with testes raise a fundamental problem in athletics –how do we decide who can compete as a woman? At the present time women with testes producing functioning testosterone and whose bodies are able to respond to it are not permitted to compete as women. The IAAF¹⁶ and

¹⁴ Simpson & others, above, n 10.

¹⁵ VA Rosario, 'Intersex and the molecular deconstruction of sex' (2009) 5 (2) *A Journal of Lesbian and Gay Studies* 267-284.

¹⁶ IAAF regulations governing eligibility of females with hyperandrogenism to compete in women's competition. www.iaaf.org
<http://www.iaaf.org/download/download?filename=fd073e9a-e217-431f-b06b-73e5349bd874.pdf&urlslug=IAAF%20Hyperandrogenism%20Regulations%20>

IOC¹⁷ recognise that such individuals are women and this therefore precludes them from competing as men; the regulations emphasize that athletic competition requires that competitors are divided strictly by gender^{18, 19} into male or female and that this division must be respected.²⁰ Therefore an athlete identifying as a woman with testicular tissue producing functional testosterone will be unable to compete *at all* in elite competitions unless she fulfils the IAAF and IOC requirements.

The current solution to the problem

For the IOC and IAAF, intersex women^{21, 22, 23} and trans women^{24, 25} can compete in the female group only if they have no functional testicular

[%20Explanatory%20Notes%20-%20In%20force%20as%20from%201st%20May%202011](#)

Accessed 31/05/2016.

¹⁷ IOC addresses eligibility of female athletes with hyperandrogenism.
<http://www.olympic.org/news/ioc-addresses-eligibility-of-female-athletes-with-hyperandrogenism/124006> Accessed 31/05/2016.

¹⁸ Both the IOC and the IAAF regulations on trans individuals state that trans men may compete as men. See IAAF Regulations Governing Eligibility of Athletes Who Have Undergone Sex Reassignment to Compete in Women's Competitions .pdf <http://www.iaaf.org/about-iaaf/documents/medical> Accessed 31/05/2016.

¹⁹ Statement of the Stockholm consensus on sex reassignment in sport
http://www.olympic.org/documents/reports/en/en_report_905.pdf Accessed 31/05/2016.

²⁰ IAAF regulations governing eligibility of females with hyperandrogenism to compete in women's competition, above, n 16.

²¹ IAAF regulations governing eligibility of females with hyperandrogenism to compete in women's competition, above, n 16.

²² IOC addresses eligibility of female athletes with hyperandrogenism, above, n 17.

²³ IOC regulations on female hyperandrogenism. 2012
http://www.olympic.org/Documents/Commissions_PDFfiles/Medical_commission

tissue.²⁶ With regard to trans women, the IOC Medical Commission decided in October 2003 that competition in their acquired gender is permitted only if they have completed legal, medical and surgical reassignment, including gonadectomy, genital surgery and hormone therapy.²⁷

In 2011 the IOC decided that any women found to have an abnormally high testosterone (and no resistance to androgens) or to show 'male characteristics' should be evaluated by a panel of experts before being declared eligible to compete as a woman.²⁸ Women with testes and total resistance to androgens (a condition referred to as complete androgen insensitivity syndrome) do not develop any characteristics associated with high testosterone and therefore are eligible to compete as women.²⁹ If considered ineligible for competition, the athlete needs to fulfil conditions stipulated by the IOC or IAAF before being permitted to compete in women's events again. The exact conditions will depend on the findings of the panel. Whilst gonadectomy for those with testicular tissue is not specified, this is presumably what is implied, since it would

[/2012-06-22-IOC-Regulations-on-Female-Hyperandrogenism-eng.pdf](#) Accessed 31/05/2016

²⁴ Both the IOC and the IAAF regulations on trans individuals state that trans men may compete as men. See IAAF Regulations Governing Eligibility of Athletes Who Have Undergone Sex Reassignment to Compete in Women's Competitions .pdf <http://www.iaaf.org/about-iaaf/documents/medical> Accessed 31/05/2016.

²⁵ Statement of the Stockholm consensus on sex reassignment in sport, above, n 19.

²⁶ K Karkazis, R Jordan-Young, G Davis & S Camporesi, 'Out of bounds? A critique of the new policies on hyperandrogenism in elite female athletes' (2012) 12 (7) *American Journal of Bioethics* 3-16.

²⁷ Statement of the Stockholm consensus on sex reassignment in sport, above, n 19.

²⁸ IOC addresses eligibility of female athletes with hyperandrogenism, above, n 17.

²⁹ IOC addresses eligibility of female athletes with hyperandrogenism, above, n 17.

be the only method of reducing testosterone to the level acceptable to the IOC and IAAF.

Is it unfair if women with testes compete as women?

In an attempt to achieve fairness, all sports are bound by rules. Those wishing to compete in that sport must agree to abide by them as a condition of taking part.³⁰ Whilst the need for rules in general is understood, the fairness and appropriateness of individual regulations can be challenged. Considering the rules concerning women with testes, Karkazis asks 'does endogenous testosterone actually confer athletic advantage in a predictable way...?' and 'If there is an advantage from a naturally occurring high testosterone, is that advantage *unfair*?'³¹ The theory behind sex segregation in athletics is based on the premise that there is an advantage and that this is unfair. The World Anti-Doping Agency (WADA) has proscribed *exogenous* administration of testosterone³² and the IOC says, with respect to *endogenous* testosterone:

The androgenic effects on the human body explain why men perform better than women in most sports and are, in fact, the very reason for the distinction between male and female competition in most sports. Consequently, women with hyperandrogenism generally perform better in sport than other women.³³

³⁰ S Loland & M McNamee, 'Fair play and the ethos of sports: an eclectic philosophical framework' (2000) 27 *Journal of the Philosophy of Sport* 63-80.

³¹ Karkazis & others, above, n 26.

³² C Cooper, 'Drug cheating the Olympics: who, what, and why?' (07/07/2012) 380 (9836) *The Lancet* 21-22.

³³ IOC addresses eligibility of female athletes with hyperandrogenism, above, n 17.

It is therefore part of the rules that high endogenous testosterone is *not* considered fair if the individual concerned is to compete as a woman. However, the hypothesis that women with testes have an advantage has not been subjected to close scientific scrutiny.³⁴ High levels of testosterone may assist a predisposition to be faster and more powerful, but athletic ability depends on a much wider range of factors such as natural talent for the sport, genetic composition, personal interest and motivation, appropriate training, nutrition and so on. The potential benefits of a higher than normal level of testosterone may never be realized in the absence of these other factors.

What constitutes fairness in sport is also open to question. It depends, to some extent, on what the sport's purpose is held to be. Normative frameworks can broadly be classed as instrumentalist, performance and performer theories.³⁵ Instrumentalist theories hold that sport serves an external purpose (political or economic, say) and, itself, has no independent moral framework. The morality of sport is therefore dependent on the external goals, which may or may not have a moral framework.³⁶ The second type of theory, based on *performance*, holds that the value of sport is the continuing improvement of physical achievement by the constant edging forward of records.³⁷ The ethical framework in terms of such a theory depends on a notion of fairness that emphasizes precision in measurement and equality of external conditions.³⁸ In 'performance' theories, constraints on physical

³⁴ NA Xavier & JB McGill, 'Hyperandrogenism and intersex controversies in Women's Olympics' (2012) 97 *Journal of Clinical Endocrinology & Metabolism* 3902-3907.

³⁵ S Loland, 'Normative theories of sport' (2004) 31 *Journal of the Philosophy of Sport* 111-121.

³⁶ Loland, above, n 35.

³⁷ Loland, above, n 35.

³⁸ Loland, above, n 35.

enhancement or limitations on physical characteristics that assist performance may be considered undesirable³⁹ and use of all available technology may be permitted. In this ethical framework, it is unlikely that women with high testosterone would be considered to be cheating. Rather, they would be considered to possess a potential advantage that may assist in producing a better performance.

Neither instrumentalist nor performance theories are considered to embody the ideals of sport expressed by the IOC and IAAF. Sport is considered to be an aspect of idealized human development for the individual *performer* and a way of 'building a peaceful and better world by educating youth. Sport should be practised without discrimination of any kind and in the Olympic spirit, which encompasses friendship, solidarity and fair play.'⁴⁰ Fairness is centred on equality of opportunity, but, as discussed by Henne, it is not entirely clear what Olympic spirit and fair play mean. The terms suggest deals of purity and *naturalness* for competing athletes, both of which are also difficult to define.⁴¹ As far as possible, individuals must have the opportunity to realize their potential and compete against those who are their equals.⁴² In this type of 'performer' theory, it is important that inequalities are compensated for, as far as is possible. It is in this context that gender segregation is considered justified and that women with testes are not permitted to compete as women.⁴³

³⁹ C Tamburrini, 'What's wrong with doping?' in T Torbjörn & C Tamburrini (eds), *Values in Sport* (London: Taylor & Francis, 2000), 200-217, 215.

⁴⁰ Olympism in Action, part of the Website of the International Olympic Organisation <http://www.olympic.org/olympism-in-action> Accessed 31/05/2016.

⁴¹ K Henne, 'The "science" of fair play in sport: gender and the politics of testing' (2014) 39 *Signs* 787-812.

⁴² Loland, above, n 35.

⁴³ Loland, above, n 35.

Is it fair to impose gonadectomy on women athletes with testes?

The need to undergo castration and other surgical and medical intervention is imposed on those women with testes wishing to pursue a career in elite sport. This is not something required for those following most other careers. It can be argued that it is too great a demand. It means undergoing surgery with the risks and morbidity entailed by this. It could also mean sacrificing fertility as a male for a trans woman, although this is usually not the case for intersex women since testicular tissue in this context has typically lost fertility.⁴⁴ There is a further problem with the demands made by the IOC on trans women. It is at least possible to see that there might be a reason for gonadectomy, but it is difficult to see how *genital* (that is penile and scrotal, rather than testicular, surgery) could be seen as influencing performance. This does not have any effect on testosterone level but the IOC requires that a trans woman athlete must undergo it before competing as a woman.⁴⁵ As mentioned previously, the Gender Recognition Act 2004 does not impose medical or surgical intervention on trans women in order to be recognized as women.⁴⁶ The fact that the IOC and the IAAF do require some sort of medical intervention for recognition is therefore at variance with the legal situation in some jurisdictions.⁴⁷

⁴⁴ A Galani, S Kitsiou-Tzeli, C Sofokleous, E Kanavakis & A Kalpini-Mavrou, 'Androgen insensitivity syndrome : clinical features and molecular defects' (2008) 7 (3) *Hormones (Athens)* 217-229.

⁴⁵ Statement of the Stockholm consensus on sex reassignment in sport, above, n 19.

⁴⁶ J Coggon, N Hammond & S Holm, 'Transsexuals in Sport- Fairness and Freedom, Regulation and Law' (2008) 2 (1) *Sports, Ethics and Philosophy* 4-17. Accessed at <http://www.tandfonline.com/doi/full/10.1080/17511320801896091> (accessed 31/05/2016)

⁴⁷ Coggon & others, above, n 46.

It might be argued that the possession of testes is no different to many other physical characteristics. Individuals differ in all sorts of possible ways and there are many other genetic differences that might confer advantages for physiological reasons.⁴⁸ It will always be the case that those of smaller stature will be at a disadvantage in almost all athletic events in comparison to taller and larger individuals, but there is no attempt to try to nullify the effects of these variables between individual performers in an attempt to impose fairness. One might argue that it is simply not fair that someone as fast as Usain Bolt is allowed to compete at all. Or to use another example, many basketball players are freakishly tall or have large hands, but this is not usually regarded as a form of cheating⁴⁹ or something that needs to be modified surgically before they can compete. Clearly these are physical advantages that assist the sportsperson in performance in his or her chosen field but it seems that women with testes are regarded as more problematic, perhaps in part because their existence interrogates the generally held idea of a clear gender binary and contravenes the notion of what is 'natural' for a woman.

Are there alternative solutions?

There are many reasons why it is important that women are able to compete in elite high profile sports. As pointed out by Schneider,⁵⁰ in many societies men dominate sport and cultural affairs in general. To limit women's participation in sport may only serve to increase this

⁴⁸ Xavier & others, above, n 34.

⁴⁹ L Hercher, 'Gender verification: a term whose time has come and gone' (2010) 19 *Journal of Genetic Counselling* 551-553.

⁵⁰ AJ Schneider, 'On the definition of 'woman' in the sport context' in T Torbjörn & C Tamburrini (eds), *Values in Sport* (London: Taylor & Francis, 2000) 123-138, 135.

dominance.⁵¹ Female athletes can provide strong and inspiring role models in countries where women's freedoms are restricted. This is an important principle of the Olympic movement.⁵² If gender categories were to be abolished, a solution argued for by Tännsjö,⁵³ and athletics involved the fastest and strongest competitors of either gender, this might mean that very few (or, perhaps, no) women would ever compete in the very high profile events, such as the sprint races. Tännsjö points out that there are sports in which there is no sex segregation and women excel, such as the equestrian sport of dressage. The female dominance is not considered a reason to introduce a male only competition.⁵⁴ However, having less men competing in dressage is very different to making it near impossible for women to compete in sprint races.

Might it be possible to devise a system in which gender categories are abolished but in which athletes are streamed on the basis of some other biological character? Any biological parameter or combination of parameters could be used, such as height or weight or a combination of them. It might be possible to devise a system of having multiple categories, based on physical abilities and parameters, in a similar way to the system used in the Paralympics, where physical impairment is classed into into one of 8 groups.⁵⁵ However, the argument against this system is that it would be complex to administer and would not guarantee women's participation.

⁵¹ Schneider, above, n 50, 137.

⁵² Official website of the Olympic Movement, 'Looking ahead to empower women and girls through sport' <http://www.olympic.org/news/looking-ahead-to-empower-women-and-girls-through-sport/244042> Accessed 31/05/2016.

⁵³ T Tännsjö, 'Against sexual discrimination in sports' in T Torbjörn & C Tamburrini (eds), *Values in Sport* (London: Taylor & Francis, 2000) 101-115

⁵⁴ Tännsjö, above, n 53, 114.

⁵⁵ S Tweedy, EM Beckman & MJ Connick, 'Paralympic classification: conceptual basis, current methods, and research update' (2014) 6 *Journal of Injury, Function and Rehabilitation* S11- S17.

Foddy and Savulescu have suggested that it cannot be just to use gender alone to stream athletes, because, as we have already seen, high testosterone levels and male gender do not correlate exactly.⁵⁶ Rather than stream people on the basis of whether they are male or female and making sure they fit into these categories as far as testosterone level is concerned, a logical alternative is to form the two groups on testosterone level rather than gender. The high testosterone group is likely to include most of those identifying as men, but also some individuals identifying as women with testes (both trans women or intersex women).⁵⁷ The low testosterone group would, most probably consist of most of those competing as women. Women with testes would be free to choose whether they wished to have gonadectomy or not. However, such a method is unlikely to be of any practical use. The advantage conferred by hyperandrogenism is complex and a single or a few measurements of testosterone in isolation may carry very little significance.⁵⁸ Therefore this solution is unlikely to offer any advantage and would have the effect of increasing the medicalisation of sport to a degree that many might consider unacceptable.

There is, however, a more feasible alternative proposal. Men and women could be permitted to compete in accordance with their self-identification but gonadectomy for women who have testes might be voluntary, not enforced. There is no reason why testicular tissue and high testosterone cannot be seen as a potential biological advantage, just like any other, as discussed previously. The argument against this is that women with testes will be competing against women without testes and, as the argument goes, the women who have testes will be at an advantage and may dominate athletic competition. If it was found that

⁵⁶ B Foddy & J Savulescu, 'Time to re-evaluate gender segregation in athletics?' (2011) 45 *British Journal of Sports Medicine* 1184-1188.

⁵⁷ Karkazis & others, above, n 26.

⁵⁸ Karkazis & others, above, n 26.

women with testes were dominant, then there could be modifications to the system, perhaps by having separate groups for women with testes and women without testes.

Permitting trans women and intersex women with functioning testes to compete may assist normalization and acceptance of different gender categories in society, analogous to the effect of the Paralympics with regard to disability. One aim of the Paralympic movement is to change perceptions of disability in society.⁵⁹ A potential difficulty is that athletes may themselves wish to conform to a binary view of gender and be regarded as 'normal', not wishing, perhaps, to have the type of media attention given to individuals such as Caster. They may choose to have gonadectomy for other reasons. Many trans women may have a strong need to undergo physical gender reassignment as treatment for gender dysphoria. For intersex women, there may be medical reasons for removal of abnormal gonads⁶⁰ and, indeed, health of the competing athletes is one of the reasons given by the IOC for identifying competitors with high testosterone.⁶¹

It may be that it would be perceived as so difficult to compete as a woman with testes that no one would chose to do so. The need to be perceived as normal is powerful, but, perhaps, we need to question why certain 'norms' are held in our society. There may be individuals who would be willing to act as pioneers, challenging the myth that everyone

⁵⁹ EA Claydon, B Gunter & P Reilly, 'Dis/Enablement? An analysis of the representation of disability on British terrestrial television pre- and post-paralympics' in D Jackson & CEM Hodges, M Molesworth & R Scullion (eds) *Reframing Disability? Media, (Dis)Empowerment and Voice in the 2012 Paralympics* (New York and London: Routledge: 2015) 37-54, 37.

⁶⁰ There is a variable risk (depending on the exact medical situation) of the development of malignant gonadal tumours in women with testes. See J Pleskacova, R Hersmus & JW Ooserhuis, 'Tumor risk in disorders of sex development' (2010) 10 (4) *Sexual Development* 259-269.

⁶¹ IOC addresses eligibility of female athletes with hyperandrogenism, above, n 17.

falls within a simple binary model of gender/sex and thereby lead a change in perception. If an athlete does choose to forego gonadectomy, then it is likely that this decision is a difficult one made following much thought and athletes making it should have their right to autonomy protected. There is evidence that this point of view may be gaining momentum in the case of sprinter Dutee Chand, bronze medallist in the 200m at the 2013 Asian Championships. She was found to have a high testosterone and was banned from competition in 2014 but she has taken her case to the Swiss Court of Arbitration for Sport. The recent judgment has overturned this ban and has questioned the IAAF rules on hypergonadism in female athletics, giving that body two years to provide scientific evidence linking high testosterone to improved athletic performance.⁶²

Conclusions

Sports such as athletics that operate strict divisions between men's and women's events offer uncomfortable insights into the problems of gender. In order to take part in any sport, competitors must abide by the rules. In athletics strict segregation of competitors on the basis of gender is one of the rules. A problem arises because it is impossible to identify the sex of some men and women using any of the tests devised so far. There are always exceptions and the problem for athletics is that women do sometimes have testicular tissue and a high level of functional testosterone. This may enhance performance when combined with other characteristics, including ability and appropriate training. In elite athletics this is considered an unfair advantage. Therefore there are individuals

⁶² J Branch, 'Dutee Chand, Female Sprinter with high testosterone level, wins right to compete' (27/07/2015) *New York times*
http://www.nytimes.com/2015/07/28/sports/international/dutee-chand-female-sprinter-with-high-male-hormone-level-wins-right-to-compete.html?_r=0 Accessed 31/05/2016.

who fall outside the limits of a strict binary categorization of sex and they may be excluded from elite athletic competition. In order to compete in women's events, under the rules of the IOC and IAAF (emphasizing fairness for the individual performer), those women with testicular tissue must follow the demands made on them by the IAAF or IOC, which may include surgical intervention to remove the testicular tissue. They have no choice but to undergo whatever medical treatment is required of them. I contend that this is too great a demand. Whilst athletes may have many reasons to choose gonadectomy themselves, I suggest that there ought to be scope for women with testes to compete as women without having to undergo surgery if they chose to do so and, looking at Dutee Chand's case, there is some evidence that this point of view is beginning to be officially acknowledged. This may have the effect of increasing visibility and promoting knowledge of sex and gender diversity in society.

CHAPTER 9:

IN CONCLUSION

As I stated at the start of the introduction to this work, I set out on this research making many assumptions regarding the nature of sex and gender that mirrored how these matters are generally perceived in society and in the practice of medicine. Having done this research, I conclude that at least some of the assumptions that are taken for granted in medical practice do not always stand up to close scrutiny. In the light of that finding, I further conclude that the law should be amended to enable an option whereby birth certification without specifying the child's sex is possible in cases where this is difficult to identify. This may help by removing any time pressure that currently exists and enable all decisions to be made with prolonged thought and consideration. Ideally, the law should be amended to proscribe all but life-saving surgery until the child has attained competence to consent.

When I began my doctoral research in 2009, a proposal to allow birth certification without specifying sex and a number of the other recommendations in this thesis would have been unlikely to attract much support and thus have a chance of implementation. As I have shown and will show further in this concluding chapter, in the last year or so there have been rapid changes in attitudes to questions of sex and gender, such as the recently published report of the House of Commons Women and Equalities Committee report on Transgender Equality, in which the possibility of gender neutral legal documentation was mooted ¹ and the

¹ House of Commons Women and Equalities Committee, Transgender Equality, 14th Jan 2016
<http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf> , 86.

recent change in International Olympic Committee regulations concerning transgender and intersex women athletes.²

Initially the thesis focused on legal and ethical issues relating to intersex in infancy, particularly surgery carried out to 'normalise' genital appearance, but the research soon demonstrated that legal and ethical issues in these areas concerning the topic of intersex cannot be evaluated in isolation and other related areas must also be examined, such as intersex in those beyond infancy. Wider issues concerning sex and gender must also be considered. As treatment of intersex may involve genital surgery on those who cannot consent, other forms of genital surgery, such as female genital mutilation or male circumcision for non-medical reasons, are closely analogous and therefore require evaluation.

The papers (for publication) written as part of this research are concerned with the binary model of sex and what happens to some of the many intersex individuals who fall outside it. These topics form the core of this thesis. Though many individuals naturally fall outside this sex binary, they may receive medical and surgical treatment in order to ensure that they fall within it. In the first of my papers, (Chapter 6) I question whether or not all aspects of intersex should be seen as an illness.³ Whilst some intersex states are associated with problems of body chemistry that require medical treatment, I argue that the problems associated with atypical genital anatomy are at least in part manufactured

² International Olympic Committee, 'IOC Consensus Meeting of sex reassignment and hyperandrogenism, November 2015'. http://www.olympic.org/Documents/Commissions_PDFfiles/Medical_commission/2015-11_ioc_consensus_meeting_on_sex_reassignment_and_hyperandrogenism-en.pdf Accessed 31/01/2016.

³ M Newbould, 'Intersex, medicine and pathologisation' in in H Carel & R Cooper (eds), *Health, Illness and Disease* (Abingdon: Taylor & Francis, 2012) 161-180

by 'normalising' medical and surgical treatment. ⁴ In my second paper ⁵ (Chapter 7), I consider the legal aspects of infants born with intersex states undergoing genital surgery at an early age in order that they are anatomically appropriate for the gender to which they have been assigned. I consider this in the context of the legal constraints on various types of infant and childhood genital surgery, including procedures carried out outside the therapeutic situation, such as female genital mutilation and male circumcision for non-medical reasons.

In my third paper (Chapter 8) I consider the issue of what happens to women with testes in elite sport.⁶ These individuals may have been seen as transgressing the binary model of sex, and not conforming anatomically to what a 'woman' is supposed to be. Until very recently the bodies governing elite sport, the International Association of Athletics federations (IAAF) and the International Athletics Committee (IOC), both ruled that women with testes could not compete unless they underwent medical treatment to lower testosterone level to the level considered 'normal' for women. In November 2015, the rules changed dramatically. Now both self-declared trans gender women and intersex women with testes can compete as women without undergoing surgery, as long as blood levels of testosterone meet specified criteria (which are discussed later in this chapter), though the IOC recognises that this is a living document and might be subject to further change in the future. ⁷

⁴ K Karkazis, *Fixing Sex: intersex, medical authority and lived experience* (Durham: Duke University Press, 2008), 220.

⁵ M Newbould, 'When parents choose gender: intersex, children and the law' Accepted for publication in *Medical Law Review* 2016.

⁶ MJ Newbould, 'What do we do about women athletes with testes?' *Journal of Medical Ethics* Published online 6 November 2015 doi:10.1136/medethics-2015-102948

⁷ International Olympic Committee, 'IOC Consensus Meeting of sex reassignment and hyperandrogenism, November 2015', above, n 2.

How I structure my conclusions

In this final chapter, I reflect on three broad and crucial topics that frame current responses to intersex and affect how the questions addressed in this thesis can start to be answered. It has proved a particularly exciting and challenging time to research this area of ethics and law, given the current rapid pace of change of attitude, regulations and law relating to matters concerning sex and gender. It is possible that there will be further developments in the near future.

My first broad topic concerned overarching matters of biology, medicine and law. Human sex differentiation is a complex matter and not all humans can be categorised into male or female. Though intersex individuals form a minority of the human population, world wide, many individuals fall into this category. The situation becomes increasingly difficult when gender is considered. There are multiple approaches to the topic of gender, and I was only able to give an extremely brief account of this very complex matter in this thesis, focussing on how theories of gender development in infants and children have influenced medical treatment of intersex. English law endorses a simple binary model of sex and gender, which does not always comfortably fit the complexity of these entities.

The second broad area that I am concerned with here has a more specific focus and involves the areas where change is needed because current practice might be thought unethical or unsatisfactory. I consider the problematic way in which intersex has been regarded by healthcare professionals over the past fifty years or so. Infantile and childhood genital surgery is ethically dubious. Other forms of genital cutting (male circumcision on those too young to consent and female genital mutilation) are similarly ethically dubious, though, in law, these forms of genital cutting are viewed very differently.

Finally I make recommendations for change, in law, in medicine and in other wider areas such as schools and in the public domain.

I will start by discussing the first of these broad topics and consider my conclusions concerning sex, gender and how the law frames them.

Sex is complex

The strict binary model of sex remains implicit in many aspects of medical practice, such as intersex. However, in England, there is currently consideration being given to possibility of change in aspects of the law regarding sex and gender.⁸ Though there is not specifically any plan to reform the medical response to intersex, this could follow if more fundamental changes in gender law were to take place.

Intersex challenges the idea that sex is strictly bipolar. Biological sex is complex and far from being fully understood.⁹ I consider some of the known biological facts about human sex development in my first paper, 'Intersex, medicine and pathologisation'¹⁰ (Chapter 6). With the practical implications of this in mind, I provide an illustration of how difficult it can be to define sex in my third paper, dealing in particular with women with testes in sport¹¹ (Chapter 8). I discussed some of the ethical issues surrounding sex testing for female athletes, attempted from the mid-1960s in order to identify men cheating by entering athletic events as women. After several decades of testing, it was realised that it was

⁸ House of Commons Women and Equalities Committee, *Transgender Equality*, above, n 1.

⁹ VA Rosario, 'Intersex and the molecular deconstruction of sex' (2009) 5 (2) *A Journal of Lesbian and Gay Studies* 267-284.

¹⁰ M Newbould, 'Intersex, medicine and pathologisation', above, n 3 (see chapter 6, page 161).

¹¹ MJ Newbould, 'What do we do about women athletes with testes?', above, n 6 (chapter 8, page 299 onwards).

impossible to devise a simple test that always could distinguish females from males.¹² In all of the investigations attempted, a minority of individuals were found to be exceptions, competing as women but owning at least one biological characteristic normally considered male.¹³

Therefore these were intersex individuals, possessing some biological characteristics normally associated with males and some normally associated with females.

There are many genes involved in the development of sex determining structures such as the ovary or testes.¹⁴ Therefore there are many stages involved in human sex development at which there may be variation from the typical.¹⁵ Anne Fausto-Sterling's comments in her essay 'The Five Sexes' are accurate; sex is indeed a continuum.¹⁶ In many individuals with intersex conditions, the nature of the underlying genetic events leading to the chromosomal, gonadal and hormonal make up of that individual are not yet understood.¹⁷ Though some of the more frequently encountered forms of intersex, such as congenital adrenal hyperplasia or complete androgen insensitivity syndrome are well understood genetically and biochemically, there are many other individuals encountered in day to day clinical practice, with anatomical

¹² JL Simpson, A Ljungqvist, MA Ferguson-Smith, A de la Chapelle, LJ Elsas, AA Ehrhardt, M Genel, EA Ferris & A Carlson, 'Gender verification in the Olympics' (2000) 284 *Journal of the American Medical Association* 1568-1569.

¹³ Simpson & others, above, n 12.

¹⁴ SC Munger & B Capel, 'Sex and the circuitry: progress toward a systems-level understanding of vertebrate sex determination' (2012) 4 *WIREs Systems Biology and Medicine* 401–412. (First published online 17 May 2012): 401–412. doi: 10.1002/wsbm.1172. Accessed 02/06/2016.

¹⁵ C Ainsworth, 'Sex redefined' (18/02/2015) 518 *Nature* 289-291. <http://www.nature.com/news/sex-redefined-1.16943> Accessed 02/06/2016.

¹⁶ A Fausto-Sterling, 'The five sexes: why male and female are not enough' (1993) 33 *The Sciences* 20–24.

¹⁷ Ainsworth, above, n 15.

and biochemical features that prove much more difficult to characterise fully.

Sex differentiation, thus, is scarcely understood; sex cannot always be determined by observation of clinical tests and it can be argued that there are not just two sexes; rather, there are many. Education of both the general public (and medical professionals) in this area would assist the optimisation of healthcare in intersex. I will now move on to consider the related area of gender.

The complexities of gender

There is a vast body of research work concerning gender and, in this thesis, only a selection of the more relevant areas are discussed. In particular, I focused on how a particular understanding of the notion of gender, and particular theories of gender identity development have influenced, and continue to influence, the medical and surgical treatment of intersex. John Money has been discussed earlier in this work as one of the major figures in early treatment of intersex. He was not a medical doctor but a psychologist and sexologist and he was influential in many areas of medicine. He was one of the first practitioners to suggest that gender could be divided into a number of components.¹⁸ One of these is 'gender role', demonstrated by an individual's outward presentation, behaviour as a sexed person and interaction with other gendered individuals around him or her.¹⁹ Gender roles can change over time, and

¹⁸ Initially Money envisaged that 'gender role' encompassed both the outer presentation and inward conviction of gender in an individual, but later the inward self-representation was termed 'gender identity' by Stoller and the outward presentation became regarded as the 'gender role'. J Money, *A First Person History of Pediatric Psychoendocrinology* (New York: Kluwer Academic, 2002) 36. Later Money accepted Stoller's definition. For example in J Money & AA Ehrhardt, *Man & Woman, Boy & Girl* (Baltimore: Johns Hopkins Press, 1972) 4.

¹⁹ Money & Ehrhardt, above, n 18, 15.

may be different in different geographical settings, but in almost all settings there are firm ideas regarding what constitutes appropriate male and female appearance and behaviour. This is applicable to life in England today and ideas regarding gender roles are enormously influential when considering the management of intersex children. The family of the intersex individual may hold definite opinions, which may be influenced, at least in part, by how their child's future gender role is envisaged.²⁰ Health care professionals live in the same environment as everyone else and their ideas regarding what might be appropriate for males and for females may be similar to those held by others and may influence how they see the child with intersex.

Medical treatment strategies for intersex were initially devised in order to try to ensure that the child developed a secure and 'appropriate' gender identity.²¹ Gender identity was defined as the individual's 'private experience of gender role'²² and 'appropriate' meant that the gender identity matched that assigned to the child at birth. Over the years, it has become clear that in some forms of intersex it is impossible to predict at birth how the individual will express and experience his or her gender as he or she grows. Whilst *many* intersex individuals have no greater problems with gender identity than others in the population do²³ and will live as adults in the gender to which they were assigned at birth²⁴ some

²⁰ For example, PA Lee, AB Wisniewski, L Baskin, MG Vogiatzi, E Vilain, SM Rosenthal & C Houk, 'Advances in diagnosis and care of persons with DSD over the last decade' *International Journal of Pediatric Endocrinology* <http://www.ijpeonline.com/content/2014/1/19> 2-3 Accessed 02/06/2016. This paper includes a discussion on the way in which families bring cultural expectations of gender role into the decision making.

²¹ Money & Ehrhardt, above, n 18, 97.

²² Money & Ehrhardt, above, n 18, 4.

²³ M Holmes, *A Perilous Difference* (Selinsgrove: Susquehanna University Press, 2008) 13-14.

²⁴ P Cohen-Kettenis, 'Psychological long-term outcome in intersex conditions' (2005) 64 (supp 2) *Hormone Research* 27-30.

experience difficulty²⁵ and they may decide to transition to live in an alternative gender role. Though this does not affect *most* intersex individuals, gender dysphoria occurs in this group more frequently than in the general population.²⁶

In medicine gender tends to be seen as largely binary and in English law at present wholly so. However, it is recognised that some people wish to identify as something other than male or female,²⁷ but they lack legal recognition as such. Whilst it is true that some societies validate a third gender, those in this category do not always share all the rights of those living in male or female genders. For example, in the Pacific, people in the third gender occupy a role somewhat external to males and females and do not have the same opportunities and rights, though their existence has been accepted for several hundred years.²⁸ Therefore even when a category is recognised, it does not mean that all problems are solved for those living within it. It would however, be a first step to gain legal recognition for those who do not want to identify as neither male nor female.

Having discussed the binary nature of sex and gender, I will now discuss how law at the present time endorses this model by the lack of official documentation for those who fall outside it.

²⁵ HFL Meyer-Bahlburg, 'Introduction: gender dysphoria and gender change in persons with intersexuality' (2005) 34 (4) *Archives of sexual Behaviour* 371-373

²⁶ See for example, PT Cohen-Kettenis, 'Psychosocial and psychosexual aspects of disorders of sex development' (2010) 24 *Best Practice and Research: Clinical Endocrinology and Metabolism* 325-334, 327. In some forms of intersex conditions (for example, partial androgen insensitivity syndromes), gender dysphoria affects up to 14%, though the study numbers are small.

²⁷ World Professional Association for Transgender Health (WPATH) 'Standards of care for the health of transsexual, transgender, and gender nonconforming people' http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351 (2012), 5. Accessed 02/06/2016.

²⁸ S Farran, 'Pacific perspectives: fa'afine and fakaleiti in Samoa and Tonga: people between worlds' (2010) 31 *Liverpool Law Review* 13-28.

English Law endorses the binary model of sex and gender

Intersex individuals often lack a social space even in countries such as England and other European countries, where there are laws against discrimination based on characteristics such as sexual orientation and gender. In England, the current law endorses the view that sex and gender are binary from the very earliest time of the child's life. For all practical purposes there are *only* two gender and sex categories into which everyone must fit from the time of birth onwards; though, when adult, they may be able to change from one gender category to the other. Some jurisdictions permit birth registration as a third gender (as discussed in Chapter 3, page 68). In England birth certification must be completed in the first forty-two days of life and requires that all children be categorised as either male or female.²⁹ This places the child in a gendered position in society and is likely to influence future gender role. The vast majority of children are not intersex and will be assigned to the sex/gender appropriate to the biological sex as inferred by simple observation of the child's anatomy. The intersex child, in spite of not belonging clearly to one category or the other, still needs registration as either male or female under English law (as discussed in Chapters 2 and 3). It is anticipated that every baby will be male or female at birth, an expectation fostered and reinforced by current laws, so the intersex infant may be seen as 'problematic', 'other' and 'abnormal' and thereby in need of medical care from the earliest stage of life.

Having surveyed these three very general ideas and laws underpinning the medical approach to intersex, I move on to more specific and practical areas of medical and surgical care in intersex and related areas. I cover these aspects in the next three sections, ending with a section considering their lawfulness. I conclude that the contact with medical carers can reinforce the labelling of those with intersex states as 'abnormal' and that the medical and surgical care given subsequently to

²⁹ *Sheffield and Horsham v United Kingdom* [1998] 3 FCR 141 at 148.

the child with this label can have negative consequences for those with intersex and also for others.

Medicine and intersex – a problematic interaction

The assumptions on which medical practice in the area of intersex is based have always been (and still are, to some extent) strongly influenced by gender norms. For example, in Chapter 2, I discussed the phallogentric nature of the early model of care for intersex infants, based on the idea that a functioning penis was seen as a vital part of being a male. In medicine, a major problem is that norms regarding sex and gender are internalised, unexamined and implicit in many policies and procedures. Those born intersex have physical characteristics that may not conform anatomically to the criteria required of someone living as a male or a female. As I discuss in Chapter 4 and in the paper ‘Intersex, medicine and pathologisation’³⁰ the notion of illness raises important epistemological issues that are not unique to intersex. In intersex, however, conventional medical management may sometimes involve surgical procedures such as clitoroplasty and gonadectomy. Not only are these procedures invasive, they also carry major implications of how the child will be expected to live in the future. They may also result in the need for future further surgery or for long-term medical care.³¹

Much of the ethical discourse regarding intersex and medicine concerns feminising clitoral procedures. There is a paucity of scientific data regarding the long-term outcome of this type of surgery. As I discussed in Chapter 2, Sarah Creighton has pointed out that the resources needed to pursue such a project are unlikely to materialise, in view of the

³⁰ Newbould, ‘Intersex, medicine and pathologisation’, above, n 3.

³¹ L-M Liao, D Wood & SM Creighton, ‘Parental choice on normalizing cosmetic genital surgery’ (2015) 351 *British Medical Journal* h5124

relatively small numbers of individuals who are involved.³² Clitoral surgery continues to be seen as a reasonable medical option, despite the absence of any scientific validation.³³

Even though various forms of surgery have been carried out now for over sixty years, there is no evidence base to suggest that it improves the future lives of those who undergo it and, strictly speaking, it remains an experimental and speculative treatment. There is empirical data detailing the anecdotal experience of intersex individuals. Much of this serves to illustrate that at least some individuals who underwent surgery as young children have been highly dissatisfied with the results and consequences of it.³⁴ To quote Cheryl Chase, founder of the now defunct Intersex Society of North America (ISNA):

as a woman, I am less than whole – I have a secret past, I lack important parts of my genitals and sexual response.³⁵

Medical intervention does not necessarily result in a 'cure' for at least some of those who undergo this surgery in infancy; rather, surgical intervention may itself create illness. Though it has long been accepted that medicine can be harmful when things do not go according to plan, sometimes, even when everything appears to go well technically, the individual concerned does not perceive the result as successful, but problematic. The need for medical attention can prove problematic for many. I discussed this in detail in 'Intersex, medicine and pathologisation'.³⁶ As Preves says about children forced into a round of multiple clinic visits and medical examinations:

³² Liao & others, above, n 31.

³³ Liao & others, above, n 31.

³⁴ For example, Karkazis, above, n 4, 231.

³⁵ Or S Preves, *Intersex and Identity* (New Brunswick: Rutgers University Press, 2003) 90. Quoting Cheryl Chase.

³⁶ Newbould, 'Intersex, medicine and pathologisation', above, n 3.

[I]ntersexuals who underwent medical sex assignment in childhood experienced consistently negative and confusing messages about their bodies and their identities. ³⁷

There is a further aspect to early genital surgery. As I note above, treatment has always been based on gender norms. Therefore surgery attempts to reform the child's body to be in line with a stereotypical idea of what a girl or boy should be. There is no room for variation:

[The doctors] used surgical force to make my appearance coincide with the medical and social standards of a 'normal' female body thereby attempting to jettison any trace of intersexuality. ³⁸

So, there is some evidence that medical and surgical care of intersex can result in harm to individuals and, in a wider sense, it can be considered to reinforce stereotypes regarding the appearance of female or, occasionally, male bodies.

What is certain is that at least some people who had surgery as young children feel that they were harmed by it ³⁹ and to some extent the numbers or proportions of those who feel that does not matter, it is enough to say that some people feel this. Given all this, in my next section I conclude that surgical treatment for intersex, particularly genital surgery on those too young to consent, cannot be considered ethical and should not be lawful.

³⁷ Preves, above, n 35, 62.

³⁸ Preves, above, n 35, 90, quoting Morgan Holmes.

³⁹ Karkazis, above, n 4, 220-228.

The current situation concerning infantile and childhood genital surgery is unethical

The present day approach to the problem of anatomical variation in the genitalia of infants and young children is ethically questionable. Those with parental responsibility give their consent for a surgical or medical procedure that they and the medical team consider will ultimately prove helpful to the child, thereby constructing a case that the procedure is in the child's best interests. They may feel that the child's future life will be unbearable, unless he or she appears 'normal'. The problem here (and in many other examples of surgery that alters appearance) is the nature of the potential benefit. Whilst some may argue that this is a *medical* benefit, this argument relies on the idea that the unusual appearance of the genitalia constitutes a medical condition rather than a difference. My argument throughout this thesis, particularly in Chapter 4 and Chapter 6 is that it *is* a difference and not a condition or pathology that can be 'cured' by *surgery*. A problem is that this is not how medical teams caring for infants with intersex states see the matter. Even recent papers, whilst acknowledging that there is evidence for dissatisfaction with feminising genital surgery, may suggest that this is because of inadequate surgical techniques of the past.⁴⁰ Feder makes the point that this is how today's surgeons and physicians frequently interpret the older studies.⁴¹ My argument in Chapter 4 is that to pursue surgery as a way of healing those with intersex states is never going to succeed in isolation. The experience of at least some of those with intersex states is much more profound and their thoughts and feelings need to be considered and at the centre of their health care. In the recent medical literature the importance of psychological aspects of care is acknowledged⁴² though,

⁴⁰ Lee & others, above, n 20, 6.

⁴¹ EK Feder, 'Reassigning ambiguity. Intersex, biomedicine and the question of harm, in (K Zeiler & LF Käll (eds) *Feminist Phenomenology and Medicine* (Albany: State University of New York Press, 2014) 161- 176, 161.

⁴² Lee & others, above, n 20, 7.

in practice this part of the medical provision for intersex individuals is frequently under-resourced in comparison to other aspects such as surgery.⁴³

Even if feminising genital surgery were perceived as beneficial by all concerned we might still need to question its ethical legitimacy, since it might be considered therapeutically unnecessary and a misguided reinforcement of sex and gender stereotypes. Also, as discussed in the section above, at least some intersex adults are far from happy with the negative consequences of the medical care they received as children, particularly the genital surgery. Though the appearance altering surgery is carried out to make the child's genitalia look 'acceptable', it is others, rather than the individual concerned that make the judgment at the point of decision making. My conclusion is therefore that genital surgery for intersex individuals should not be performed at all, at least until the person is fully capable of providing valid informed consent. This conclusion might be widened from clitoral surgery to apply to other forms of appearance altering surgery on the genitalia of young children, such as hypospadias repair (surgery to normalise the position of an aberrantly positioned urinary opening in males), as there are close analogies between them.

What of the lawfulness of infantile genital surgery? Earlier in the thesis I also discussed non-medical male circumcision and female genital mutilation, procedures that are, in some ways, analogous to intersex surgery.

⁴³ Liao & others, above, n 31.

The lawfulness of infantile genital surgery

In my paper 'When parents choose gender'⁴⁴ (Chapter 7) I questioned whether all forms of genital surgery for non-medical reasons performed on those too young to consent should be considered unlawful. Surgery carried out on infants and young children must be in their best interests and, in view of the problems associated with genital surgery, it might be argued that it is not necessarily in the child's best interests to undergo it, as I suggested in the foregoing section. This may also apply to male circumcision and to any form of genital cutting. At the present time only female genital mutilation is unlawful in England.

Non-therapeutic circumcision on males who are too young to consent is, in England, lawful.⁴⁵ I discuss this in Chapter 5 and also in Chapter 7. This has been considered (in passing only) in *Brown*,⁴⁶ and *Re J (child's religious upbringing and circumcision)*.⁴⁷ Whilst the Law Commission on *Consent in the Criminal Law* suggested in the mid 1990s that it would help if the position were clarified and its lawfulness were put beyond doubt,⁴⁸ this has never happened. The BMA⁴⁹ has long advocated that both of those with parental responsibility (if there are two) must give consent for male non-therapeutic circumcision, if the child himself is not

⁴⁴ Newbould, 'When parents choose gender: intersex, children and the law', above, n 5.

⁴⁵ British Medical Association, 'The law and ethics of male circumcision: guidance for doctors' to be found at <http://www.bma.org.uk> Accessed 02/06/2016) s4.1, p2. (also published *Journal of Medical Ethics* 30 (2004): 259-263.)

⁴⁶ *R v Brown* [1993] 2 All ER 75 at 78-9, per Lord Templeman.

⁴⁷ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345 at 355-362

⁴⁸ Law Commission. 'Consent in the criminal law', *Law Commission Consultation Paper no 139*. (London: HMSO, 1995) Can be found at https://sexualitymatters.files.wordpress.com/2013/01/cp139_pt09.pdf Accessed 30/05/2016) s9.27, 128.

⁴⁹ British Medical Association, above, n 45, s4.2.2, p3.

competent to do so. It is an odd state of affairs that a procedure is acceptable if both parents consent to it, but not necessarily if only one does. The risks and complications of that procedure are the same. The courts in England have never contended that it might never be appropriate to circumcise a male child who cannot give his own consent. For the three boys central to the circumcision cases considered by the courts in England⁵⁰ (and discussed in more detail in Chapter 7, 'When parents choose gender'⁵¹) circumcision would have gone ahead *without* further consideration had both parents wished it to take place. The view taken in English law seems to be that it will be in his best interests to undergo circumcision if he is to live in a community where it is the norm. The point of view that it can *never* be in his interests to have unnecessary and invasive surgery, which he may come to regret in his adult life and that carries risks of morbidity and mortality,⁵² has not been considered by the courts. It is, however frequently considered in the ethical and legal literature.⁵³

As far as therapeutic forms of genital surgery are concerned, it is usually assumed that a procedure performed by a qualified medical practitioner in the medical setting is not primarily intended to cause harm and that it is therefore lawful, as Lord Templeman says in *R v Brown*.⁵⁴ Genital surgery carried out on intersex children and boys with hypospadias

⁵⁰ *Re J (child's religious upbringing and circumcision)* [1999] 2 FCR 345, *S (Children)* [2004] EWHC 1282 (Fam), *Re S (change of name: cultural factors)* [2001] 3 FCR 648.

⁵¹ Newbould, above 'When parents choose gender: intersex, children and the law', above, n 5, chapter 7, 220.

⁵² Occasional deaths, such as that of Goodluck Caubergs mean that this is not a procedure that is free of serious adverse consequences. See A Fogg, 'Male circumcision: let there be no more tragedies like Baby Goodluck' <http://www.theguardian.com/commentisfree/2012/dec/17/male-circumcision-baby-goodluck> Accessed 02/06/2016.

⁵³ M Fox & M Thomson, 'Foreskin is a feminist issue' (2009) 24 (60) *Australian Feminist Studies* 195-210, 195.

⁵⁴ *R v Brown* [1993] 2 All ER 75 at 78-9.

(described on page 259) is always performed in this clinical setting and *is* therefore seen as a lawful activity at the present time, providing that there is valid consent and it is carried out in accordance with the child's best interests. Those performing it perceive it as medical treatment for a medical disorder. It is usually seen as improving the subsequent lives of those infants or children who undergo it. This has never been tested in the English courts so that it is completely unknown what position might be taken if a case were to be considered. A closer look at the medical evidence reveals that it is difficult to justify that this is surgery carried out in the child's best interests, since outcome studies are few and those that there are reveal a high incidence of complications and need for further surgery.⁵⁵ Therefore this aspect of the justification of its lawfulness does not stand up to scrutiny and there is a strong presumption it should *not* be lawful in all but the most extreme cases.

There are analogies between some forms of FGM and genital surgery for girls with congenital adrenal hyperplasia (CAH), though FGM is unlawful in England and many other countries. Girls with CAH are deemed to have a larger than normal clitoris which is surgically reduced to a more 'normal' size. Clitoral surgery forms a part of some of the less extensive forms of FGM. However, the analogy between the two is not exact. FGM is often carried out on pre-adolescent girls (rather than young infants) and may be performed by a traditional practitioner, rather than within the therapeutic setting, with the increased risks of morbidity and mortality that the non-medical procedure carries. Some aspects of the proscription of female genital mutilation might be seen as anomalous, however. In England, cosmetic genital procedures are lawful, though a procedure deemed FGM carried out under general anaesthesia by a suitably qualified surgeon on a freely consenting and well-informed competent adult woman is unlawful. It is difficult to see why procedures labelled 'cosmetic surgery' and involving the vagina and vulva and FGM

⁵⁵ SM Creighton, CL Minto & SJ Steele, 'Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood' (2001) 358 *Lancet* 124-125.

are seen to be so different if consenting adult women are involved.⁵⁶ Here motivation appears to be the difference and it is unusual that the law makes a distinction on this basis. It is even difficult to identify a major difference in motivation, since an individual's reasons for submitting to cosmetic surgery are complex and, at least in part, driven by strong cultural pressures to conform to what is perceived as an ideal.⁵⁷ In most parts of the world, both male circumcision and genital surgery carried out on intersex children are lawful. Recently, two jurisdictions have prohibited genital surgery for intersex. In April 2015, the government of Malta issued a prohibition on all but essential surgery on intersex infants.⁵⁸ The Chilean Ministry of Health has very recently (January 2016) instructed doctors to stop carrying out 'normalising' genital procedures on intersex children.⁵⁹ There was one early attempt to effect a prohibition on intersex surgery. An initial ban in The Constitutional Court of Colombia in 1996 (*the Decision of YY*)⁶⁰ was rejected and replaced by a model involving enhanced consent.⁶¹ There

⁵⁶ S Sheldon and S Wilkinson, 'Female genital mutilation and cosmetic surgery: regulating non-therapeutic body modification' (2002) 12 *Bioethics* 263-285.

⁵⁷ L Michala, L-M Liao & SM Creighton, 'Female genital cosmetic surgery: how can clinicians act in women's best interests?' (2012) 14 *The Obstetrician and Gynaecologist* 203-206.

⁵⁸ Press Release 'Huge intersex rights victory in Europe: Malta bans Intersex genital mutilation' (02/04/2015) United States affiliate of the Organization Intersex International website. <http://oii-usa.org/2432/press-release-intersex-rights-victory-in-europe/> Accessed 02/06/2016.

⁵⁹ Morgan, Chilean Ministry of Health issues instructions stopping 'normalising' interventions on intersex children (11/01/2016) <https://oii.org.au/30250/chilean-ministry-stops-normalising/> Accessed 02/06/2016.

⁶⁰ R White, 'Preferred private parts: importing intersex autonomy for *MC v Aaronson*' (2013) 37 *Fordham International Law Journal* 777-821, discussing *The Decision of YY* Corte Constitucional [CC] [Constitutional Court], octubre 23, 1995, Sentencia T-477/95, Gaceta de la Corte Constitucional [GCC] (Colom.)

⁶¹ White, above, n 60, discussing the two cases, *The Decision of XX* Corte Constitucional [CC] [Constitutional Court], May 12, 1999, Sentencia SU- 337/99, Gaceta de la Corte Constitucional [GCC] (Colom.) *The decision of NN* Corte Constitucional [CC] [Constitutional Court], Aug 2, 1999, Sentencia T-551/99, Gaceta de la Corte Constitucional [GCC] (Colom.)

is a growing jurisprudence concerning intersex surgery, discussed in Chapter 5 (page 133 onwards, with case law on page 137 onwards), though few cases have involved the specific question of the lawfulness of genital surgery. Male ritual circumcision was briefly banned (in the absence of consent from the affected individual) in the Court of Cologne but the ban was overturned by the German *Bundestag* and since January 2013, circumcision on young male infants has been lawful in the whole of Germany.⁶²

If genital cutting is unlawful for girl children then it should be unlawful for male children (in the form of male circumcision) and for the situations where genital surgery is considered to be medical treatment (intersex children and boys with hypospadias (described on page 259). However, even when a procedure is prohibited, legislation seems to be ineffective in actually preventing it; though female genital mutilation has been prohibited in effect in England and Wales since 1985,⁶³ there continue to be reports of new cases.⁶⁴ Furthermore, the decision taken by the court of Cologne to ban male circumcision was rapidly overturned, partly because of fears that dangerous ‘backstreet’ practices may develop.⁶⁵ Effective bans on genital cutting have proved difficult to implement. It might, though, be easier in the case of Intersex surgery which would be performed in hospital by qualified surgeons and thereby more amenable to regulation. With regard to intersex, one problem raised by Creighton and her group is that though all protocols state that on-going psycho-

⁶² K Dyer, ‘Lessons from Germany: should UK legislation circumnavigate or circumvent the issue of male circumcision?’ (2013) 25 *Denning Law Journal* 225-239.

⁶³ Prohibition of Female Circumcision Act 1985, replaced by the Female Genital mutilation act 2003.

⁶⁴ J Tyler, ‘Over 600 new FGM cases in West Midlands in six months’ (24/06/2015) *Birmingham Mail* <http://www.birminghammail.co.uk/news/midlands-news/over-600-new-fgm-cases-9518251> Accessed 02/06/2016

⁶⁵ Dyer, above, n 62.

educational care for the intersex child and his or her family is essential, in reality this is rarely available. ⁶⁶ If surgery were to be prohibited, education and support for all the family and others who are to interact with the child would be essential, but as yet, the infrastructure that might permit this option is lacking and the:

hospital payment structure encourages controversial, invasive, and expensive surgical interventions rather than low cost alternatives. ⁶⁷

This group suggests the first step in having a solution to this is to devise an additional non-surgical protocol taking the need for psychological support of the family into account, particularly if they decide that surgical options are not appropriate for their child. ⁶⁸

Having considered the ways in which medicine and law are unsatisfactory in dealing with intersex, I will now make recommendations for changes in law and practice that would better address the problems identified in this thesis.

The way ahead

One way of enabling transformation of the current situation is to change the law in England so that there is no need to identify sex/gender in official documentation, such as birth certification, driving licences and passports. Some countries have started to accept that '[n]ot all human beings can be classified by sex as either male or female'. ⁶⁹ As I discussed in Chapter 3, legislation permitting this may be coming in the

⁶⁶ Liao & others, n 31.

⁶⁷ Liao & others, n 31.

⁶⁸ Liao & others, n 31.

⁶⁹ T Bennett, 'No man's land': non-binary sex identification in Australian law and policy' (2014) 37 (3) *UNSW Law Journal* 847-873. Quoting *NSW Registrar v Norrie* [2014] HCA 11.

near future. Maria Miller, chair of the Women and Equalities Select Committee, has recently published the report of an enquiry that she led into transgender equality issues and this is one of the recommendations.

⁷⁰ Birth certification legislation should be reformed so that assigning a sex on the certificate could be deferred for cases where this is difficult to identify. The ideal situation would involve a voluntary system that avoids giving the neonate any sort of sex/gender label, allowing more time to contemplate the best options for the child by all involved. If this were the law, it might assist in reforming the medical approach to intersex. There would be more time and an opportunity to see how the child develops before making any decisions.

English law should proscribe surgical intervention on intersex children too young to consent. In Chapter 5, I discussed the growing interest taken in intersex individuals by bodies such as the UN ⁷¹, WHO ⁷² and EU. ⁷³ If the Courts in England were ever asked to consider the lawfulness of intersex surgery, the most logical conclusion might be that genital surgery is potentially harmful and should not therefore be imposed on those who are too young to give consent unless for a sound therapeutic reason.

⁷⁰ House of Commons Women and Equalities Committee, *Transgender Equality*, above, n 1, 86.

⁷¹ JE Mèndez, 'Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or Punishment' (1 February 2013) United Nations General assembly, Document A/HRC/22/53 page 23 paragraph 88 This looks specifically at human rights abuses in the health care setting. Accessed 04/06/2016.
http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf Accessed 04/06/2016.

⁷² WHO, 'Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement' WHO 2014,
http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf 7. Accessed 04/06/2016.

⁷³ FRA Focus *The fundamental rights situation of intersex people*
<http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> Accessed 04/06/2016.

'Every infant has a right to bodily integrity.'⁷⁴ Svoboda, discussing male circumcision, argues that removing healthy tissue from an infant must always be in response to an immediate medical indication.⁷⁵ If there is no sound medical reason (such as urinary obstruction) then it is always possible to delay a procedure until the child is able to consent for himself.

It is of some interest in this context that sterilisation of girls unable to give consent had been considered a lawful practice in England and Wales and had proceeded unimpeded until considered in court in 1976 in the case of *Re D*.⁷⁶ As discussed in 'When parents choose gender'⁷⁷ it was only in 1987 that it became necessary to have a court authorisation for sterilisation of a minor.⁷⁸ There are several circumstances that could lead to a case of intersex reaching the English courts. A disagreement between the two people in a position of parental responsibility regarding the child's best interests is one example. There could be a disagreement between the family and the medical team about how best to proceed. The medical team themselves may wish to gain court approval before undertaking surgery, given the interest currently taken by the UN, EU and WHO. It is even possible that a third party in the wider medical team caring for the child, such as the educational psychologist in *Re D*,⁷⁹ may hear of the decision to carry out surgical intervention to change the appearance of the child's genitalia and may feel that this decision requires ratification by a court before any surgery is carried out. The child on reaching the age of majority may consider that they have been

⁷⁴ JS Svoboda, 'Circumcision of male infants as a human rights violation' (2013) 39 (7) *Journal of Medical Ethics* 469-474.

⁷⁵ Svoboda, above, n 74.

⁷⁶ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326.

⁷⁷ Newbould, 'When parents choose gender: intersex, children and the law', above, n 5 (chapter 7, 217-218).

⁷⁸ *Re B (a minor)(Wardship: Sterilisation)* [1988] AC 199

⁷⁹ *Re D (a minor) (Wardship: Sterilisation)* [1976] 1 All ER 326.

harmful by the medical or surgical care that they received and may take the medical (and possibly their parents) to court, alleging that the surgery constituted a battery on the grounds that it was not in their best interests. Any of these circumstances would grant the courts an opportunity to consider the lawfulness of surgery for intersex in young children. In Chapter 5, I discuss the South Carolina case of *MC v Aronson* involving an intersex child who had genital surgery in infancy who has filed a complaint against the hospital and South Carolina Social Services (who were responsible for his medical decisions at the time).⁸⁰ Though this has not yet happened in England, it could do. Given the statements issued by the UN, EU Fundamental Rights Agency and WHO, It might be the time to consider prohibitive legislation, similar to that introduced in Malta.

Raising general awareness of human sex diversity may be the most effective long-term remedy to effect change. This could be partly achieved through education, starting in school and perhaps as part of 'sex' education. At present in England there is sex and relationships education from year 7.⁸¹

I suggest in my paper 'What do we do about women with testes'⁸² (Chapter 8) that raising awareness of sex and gender diversity might be assisted by changing the rules regarding sex segregation in elite sport. In November 2015, the rules underwent a dramatic change.⁸³ Trans

⁸⁰ MC is a minor but the complaint has been filed by and through his adoptive parents. Harvard Law, Bill of Health – A blog by the Petrie-Flom Center and friends, '*MC v Aronson. Update 2015*' (05/03/2015) <http://blogs.law.harvard.edu/billofhealth/2015/03/05/m-c-v-aaronson-update/> Accessed 04/06/2016.

⁸¹ Gov.uk, 'The National Curriculum' <https://www.gov.uk/national-curriculum/other-compulsory-subjects> Accessed 04/06/2016.

⁸² Newbould, 'What do we do about women athletes with testes?', above, n 11.

⁸³ International Olympic Committee, 'IOC Consensus Meeting of sex reassignment and hyperandrogenism, November 2015'. Located at <https://www.olympic.org/documents> Accessed 04/06/2016

gender athletes can now compete in gender categories on the basis of self-declared gender, without the need for surgery, as long as they fulfil regulations regarding blood testosterone level⁸⁴ (which should be no more than 10 nmol/litre.⁸⁵) As far as intersex athletes are concerned, the International Olympic Committee (IOC) consensus recommends that International Association of Athletics Federations (IAAF) follow the ruling of *Chand v AFI and IAAF* at the Swiss Court of Arbitration of Sport (CAS).⁸⁶ Chand is a sprinter from India who competed as a woman but was found to have a testosterone level above the permitted female range and therefore subjected to a ban, against which she appealed. The court heard her case in 2015 and permitted her to continue to compete as a woman, whilst further scientific work is carried out to clarify if any advantage is actually conferred by having a higher than normal testosterone. In the event of no such work being forthcoming, the previous IAAF regulations⁸⁷ will be declared void. In my paper, 'What do we do about women athletes with testes?'⁸⁸ (Chapter 8, page 241) I suggested a system of streaming athletes on the basis of testosterone

⁸⁴ International Olympic Committee, 'IOC Consensus Meeting of sex reassignment and hyperandrogenism', above, n 83.

⁸⁵ This level is at the lower end of the male range. BB Yeap, AH Chubb, DJ Handelsman, GJ Hankey, PE Norman & L Flicker, 'Reference ranges and determinants of testosterone, dihydrotestosterone, and estradiol levels measured using liquid chromatography-tandem mass spectrometry in a population based cohort of older men' (2012) 97 (11) *Journal of Clinical Endocrinology and Metabolism* 4030-4039.

⁸⁶ AFI is the Athletic Federation of India. Court of Arbitration for Sport, 'Athletics- Case Dutee Chand v/ AFI & IAAF' CAS 2014/A/3759 *Dutee Chand v AFI & IAAF* http://www.tas-cas.org/fileadmin/user_upload/award_internet.pdf 160, Accessed 04/06/2016.

⁸⁷ IAAF regulations governing eligibility of females with hyperandrogenism to compete in women's competition. Accessed 04/06/2016 at www.iaaf.org Link-<http://www.iaaf.org/download/download?filename=fd073e9a-e217-431f-b06b-73e5349bd874.pdf&urlslug=IAAF%20Hyperandrogenism%20Regulations%20-%20Explanatory%20Notes%20-%20In%20force%20as%20from%201st%20May%202011> Accessed 04/06/2016 at www.iaaf.org

⁸⁸ Newbould, 'What do we do about women athletes with testes?', above, n 11.

levels and the IOC rules appear to be along those lines, particularly since it has been decided that trans women and intersex women who have testosterone levels outside the range acceptable for women may compete as men. In the paper I reject this as an impractical suggestion because of the degree of medicalisation entailed. However, the IOC is clear that this is a living document that might be subject to change should the rules prove difficult to administer in practice.

Olympic and world-class athletics are high profile events very closely followed throughout the world. Including trans athletes and intersex athletes in competition might serve to facilitate further public understanding of sex and gender diversity in a similar way to the role the Paralympics has in raising public awareness of disability issues.⁸⁹

Finally:

As a doctor I am used to using scientific papers and textbooks to answer queries that I might have regarding problems that I encounter. Scientific data is invaluable and is necessary to solve many of the problems that are encountered in day-to-day medical practice. However, there are issues that, at first sight, seem to be simple medical questions but which, on closer inspection, involve conceptual and ethical issues.

As a paediatric histopathologist I am asked to examine clitoral tissue from infant and young girls who have undergone clitoroplasty or testes from teenage girls recently diagnosed with intersex disorders and I previously never considered the assumptions on which such surgical intervention is based or the devastating effects that these procedures may have on

⁸⁹ EA Claydon, B Gunter & P Reilly, 'Dis/Enablement? An analysis of the representation of disability on British terrestrial television pre- and post-paralympics' in D Jackson & CEM Hodges, M Molesworth & R Scullion (eds) *Reframing Disability? Media, (Dis)Empowerment and Voice in the 2012 Paralympics* (New York and London: Routledge: 2015) 37-54.

those who undergo them. In Chapter 4, I examined intersex through the perspective of a number of different philosophical approaches and found that a phenomenological approach can be extremely valuable in providing additional insight into what these procedures can mean to the patient involved.

The clinical management of intersex raises questions that cannot be answered by medical science alone. Study of medical humanities, such as bioethics and medical law is needed in order to try to understand the nature of the questions involved. These disciplines ought to be studied by all health care professionals. Certainly as far as medical education is concerned, aspects of medical humanities have been an important part of the current core curriculum for trainee doctors for the past ten years or so.⁹⁰ There is therefore some evidence that bodies such as the GMC are leading medical education in an appropriate direction.

Many of the laws and attitudes towards gender and sexuality have undergone dramatic changes in the past decade or so, in England and throughout the world. The pace of change is increasingly rapid. There is also increasing recognition of the problems associated with intersex and medical intervention. It is therefore entirely credible that there could be extensive change in the medical management of intersex over the next few years along the lines suggested in this thesis.

⁹⁰ For example, General Medical Council, 'General Paediatrics Curriculum' http://www.gmc-uk.org/April_2015_General_Paediatrics_Curriculum.pdf_60877537.pdf 61 Accessed 04/06/2016. Knowledge of ethics is considered an important part of the core knowledge required of someone training to be a consultant in paediatrics. The same is true in all other medical specialities.

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